Current Clinical Psychiatry
Series Editor: Jerrold F. Rosenbaum

H. Kent Wilson
Ellen B. Braaten *Editors*

The Massachusetts General Hospital Guide to Learning Disabilities

Assessing Learning Needs of Children and Adolescents

Humana Press

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Preface

Every child in the United States has the right to a free appropriate public education. While estimates vary, roughly 8–10% of children are identified as having learning disabilities, and over 20% of children have a diagnosable mental illness than can impact learning and school functioning. Intervention for children experiencing such challenges supports a positive developmental trajectory, and a comprehensive assessment to better understand the etiology of the learning challenge and to inform the intervention choices is essential.

This book enlists the help of experts in the field of child assessment and treatment to provide child psychiatrists with knowledge in evaluation and special education programming. This book provides a review of the latest science behind common learning disabilities and psychiatric conditions that present in childhood and also includes best practices in the assessment of these conditions and the school-based interventions that are indicated. With this knowledge, the reader can be a more informed consumer of assessment reports and can help to advocate for their patients' school-based needs more effectively.

The book is divided into four parts. The first part is comprised of a single chapter that provides the reader with background behind the principles of standardized assessment. The second part, which includes eight chapters on neurodevelopmental disorders like learning disabilities and ADHD, and the third part, which includes three chapters on other common psychiatric disorders in childhood that impact school functioning, provide a review of the science of the disorder, best practices for assessment of the disorder, and interventions that are commonly indicated for the disorder at school; these chapters also include a case example to highlight issues in the assessment of these conditions. Finally, the fourth part is comprised of two chapters that cover issues relevant across disorders including a chapter on managing the needs of transitional age youth and another chapter detailing special education laws and procedures.

We believe this book will be a valuable reference for all child psychiatrists as well as other professionals who treat children on an outpatient basis who encounter school-related difficulty. We hope that the book will help support more efficient/effective use of assessment for understanding and managing learning challenges.

We would like to acknowledge the authors for their contribution to this project as well as the staff and our patients at MGH; being trusted with the assessment of someone's child is an honor, and through this work we learn how to more effectively support a child's development. We would like also to acknowledge and thank the Springer Editors, specifically Nadina Persaud and Karthik Periyasamy, for their patience and support from the inception to the completion of this project.

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Part I

Introduction to Assessment

1 An Introduction to Assessment

H. Kent Wilson and Ellen B. Braaten

Core Components of Assessment

Assessment, broadly defined, is used in all clinical practice to help answer pertinent clinical questions and to make informed decisions about diagnosis and treatment. A pediatrician conducts an assessment when reviewing a sick child's symptoms, and a psychiatrist uses assessment when inquiring about a patient's response to medication. For the purposes of this book, however, assessment is defined as a process through which hypotheses are generated and then formally tested using a variety of procedures. These types of evaluations use measures that have been standardized to have adequate reliability and validity. Most of this chapter will focus on psychological assessment, but principles of psychological assessment are also used in other formal assessments completed in other professions (e.g., a speech/language evaluation). Jerome Sattler [14] describes the "four pillars" of assessment as consisting of interviews, behavioral observations, informal assessment procedures, and norm-referenced measures. It is the integration of this data that allows the assessor or examiner to make informed clinical interpretations about a person's functioning and the etiology of his or her challenges.

Interviews provide important information for an assessment as they help an examiner understand a child's history and context. Interview sources almost always include parents/guardians, the child being evaluated, and often other caregivers, such as teachers. In a formal assessment, the interview can take several forms. Unstructured interviews are open-ended and flexible. Semi-structured interviews (e.g., the Autism Diagnostic Interview – Revised; ADI-R) provide a specific list of questions that are often focused on the reason for referral but can be changed as needed. Structured interviews (e.g., the Structured Clinical Interview for DSM-5; SCID-5) provide a regimented and comprehensive set of questions that are usually designed to determine if a child meet's diagnostic criteria for any specific psychiatric disorder.

Behavioral observations are an essential component of an assessment. They provide indications about a child's mental status, social functioning,

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relationship with parents, and attitude toward the assessment. Observations about a child's effort, cooperation, and attention help to inform whether test data is valid. Furthermore, process-oriented observations (i.e., observations focused on how a child engages with test items) enrich test data and interpretation by informing what factors contributed to the scores they achieved. For example, difficulties with fine motor control might be observed on a construction task that assesses visual perception, and thus, a below-average score on such a measure may reflect fine motor difficulties instead of the primary construct it measures. In addition to observations of a child during a formal assessment, observations are sometimes completed of a child at school or in other settings to obtain information about social and behavioral functioning in a naturalistic environment. These can range from being unstructured observations that focus on a range of factors (e.g., child's attention, social interactions and relationships, knowledge of routines, etc.) to more structured observations of specific behavioral targets. For example, frequency coding is sometimes used to assess on-task behavior and attention, or functional behavioral assessments are used to help determine the purpose or reason for a behavior with data focused on gathering information about antecedents to behavior and potential reinforcers for the behavior.

Informal assessment procedures are procedures that deviate from the standardized procedures of a test, have standardized procedures for administration but are interpreted qualitatively, or are informal activities that are implemented by an examiner to obtain additional information about a child's functioning. These may include reviews of records and previous evaluations to understand history and to assess progress, playing with a child to assess social functioning, projective drawings, and testing limits. Limit testing in particular is a strategy that seasoned examiners will employ to better understand factors that contribute to a child's difficulties on specific measures. Once standardized procedures have been completed for a formal test (yielding the "score" for that test), an examiner may adjust procedures for the task and readminister items or administer other items for a variety of reasons, such as to see if a child can complete a task that they could not do earlier with additional structure or support.

Norm-referenced measures are the most important aspect of formal assessment that distinguishes it from other sorts of evaluations. A norm-referenced measure is a measure or "test" that has been standardized on a group that is clearly defined in some way; this group is called the "norm group." The norm group is the group of individuals who took the test when it was developed, and the group is typically chosen so that the test can then be used on a similar population with findings that can be generalized to that population. Therefore, characteristics such as the age, gender, socioeconomic status, geographical location, and ethnicity of the norm group are important to consider to determine if a norm-referenced measure is standardized with a group that is representative of the child being assessed. Most test developers use US census data to select a sample of children that is representative of the nation as a whole. Typically, the normative group for tests is a "non-clinical" sample, meaning individuals without disabilities/diagnoses. However, some measures include clinical samples or are solely normed on a sample of individuals that meet criteria for a specific diagnosis or disability; this allows for comparisons of the child's functioning or symptoms to those who have the disorder in question and is particularly helpful when a disorder is rare. Another core characteristic of norm-referenced measures is that their authors design specific standardized procedures for administration. Examples of standardized procedures include a specific script that is used when introducing a measure to an examinee and specific scoring rules that dictate when tests are to be discontinued. Standardized procedures help to limit sources of error and examiner bias and maximize the extent possible that assessment results can be compared equitably across settings and examiners (i.e., because an examiner in Minnesota administers a measure in exactly the same way as an examiner in Georgia, the results can be considered to be comparable). Because norm-referenced measures place a high value on standardization and data-driven analysis, quality norm-referenced measures are researched thoroughly in their development and after their publication to ensure that they have sound psychometrics.

Psychometrics of Norm-Referenced Measures

When conducting an assessment and choosing the measures that will be used, it is incumbent on the examiner to understand the theoretical underpinnings of a measure, practical applications (e.g., time needed for administration, appropriateness of the standardization sample, etc.), and the measure's psychometrics. Psychometrics refers to the construction of assessment measures and the study of the measure's reliability and validity. While each measure is typically published with a technical manual that details its construction and a data analysis of reliability and validity, there are also handbooks that are published regularly that provide descriptions of common tests and reviews of their psychometrics. Examples of these handbooks include *Measures for Clinical Practice* [8] and the *Mental Measurements Yearbook* [2]. Reviews of measures are also commonly published in peer-review assessment journals. Key components that inform the utility of an assessment measure are discussed in greater detail below.

Standardization Sample

Norm-referenced measures provide data that indicate how scores on the measure were distributed in the standardization sample (i.e., the variation in performance on a measure that was observed in a sample); this data then allows one to measure how someone's performance compares to the typical distribution seen in the sample. In child/adolescent assessment, the sample is particularly important because development results in rapid changes in a typical child's capabilities. However, the extent to which an individual's performance on a measure has meaning depends on how similar that individual is to the group on which the test was normed [3]. For example, if a test was standardized on a group of adolescents aged 14–18 in an inpatient psychiatric setting, then useful comparisons can be made as to how similar or dissimilar the individual being assessed is to such a sample. If an individual is dissimilar from the standardization group, then limited information can be drawn from assessment results. Therefore, a competent examiner will consider the standardization sample in the interpretation of assessment results.

Groth-Marnat [5] suggests that there are three primary questions that an examiner should consider to determine if the norms of a test are adequate. The first question is whether the standardization sample is representative of the individual that is being assessed. As noted earlier, many of the most common assessment measures use stratified sampling to obtain a sample that is representative of the nation as a whole; therefore, for these measures, the most common comparison group is that of a typically developing person in the United States. This is important to consider as how an individual compares to the average child in the United States may be different from how they compare to the average child in their community. For example, a child who obtains an "average" IQ score may not be "average" in their community if their community has a high level of socioeconomic advantage. Not only should the makeup of the sample be considered, but the size of the sample is also important. If the sample size is too small, then test results may not provide valid estimates because the sample cannot account for random fluctuation. Finally, Groth-Marnat suggests that, in addition to national norms, a test that has specialized subgroup norms allows an examiner to make more specific comparisons between the individual being assessed and a subgroup to whom that individual may belong (e.g., if there is a question of an autism spectrum disorder, then having norms for a subgroup of individuals with autism can be helpful).

Reliability

A measure's reliability refers to its consistency, stability, and predictability. Measures are published with a variety of reliability statistics that convey the extent to which scores that are obtained by an individual will be the same if that individual is assessed again on the same measure in different conditions (e.g., if assessed by a different person). Thus, several of the different estimates of reliability that will be reviewed below provide an estimate of the possible range of error that is seen in scores. It is understood that all measures have error that cannot be eliminated (e.g., examinee mood, rapport between examiner and examinee, administration or scoring errors, inattention by examinee); nonetheless, one of the primary goals when constructing a measure is to reduce the amount of measurement error as much as possible. Standardized administration procedures are one of the primary methods used to reduce measurement error. The more that measurement error is reduced, the more likely that differences between the individual being assessed and the sample are due to true differences rather than random fluctuation. While there are many different measures of a test's reliability, the primary areas that are considered are how reliable a test's results are from one time to another (test-retest reliability), the internal reliability of a test as a whole (alternate forms reliability), the consistency of a test's specific items (split-half reliability), and the consistency in agreement between examiners (interrater reliability).

Test-retest reliability is assessed by administering a test and repeating it on another occasion; the reliability coefficient that is calculated then reflects the correlation between the scores on a test from the same person on two separate occasions. A high correlation indicates that test results are less due to random fluctuation and can be generalized from one setting to another. High test-retest reliability should be expected if the construct being assessed is considered to be stable. For example, intelligence is considered to be relatively stable beginning in middle childhood; whereas anxiety is less stable and can be more dependent on situational factors. Therefore, establishing high test-retest reliability for an intelligence test is more important than it would be for a test of anxiety. In addition, the amount of time between test administrations can affect test-retest reliability. Some tests should not be repeated within a specified amount of time due to "practice effects." Practice effects reflect improvement on the second administration of a test due to the impact that practice and memory (from the previous administration) has on the second. Therefore, when a test is developed, test-retest reliability estimates are used to generate guidelines for how much time should pass before a test can be administered again reliably. This is an important area for examiners to consider when conducting reevaluations to assess an individual's progress.

Alternate forms reliability refers to the consistency between an individual's performance on a test and a parallel form of the test. Many measures are developed with parallel forms to minimize problems with test-retest practice effects. While these measures eliminate memory of specific items, they cannot eliminate effects that can occur when an individual adapts to the material or content of a measure because of increasing familiarity. In addition, the parallel forms of the measures must indeed be parallel (i.e., test the same construct in an equivalent manner). Therefore, alternate forms reliability coefficients provide information as to how consistently these alternate forms of a test measure the same construct.

Split half reliability is used to measure the internal consistency of a test by splitting test items in half and measuring the correlation between one half and the other. Effects of time have little to no effect on this form of reliability as the test is completed in one administration (versus test-retest reliability). In general, the more items a test has, the greater the reliability, because a larger sample size can limit fluctuations related to error. Therefore, the split-half method can have limitations as it reduces sample size of test items by half.

Interrater reliability is important for any test that has items that can involve examiner error or subjectivity in its scoring. For example, while many projective measures (such as the Rorschach Inkblot test) or observation measures (such as the Autism Diagnostic Observation Schedule) have specific standardized procedures regarding administration and scoring, there is subjectivity involved in the scoring. To ensure that measures that involve subjectivity can be scored reliably, test-retest reliability analysis is needed. Common strategies for assessing interrater reliability are to obtain responses to a measure from a single participant and have two separate examiners score those responses. The two sets of scores are then correlated to determine a reliability coefficient. Establishing evidence that a test can be administered reliably between two examiners does not ensure that any examiner can administer that test; this is why assessment requires advanced supervised training to ensure that examiners develop competence with the measures that they administer.

Validity

Without adequate validity, an assessment measure is useless. While reliability describes how consistently a measure assesses a construct, validity determines whether the construct is being measured accurately. Reliability is necessary for a measure to have validity, but validity is not necessary for a measure to have reliability. Therefore, a valid measure is one that accurately assesses the area that it is intended to measure in a reliable manner. Validity can be difficult to establish or assess as many variables, particularly those in psychological assessment, are not tangible (e.g., intelligence, personality). When abstract concepts are being assessed, the developer of the test should use evolving research to define/describe that concept and develop test items that are informed by theory and/or research to measure the concept. To establish validity, a relationship must be established between those items and a tangible piece of data that is outside of the evaluation. The three primary methods of establishing this validity are construct-related, content-related, and criterion-related.

Construct validity is focused on measuring the extent to which a test assesses a concept. Groth-Marnat [5] describes three general steps for assessing construct validity. First, the test developer analyzes the trait or concept. Through this analysis, the developer can identify how the concept may relate to other measurable variables. Finally, the developer tests whether or not the relationship between the test and those variables indeed exists. For example, a test measuring intelligence would be expected to correlate with performance on academic measures. Construct validity is also sometimes established by correlating performance on a test with performance on a test that assesses the same trait. The other two major forms of validity described below help to establish overall construct validity.

Content validity is an important consideration in the initial development of a test. When selecting/creating items for a test, developers should be considering the inherent skills or traits involved in the variable that is being assessed. Test items are created based on this process, and ultimately the collection of items is analyzed to determine the extent to which they sufficiently assess all aspects of the concept/trait that is being measured. This is typically described in a measure's technical manual with research that justifies the content of the test items.

Criterion validity is also referred to as predictive or empirical validity. To have criterion validity, performance on the test should be related to a different measure that is theoretically related to the construct being assessed. Criterion validity has two different forms, concurrent validity and predictive validity. Concurrent validity refers to the relationship between performance on the test and a related measure that is taken at the same time. For example, concurrent validity for a test of intelligence may be established by comparing it performance on a recent test of academic achievement. Predictive validity is established by comparing performance on the test with performance on a related measure some time later. For example, performance on an aptitude test may be compared to ratings of job success a year later. Thus, the importance of concurrent validity or predictive validity depends on the purpose of the assessment, to understand current functioning or to help with making decisions about future functioning.

Common Assessment Procedures

When an assessment is completed, it typically follows a common set of procedures. This chapter will focus specifically on procedures for psy chological/neuropsychological assessments, but these procedures are common to most other evaluations that use standardized assessment with norm-referenced measures. Once a child is referred for and scheduled for an assessment, the examiner will use information gathered during the intake (i.e., reason for referral, presenting problems, relevant history) to generate hypotheses that help to inform the assessment. In some cases a fixed battery is selected (e.g., the Halstead-Reitan battery is a fixed battery used for some neuropsychological assessment or fixed batteries are often used in assessment for clinical research), but in other cases, a flexible approach is used for assessment. A flexible approach is most often used in child clinical settings, particularly those that do not have a research component. Hypotheses around differential diagnosis, current level of functioning, and a child's temperament/cooperativeness are used to select a battery of tests. This approach allows the examiner to change the course of the assessment (i.e., add additional measures or choose a different measure) depending on the performance of the child during the assessment. A flexible approach is particularly important in child assessment as the ability level of children can vary greatly and performance can be so dependent on cooperation and rapport (i.e., a positive relationship between the examiner and examinee). Thus, when a child and his or her guardian present for the assessment, it is incumbent on the examiner to focus initial interactions on establishing a good rapport with the child, ease any possible anxieties or misconceptions about the assessment, and obtain consent for the assessment to proceed. Using the four pillars of assessment, the examiner will conduct interviews with the guardian and child, keep notes regarding behaviors that are observed during the assessment, use informal assessment procedures, and use norm-referenced tests to address the referral questions. Once the face-to-face assessment is completed, examiners score all tests and analyze findings from both formal testing and other sources of information to help interpret the data. Oftentimes collateral information is sought as well, such as interviewing a teacher, consulting with a treating psychiatrist, or seeking records from other institutions. The results and interpretation based on this information is then written into a report. Usually guardians are invited to meet with the examiner after this process is completed for a "feedback session" during which time assessment results are explained. Assessments themselves, and the feedback session in particular, can be a moment for effective therapeutic intervention. Various therapeutic models of assessment have emerged [6, 7, 11] that define a brief, structured, and empirically based approach to completing evaluations and delivering feedback in a manner that makes the assessment process itself therapeutic rather than simply a precursor to the treatment that usually follows assessment. Indeed, a meta-analysis of psychological assessment as a therapeutic intervention identified robust findings whereby psychological assessment procedures that are combined with personalized and collaborative feedback had positive effects on the subsequent treatment [12].

When a child receives a formal assessment via the public school system in the United States, it is typically part of a process for evaluating whether or not the child is eligible (or continues to be eligible) to receive special education services. The procedures for initiating these evaluations are discussed in Chap. 13 of this book. In the case of these assessments, the feedback that is provided regarding findings is typically delivered in a "Team" meeting when individuals who can interpret the assessments share the findings with the educational "team" including the child's caregivers. The types of assessments that are completed in special education evaluations are based upon the suspected area of disability and are divided by specialty area. Such specialty assessments are also available in other settings. The various types of assessments that a child could be referred for are described briefly below.

Types of Assessments

There are many different assessments that can be completed in childhood, and this chapter will focus on formal assessments that use norm-referenced measures. The following are the types of assessments that a child may undergo to help guide when such a referral might be indicated.

Developmental assessments are completed for infant to preschool-aged children who have suspected developmental delays. The developmental assessment can be completed by a single examiner or by a team of professionals that could include a pediatrician, speech/language specialist, audiologist, physical therapist, occupational therapist, and child psychologist. While there are formal tests that can be completed in children as young as newborns, these assessments are more reliant on behavioral observations and data from caregivers than are assessments in older children.

Psychological assessments can be quite variable but generally consist of an assessment of an individual's cognitive functioning (usually including tests of intelligence) and adaptive functioning including daily living skills and emotional/behavioral functioning. A psychological assessment is necessary when ruling out an intellectual disability and can be combined with an educational assessment to form a psychoeducational assessment for ruling out learning disorders. Psychological testing to assess personality and psychiatric functioning in children can consist of norm-referenced questionnaires and personality inventories and projective tests.

Projective tests are measures that are used to evaluate a child's psychological or emotional functioning. Psychological functioning includes how well people manage and express their emotions, perceive the world realistically, cope with conflict, and understand themselves and their relationships and effects on others. Projective tests are based on the assumption that individuals project their unconscious feelings and beliefs when they respond to ambiguous stimuli. These tests require individuals to give answers to questions about vague stimuli, such as inkblots or pictures, or respond to open-ended instructions such as "draw a picture of your family doing something together." The Rorschach is arguably the most widely used projective test, and while it has been the subject of thousands of studies, it and other measures of projective functioning are not standardized measures.

Educational assessments obtain data about a child's academic skills primarily in the three foundational academic areas: reading, written expression, and mathematics. These tests can be paired with information about cognitive functioning to determine if children are achieving academically at a level that is commensurate with their cognitive or intellectual potential. This method of identifying learning disorders is commonly referred to as an ability/achievement comparison, with the premise being that if a child's academic skills are substantially lower than one would expect based on the child's intelligence, then the child may have a learning disorder (provided that medical or contextual factors are not the primary cause of the delays). Learning disorders may also be supported by findings that indicate that a child's academic skills are below age/grade level even after the child had been receiving of intervention.

Occupational therapy assessments examine a child's gross motor, fine motor, visual motor, visual perceptual, handwriting, and daily living and sensory processing skills. The focus of an occupational therapy evaluation is to determine if there are underlying skill deficits or processing difficulties that impact an individual's ability to perform daily living activities. For example, fine motor delays can lead to problems with daily activities such as tying one's shoes or handwriting.

Speech/language assessments measure a child's communication skills. This includes examining both receptive (i.e., comprehension) and expressive language. These evaluations are also used to obtain in-depth information regarding a child's use of grammar and syntax, fluency and prosody of speech, and articulation. Problems with communication or following directions or comprehending material can indicate the need for a speech/language evaluation.

Physical therapy assessments are conducted when there are questions about a child's strength, balance, and general gross motor skills. A physical therapy assessment is necessary for identifying areas that need attention in physical therapy if there are gross motor deficits. These evaluations are often conducted in a one-on-one setting using play-based techniques (e.g., climbing upstairs, jumping off steps, catching a ball).

Neuropsychological assessments are comprehensive evaluations of cognitive processes. While cognitive functioning is evaluated in a psychological assessment, a neuropsychological assessment provides more in-depth information about the neurological processes that might be impacted by various medical or psychiatric conditions while also considering other aspects of development. A neuropsychological assessment may assess attention and concentration, verbal and visual memory, language and auditory processing, visual-spatial processing, gross and fine motor functions, executive functioning, academic achievement, social skill development, and emotional and behavioral functioning.

Understanding and Interpreting Scores in Assessments

As noted above, interpretations offered in assessment reports are based on the integration of findings from interviews, behavioral observations, informal assessment procedures, and norm-referenced measures. In particular, results from norm-referenced measures are quantitative in nature and are the central data for an assessment. They provide information about a child's performance relative to the norm group, and this data is typically provided in assessment findings through the report of a number of different scores. This section of the chapter will describe how scores are derived and will detail common scores found in assessment reports to help the reader better understand the meaning of these scores and how they can be interpreted.

Standardizing Scores and the Normal Curve

A child's direct performance on an assessment measure results in a *raw score*. The raw score is essentially a report of the number of points that a child earned based upon correct or incorrect responses or the frequency of some behavior. For some measures, a single raw score number may be directly associated with a single correct response on an item, but for other measures, a single item may be worth more than one point. Thus, raw scores are not measured in equal units, which makes comparison of these across tests meaningless. In order to make a raw score (or the child's performance) meaningful, a referent is required. In norm-referenced measures, the referent is the distribution of scores from the standardization sample or norm group, which allows a child's performance to be compared to the typical distribution of scores from the norm group. As noted earlier, for this comparison to be meaningful, the norm group should be adequate (i.e., of a sufficient size) and relevant to the child being assessed. In order to interpret raw scores, they are compared to the distribution of scores from the norm group to calculate a standard score. Two of the most important properties of the norm group are the mean and standard deviation of scores. The *mean* is the average score for the norm group, and the *standard deviation* provides information about how much variability in performance is seen in the norm group. For example, when a test has a low standard deviation, the individuals in the norm group achieved scores that were fairly close to each other, whereas a test with a high standard deviation saw more variability in performance among the norm group. Having an established mean and standard deviation from the norm group allows for an individual's performance on a test to be compared to the norm group, and this information is used to standardize a raw score on the normal curve or the bell curve. The *normal curve* (see Fig. 1.1) is a graphical representation of the distribution of scores, which operates under the assumption that the performance of most people will be close to average (or the mean) and that great variations from the mean are rare. Using the normal curve, approximately 68% of individuals will score within a standard deviation of the mean, approximately 95% will score within two standard deviations of the mean, and approximately 98% will score within three standard deviations from the mean. For example, for a test of reading accuracy, a sample of 100 7-year-olds found that the average number

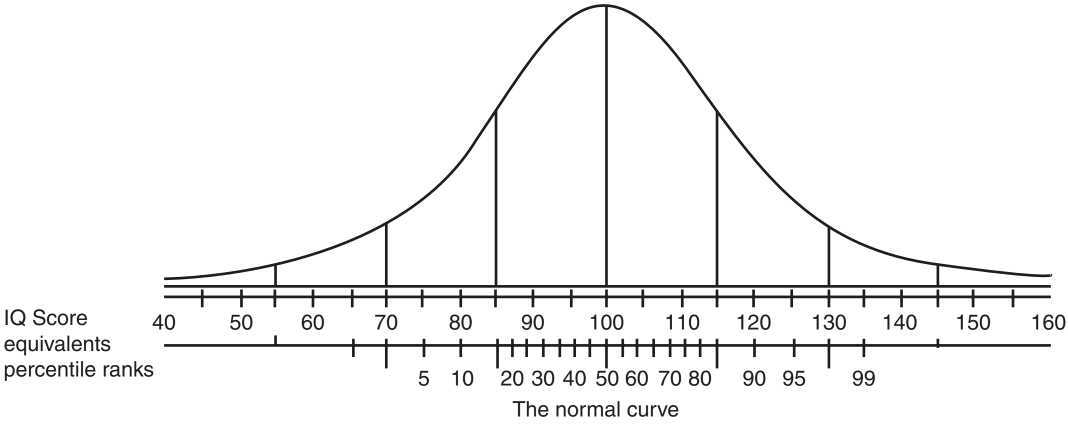

Fig. 1.1 The normal curve expressed in percentiles and standard deviations

of words that could be read accurately was 100 with a standard deviation of 10. In this case, if an 8-year-old child took the test and accurately read 105 words, they would have scored within one standard deviation of the mean.

By standardizing raw scores, a child's performance on a test can be easily compared to another child's performance. In addition, standard scores are on a scale that is measured in equal units, which allows scores to be compared to each other. This is important when identifying a child's strengths and weaknesses as achieved standard scores that are significantly higher than other achieved standard scores identify areas of strength. A general rule of thumb is that if the difference between two standard scores is equal to or greater than a standard deviation, then that difference is statistically meaningful. Statistically meaningful differences among scores are used by examiners to inform interpretation regarding an individual's strengths and weaknesses.

Identifying the Referent or Norm Group

As noted above, standard scores are based on the referent, so it is important for an assessment report to detail the sample to whom the individual being assessed is compared. Most commonly, performance on assessment measures compares an individual's performance with that of someone in his or her age-group using *age-based norms*. In some cases, however, comparing individuals based on age may be inappropriate. For example, *grade-based norms* that compare an individual to other individuals who are in the same grade would be indicated if an individual is in a grade that does not typically correspond with his or her age. For example, a 10-year-old child with a late birthday who has also been retained a year in school could be in the third grade, and comparing that child's performance on academic tests with the performance of other 10-year-olds would be inappropriate as most other 10-year-olds in the sample would have received education at a higher grade level. Similarly, *gender-based norms* are sometimes used, particularly when assessing emotional/behavioral functioning. Comparing an individual with a sample of individuals who are the same gender can be more appropriate when assessing a behavior that varies in frequency by gender. For example, hyperactivity is more commonly seen in males than in females, so gender-based norms can help to distinguish atypically high levels of hyperactivity in a female compared to a sample of other females more effectively than if using a sample that combines males and females.

Types of Standard Scores

One challenge when reading an assessment report is that standard scores are often reported according

Table 1.1 Scales for common standard scores in assessment reports

Scale	Mean	Standard deviation
Z-score	0	1
Wechsler IQ or standard score	100	15
Stanford-Binet IQ	100	16
T-score	50	10
Scaled score	10	3
Stanines	5	1.96

to different scales. The scales with which a score is reported can vary depending on the test. Table 1.1 depicts the most common standardized scores, with their mean score and standard deviation. The Z-score is the easiest standardized score to interpret because the mean is anchored at zero and a standard deviation is a single unit. Z-scores will be used here as an illustration for how standard scores are calculated. When calculating a child's standard score from a test, the examiner uses data provided by the test developer regarding the distribution of raw scores. Oftentimes, this distribution of scores is provided in a conversion table in the measure's manual that details what the conversion is between the raw score and the standardized score. This conversion is based on the following formula: a standardized score (Z) is equal to the difference between a child's raw score (X) and the mean (M) for the norm group divided by the standard deviation (SD) of the norm group or $Z = (X - M)/\text{SD}$. Using the previous example of the performance of an 8-year-old child on a test of reading accuracy, a raw score of 105 in a sample that has a mean of 100 and a standard deviation of 10 results in a standardized *Z*-score of 0.5. Tests often do not report standardized scores using *Z*-scores because half of the *Z*-scores that would be achieved are negative and *Z*-scores use decimals that can make them appear awkward and difficult to interpret. For example, IQ scores are typically reported using Wechsler Standard Scores (mean of 100 and standard deviation of 15), which makes telling parents that their child has an IQ of 85 much less awkward than reporting an IQ of −1. However, the use of different metrics for reporting standardized scores can be confusing, so understanding the scales can allow someone to compare them effectively.

Other Common Scores

There are several other derived scores (i.e., scores that are converted from raw scores) that are often found in assessment reports. These relative-status scores are percentiles, age-equivalents, and grade-equivalents. While these can convey important information, they can be easily misinterpreted. These relative-status scores are not standardized scores and thus do not present information in equal units. A standardized score can be easily compared to another standardized score (i.e., the difference between one standardized score and another means the same thing regardless of the score). However, these relative-status scores are *ordinal units* or ranks, and the difference between units is not equal.

Percentiles are based on the standardized score and represent a point in the score distribution whereby a certain percentage of the normative population fell below. For example, if one obtains a standardized score that is at the mean, it would be at the 50th percentile, indicating that 50% of the population scored below that individual. While these ranks can be easy to interpret, they can also be misleading. The difference between the 37th percentile and the 63rd percentile may appear large (26 points) but in actuality represents just about half of a standard deviation of difference. In contrast, the difference between the 98th percentile and the 99th percentile is a full standard deviation. The reason for this is that percentiles in the middle of the distribution fall in the middle of the normal curve, which is also where most of the population falls. Table 1.2 illustrates how percentiles correspond with various standardized scores that are commonly provided in assessment reports.

Age- and grade-equivalents are similar to percentiles in that they provide some information about the individual's score relative to the norm group, but the measure that is provided is not standardized. *Age-equivalents* translate an individual's test performance in terms of the performance of a typical child of a given age. For example, an individual who achieves an age-equivalent of 6:3 could be said to have scored as well as a typical 6-year, 3-month-old.

Table 1.2 Conversion table for common standard scores

Standard score (*M* = 100; SD = 15)	T-score (*M* = 50; SD = 10)	Scaled score (*M* = 10; SD = 3)	Z-score (*M* = 0; SD = 1)	Percentile
145	80	19	3	99.9
140	77	18	2.67	99.6
135	73	17	2.33	99
130	70	16	2	98
125	67	15	1.67	95
120	63	14	1.33	91
115	60	13	1	84
110	57	12	0.67	75
105	53	11	0.33	63
100	50	10	0	50
95	47	9	−0.33	37
90	43	8	−0.67	25
85	40	7	−1	16
80	37	6	−1.33	9
75	33	5	−1.67	5
70	30	4	−2	2
65	27	3	−2.33	1
60	23	2	−2.67	0.4
55	20	1	−3	0.1

Notes: *M* is mean, *SD* is standard deviation, *T*-score and *Z*-score numbers are approximated in some cases

Similarly, a *grade-equivalent* translates an individual's performance in terms of the performance of a typical child of a given grade level. For example, an individual who achieves a grade-equivalent of 2.0 could be said to have scored as well as typically developing child at the beginning of the second grade. Age- and grade-equivalents are calculated using raw scores, with the equivalent score being the median score that is obtained by individuals at that age or grade level. While age- and grade-equivalents have intuitive appeal, they should be interpreted with caution as they can exaggerate the significance of small differences. In some cases, individuals who score within a standard deviation of each other (thus achieving scores that are not significantly different from each other) could have age- or grade-equivalents that vary by several years. However, because they are based on raw scores, they can be useful as a rough metric for measuring progress from one assessment to another. For example, when comparing an individual's scores on a test of reading from a current evaluation and from an evaluation completed a year earlier, it can be difficult to assess progress based on standardized scores because they are typically standardized based on age. Two scores that are exactly the same might intuitively suggest to someone that the individual has not made progress, but because the score is based on age level, it would actually indicate that the individual made about as much progress as typically developing peers within that year. Age- and grade-equivalents can show that progress more explicitly as any increase in raw scores from one evaluation to the next evaluation will result in an increase in the age- or grade-equivalent.

Consuming an Assessment Report

Typical Structure of an Assessment Report

While assessment reports can vary widely in length and style, there are several commonalities that are seen in nearly all reports. These will be reviewed briefly to guide the reader to understand the purpose of the section and how to consume these most effectively. The *reason for referral* begins most reports and typically includes brief background information on the patient such as age and presenting concerns, the name of the referring provider, and the specific questions for the evaluation. Because an assessment should be driven by the referring concerns/questions, the information contained within this section helps to guide what measures were selected and should be directly addressed by the findings. *Background information* is also included in most reports, which should detail the history relevant to the patient and the presenting problems including relevant family history, medical and developmental history, academic history, and history of presenting problems. As will be discussed further below, data obtained from norm-referenced measures should be interpreted within the child's context, so this background information should be essential to understanding the child and help to inform the assessment findings. *Behavioral observations* are always included in assessment reports and should include a statement of validity. Behavioral observations describe what was observable during the assessment, which may not be captured by norm-referenced measures. It can include qualitative information about a child's mental status, language, social reciprocity, comfort in the evaluation, and cooperation and effort. This information helps to inform validity of test results, which should be stated somewhere within the report. To interpret test results, one must first consider whether they are valid or not. Selecting measures with good reliability and validity as described earlier is the first step, but ensuring good rapport, cooperation, and effort from the child is essential for validity. In some instances, however, oppositional behavior, impulsivity, inattention, poor language comprehension, anxiety, and other factors can interfere with testing, and it is the examiner's responsibility to provide an opinion as to whether such factors indeed impacted test results and to use caution when interpreting such data. There is much variability in how *test results* are presented in reports. Most reports include tables that provide standardized scores from norm-referenced measures and other key scores such as percentiles, and age- and grade-equivalents as described above. However, simply providing scores is inappropriate, and a narrative description of the scores that offers interpretation should be included. This can often be a lengthy section of the report and serves as a useful area of reference when interested in a specific finding. The *summary* section of the report should provide the interested reader with the key findings from the evaluation and should address the questions that led to the referral. It may include diagnoses, when relevant, and should be written in language that is friendly to a lay audience, since the primary consumer of assessment reports in child assessment is often parents. Finally, all reports should include *recommendations*, which should flow directly from test results and relate directly to the individual child's needs. These are informed by the presenting concerns discussed earlier and how test results help to understand those concerns. Individualized recommendations regarding needed treatment or referrals for other evaluations should be included as well as guidance to parents and other caregivers (e.g., teachers).

Important Factors to Consider When Reading an Assessment Report

Context is an essential factor that should be considered by examiners when interpreting data and making diagnostic decisions or case conceptualization. Treatment history can impact test results and should be considered. For example, if a child is taking medication for symptoms of an attention-deficit/hyperactivity disorder (ADHD) on the day of the evaluation, and test findings indicate intact attention, then it is essential to know that such findings occurred while taking medication. Similarly, interpretation of findings from academic testing can vary considerably depending on context. For example, if a child with a history of reading difficulty who has been receiving one-on-one reading tutorials for 5 years scores within the lower end of normal limits on tests of reading, the interpretation could be much different than if a child without such a history has similar findings.

Multicultural assessment reflects an awareness that context is important with regard to test findings and represents an attempt to consider and mitigate how cultural context can impact assessment results and decisions. The American Psychological Association has ethical standards that dictate that "when interpreting results … psychologists take into account the purpose of the assessment as well as the various test factors, test-taking abilities, and other characteristics of the person being assessed, such as situational, linguistic, and cultural differences, that might affect psychologists' judgements or reduce the accuracy of their interpretations" (Ethical Standard 9.06, [1]). Multicultural assessment involves understanding the cultural context in which the assessment is conducted and interpreting results within that context. Culturally competent assessment requires not only knowledge of and experience with populations from different backgrounds than the examiner but also an awareness of one's own personal biases and the biases that can be present in norm-referenced testing. Entire books are written on culturally competent assessment and biases in testing, and the reader is referred to the handbook edited by Suzuki and Poterotto [15] for a particularly good review in this area. As a consumer of psychological assessment reports, the reader needs to have reasonable assurance that the assessment that was completed was done so in a culturally competent manner. Clues to this come from how an evaluator qualifies and interprets findings.

Linguistic proficiency is one important thing to consider. A recent survey of neuropsychologists in the United States found that a vast minority (15%) reported performing assessments in a language other than English and only 41% of those who provide such assessments do so at a native/bilingual proficiency [4]. This reflects a dearth of clinicians available to provide assessments in a person's native language. A patient's limited fluency in English can artificially lower test scores, and even nonverbal tests have been shown to have cultural bias [13]. While many individuals who assess others in their non-native language report using interpreters, this can compromise standardization as most common tests administered were not standardized and normed with the use of interpreters. When a patient is being evaluated in their second language or with the use of interpreters, caution should be applied to test findings, and it is incumbent on the examiner to explicitly note when issues related to linguistics may have impacted performance.

Understanding an individual's background should help to inform culturally competent assessment. For example, a child who spent 2 years in a foreign orphanage before being adopted may present with English as their primary language at the time of an assessment at age 14, but a lack of early language exposure may have limited overall language development. Results from intelligence testing might find weaknesses in verbal abilities that deflate the overall intelligence quotient, and a culturally competent examiner would understand these findings in light of the history versus describing the individual as having below-average cognitive potential. Likewise, tests of vocabulary may include items that are biased toward Caucasian/Western cultures and reflect one's Western vocabulary versus their pure vocabulary knowledge. Nonverbal tests have been considered to be more "culturally fair" than verbal tasks, but studies have identified that biased items are as likely to be found on nonverbal tests as they are on verbal tests [13]. While nonverbal testing certainly offers advantages when there are concerns about an individual's linguistic understanding during an evaluation, it should not be the only approach. Supplementing findings with information from collateral contacts and behavioral observations helps to contextualize and interpret data. Some tests also include alternative norms, such as making comparisons of performance not just against those of the same age as the patient but against those who have the same educational level. Some tests also allow for adjustments based on bilingualism, socioeconomic status, and racial/ethnic groups, but these are less widely accepted [9]. While race-based norms can reduce the rate of false-positive errors (e.g., identifying someone who is cognitively intact to be impaired), [10] argues against the use of race-norming by suggesting that they can help to support inferior/superior treatment of people from different racial groups, may result in false negative errors, and have other issues such as having an impossibly high number of groups from which norms may be needed. These are a few of the many issues that a culturally competent assessor will consider when attempting to identify appropriate tests to use for an individual and how to interpret data.

Analyzing Data

It is the responsibility of the examiner to interpret scores and to present data in an easily understandable manner. However, there is much variability in the quality of reports and their accessibility to lay people, and there is rarely a single individual who can help to integrate multiple assessment reports. Therefore, a brief guide to reviewing scores within an assessment report is provided. First, as noted above, it is important to understand the context within which scores were produced and reports should detail validity of test findings, whether the patient was taking medication on the day of the assessment, and other key information that impacts findings. While they have advantages, caution should be made in making comparisons of scores based on percentiles or age/grade equivalencies given the limitations of these scores as described above, and use of standardized scores allows for comparison of scores across tests. Table 1.1 should provide a useful guide for doing so when tests are reported using different types of standardized scores. In general, strengths and weaknesses of the individual can be understood by comparing how the individual performed on tests as compared to peers and how they compared to themselves. Standardized scores provide a peer-based measurement, and a general rule of thumb is that if a score is more than a standard deviation above or below the mean, then it reflects a strength or a weakness, respectively, compared to the peer/referent group.

Ability/achievement discrepancies can be helpful for understanding an individual's personal strengths and weaknesses. For example, a highly intelligent individual may score within to above normal limits across all tests in an assessment, and a simple comparison to peers would not reveal concerns. However, discrepancies within the individual's profile can reflect underlying difficulties. For example, an individual whose Full Scale Intelligence Quotient is 130 (two standard deviations above average) may score within normal limits across tests of reading, but these scores are within the lower end of average (e.g., a standard score of 90). A 40-point discrepancy between their ability and their achievement is statistically significant (again a general rule of thumb for identifying statistically meaningful differences between scores is a standard deviation, and a more conservative difference would be a standard deviation and a half). If that individual also has a history of difficulties with reading acquisition, a family history of dyslexia, and relative weaknesses in other areas associated with dyslexia, then that profile could lead to a diagnosis of a learning disability, when a simple peer-based comparison would indicate "average" reading skills.

Inter- and cross-domain scatter (i.e., scores that are discrepant from each other) can also signal underlying strengths and weaknesses. Significant differences across domains speak to an individual's personal strengths and weaknesses and can in some instances inform diagnostic decisions. For example, a significant weakness in verbal abilities compared to nonverbal abilities in an individual who was assessed in their native language might signal the presence of a language disorder or significant weaknesses in working memory and/or processing speed could signal the presence of a learning disability or an attention-deficit disorder. Likewise, differences within domains help to provide further information about an individual's profile. Significantly different scores on two tests of working memory could reflect lapses in attention, differences between verbal and visual memory, limited validity of testing (e.g., poor understanding of task demands or poor cooperation), and many other possibilities. These should be explored by the assessor in the report, and when discrepant scores are seen in tables of scores, the reader should refer to the narrative for more information regarding the possible interpretations that come from those discrepancies.

Assessing progress can be particularly challenging when comparing scores from one assessment to another. Because scores are calculated using a referent as described above, the score that is provided in an assessment report represents an estimate of how one compared to the referent *at that time*. Thus, a simple comparison of scores can be misleading. A standard score of 95 on a reading test during an evaluation at age 8 and a standard score of 85 on the same reading test at age 9 do not expressly indicate that the individual regressed over the past year. Instead, it suggests that the gap between their ability and those of peers widened during that time. Thus, when attempting to assess progress, comparing standardized scores can help to inform whether the individual has worked toward "closing the gap" on key areas. Raw scores provide a more direct way of comparing performance across evaluations, and relative-status scores such as age- and grade-equivalences are almost always based on raw scores and thus can be used to directly compare performances between testing periods. However, these should be interpreted with caution in section "Understanding and Interpreting Scores in Assessments" of this chapter, and progress should also be considered within the context of the individual's aptitude and the level of intervention that is being provided. Finally, it is impossible to remove error from testing, so small fluctuations in scores across testing periods could also reflect error.

Summary

A high-quality assessment can be invaluable in understanding a patient's current level of functioning to inform diagnostic and treatment decisions, and repeated assessments can be helpful for measuring progress. High-quality assessments are completed by examiners who select measures that have well-documented reliability and validity, who consider the patient's history and cultural context when interpreting findings, and who describe results in an understandable manner that directly addresses the referral question. By better understanding factors that underlie assessment, the reader should have the background knowledge to consume assessment reports and make use of subsequent chapters in this book that describe how assessment can clarify specific learning and psychiatric issues that present in childhood and adolescence.

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Part II

Neurodevelopmental Disorders

Reading Disorders/Dyslexia

2

Amanda Ward, Hillary Bush, and Ellen B. Braaten

Introduction

Children and adolescents with reading disorders display a range of potential difficulties related to foundational academic skills, including deficits in basic word reading, decoding unfamiliar words (i.e., using phonological processing to "sound it out"), reading words accurately and fluently, and comprehending written material. Further, there can be significant variability in response to reading intervention and treatment outcomes. According to the current diagnostic manual (DSM-V), reading disorders are broadly recognized as *neurodevelopmental disorders* with biological underpinnings that manifest as cognitive weaknesses associated with behavioral symptoms (i.e., challenges with reading). That is, this brain-based disorder impacts an individual's ability to process verbal information in the same way as typically developing peers, which is likely due to a combination of genetic (i.e., heritability), epigenetic, and environmental factors (e.g., prematurity/low birth weight; health factors). Given the complexities associated with the etiology of reading disorders, as well as in understanding the specific nature of reading difficulties, a comprehensive assessment approach is critical (i.e., obtaining developmental history; neuropsychological and educational testing) in developing tailored educational programming for students. To better understand the diagnosis and treatment of reading disorders, as well as a specific type of reading disorder called *dyslexia*, this chapter will review the current state of the literature, the developmental course (i.e., early signs and patterns of academic performances among individuals with reading disorders/dyslexia), and discuss various assessment approaches and tools. Additionally, this chapter will highlight conditions that commonly co-occur with reading disorders, provide a case study, as well as review gold standard treatment approaches and interventions.

Current State of the Research

A specific learning disorder in reading is characterized as a developmental disorder that is typically recognized by school age, although it may go undetected until later for various reasons [2].

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Importantly, the APA highlights a distinction between reading development and acquiring other developmental milestones (e.g., talking; walking), namely, that reading requires explicit teaching rather than a skill that emerges as a function of growth and maturation. That is, reading disorders are not the result of limited or poor academic instruction, and reading weaknesses must persist for at least 6 months despite targeted interventions. These challenges result in an “unexpected academic underachievement” or performance that is far below what would be expected for the individual’s age (i.e., age discrepancy). Finally, these challenges are also not better accounted for by other factors such as intellectual disability, physical challenges (e.g., vision/hearing difficulties), or other neurological disorders. Of note, reading disorders occur in individuals who are of normal intelligence, as well as those who demonstrate very high or gifted levels of intelligence (i.e., IQ discrepancy). For example, a student with a reading disorder may be able to maintain age-appropriate academic performances (i.e., average range for their age); however, this achievement is likely due to significant effort on the part of the student and their ability to compensate by using other cognitive skills.

A Specific Type of Reading Disorder: Dyslexia

While there are many areas in which reading skills may be compromised, one of the most common difficulties is learning to decode words – using language/phonological skills to link sounds to letters – for fluent and accurate reading [60, 64]. This distinct language-based weakness is referred to as *developmental dyslexia* and is often associated with encoding (i.e., spelling) challenges. Of note, although reading comprehension represents the most complex reading task (e.g., the ability to make sense, understand, or comprehend written material), these skills may be at age/grade level for some individuals with dyslexia [52].

While there has been some controversy over determining the most appropriate definition of dyslexia, the most robust evidence is in favor of the phonological model [59]. This theory gained favor after scientists recognized the integral role of early speech-language skills in the development of later reading skills [36]. Still, other models have suggested that basic visual processing deficits were at the heart of reading challenges (e.g., reversing letters). Later frameworks then proposed a dual-route theory (e.g., visual and phonological) for understanding symptoms of dyslexia [12]. These authors suggested that a direct/visual (orthographic) route and indirect (phonological) route are both integral in reading. More specifically, the direct route is utilized when an individual automatically recognizes a familiar word on the page (e.g., sight words), which becomes common as readers become more skilled over time. However, the indirect route is used when a reader encounters an unfamiliar word and must “sound it out” (i.e., decoding via phonological processing). Phonological awareness (i.e., the ability to associate letters with sounds) underlies the automaticity of reading and is critical in early reading development, and this skill set is often significantly impaired in individuals with dyslexia [64]. Further, phonological deficits and reading challenges have been linked across all cultures and languages [29], and Vellutino [77] showed that reversal errors were restricted to an individual’s native language highlighting linguistic over visual weaknesses. Although the visual system may play a role in specific reading challenges, deficits in language processing and the phonological system (i.e., the phonological model) remain the most compelling [52]. Importantly, Shaywitz et al. [63] highlighted that based on findings from multiple studies, dyslexia is not an “all-or-nothing phenomenon,” but rather symptoms may occur on a continuum of severity.

It is important to note, however, that not all individuals with reading challenges demonstrate the specific pattern of weaknesses associated with dyslexia (i.e., a student might have challenges with reading comprehension despite age-appropriate skills in other areas of reading). This highlights the importance of understanding the nature of reading errors, as well as remaining cognizant of other comorbidities that can mask or exacerbate reading difficulties (see

"Comorbidity" below). Still, reading disorders and dyslexia can contribute to difficulty in other academic areas (e.g., social studies; science), as well as impact self-esteem and socioemotional functioning (e.g., anxiety/depression) and lead to higher rates of school avoidance/dropout, as well as lifelong functional/adaptive impairments (e.g., employment difficulties).

Prevalence Rates In terms of prevalence, reading disorders are apparent across languages, cultures, racial/ethnic, and socioeconomic groups [52]. While the APA [2] estimates that between 5% and 15% of school-aged children suffer from any type of learning disorder (and about 4% of adults), recent statistics from the [46] suggest that reading disorders and dyslexia are the most common types of learning disorder (i.e., approximately 70–80% of those with a learning disorder meet criteria for a reading disorder). In regard to gender ratios, the APA [2] indicates that learning disorders, in general, are more common in males than females (between 2:1 and 3:1), although other findings related to gender differences have been mixed. That is, while higher rates of reading disorders have been reported for males, particularly in clinically referred samples, research samples have indicated ratios closer to 1:1 [28, 62, 65]. It is also important to note that reading disorders commonly co-occur with other neurodevelopmental or behavioral disorders, and referral bias may play a role in who is referred for assessment and services.

Etiology of Reading Disorders/Dyslexia In regard to the etiology of reading disorders, the literature has identified environmental/child heath factors and neurobiological and neurocognitive factors that may be related to the development of reading difficulties. While each may play a unique role in the manifestation of reading impairments, Pennington's [49] multiple-deficit model posits that developmental outcomes (i.e., reading disorders) are likely related to interactions between multiple variables. That is, like most behavioral disorders, the causes may be multifactorial and include a combination of risk factors.

Environmental Factors At the environmental level, prematurity and low birth weight have been identified as risk factors for the development of later reading challenges [5, 10], as well as early language impairment [7]. Further, a recent longitudinal study revealed that prenatal nicotine exposure was negatively associated with reading performance among school-aged children [11].

Genetic Factors In addition to these environmental factors, reading disorders, and specifically dyslexia, show a strong genetic basis [48, 51, 64]. Family studies have located specific chromosomes that may carry genes or multiple genes that influence the manifestation of dyslexia [19, 26]. Still, it is important to highlight that genetic risk factors, as well as the environmental and child health factors discussed above, must be considered in the context of their dynamic interplay with one another and the child's environment (e.g., home literacy environment). That is, a recent longitudinal study revealed that children with a high familial risk of dyslexia are often exposed to a greater number of risk factors overall [15], which suggests that genetic risk likely reflects a gene X environment interaction. Still, another recent meta-analysis of 95 studies indicated that there is not strong evidence that children from at-risk families are raised in significantly different environments from control samples [68]; however, they do show deficits in phonological processing that may represent a phenotype of dyslexia and place children at ongoing risk for development of reading challenges.

Neurological Factors Finally, research has also documented neurological underpinnings in reading disorders and dyslexia. While this area of research continues to grow in conjunction with advances in technology, dyslexia appears to be a disorder associated with changes in brain circuitry [32]. Studies examining the brains of individuals with dyslexia via postmortem examination have also identified unique structural differences. In Siegel's [64] review, he highlighted abnormalities in the planum temporale (e.g., includes Wernicke's area – involved in language processing), as well as within the corpus callosum (e.g., communication between hemispheres). Other researchers have corroborated differences in the planum temporale via functional magnetic resonance imaging (fMRI) [35], as well as documented underactivation in the left hemisphere (i.e., language/verbal) and overactivation in the right hemisphere (i.e., visual spatial) [80]. Further, another review paper showed consistent underactivation in the occipitotemporal region, which includes the visual word form area (VFWA; see [52]). Finally, diffusion tensor imaging (DTI) has also explored the association between white and gray matter in dyslexia, and results have consistently revealed decreases in a variety of sites in the left hemisphere [47, 66]. Although these brain differences appear to be related to reading challenges, research has also shown that high-quality intervention has the potential to alter brain activity and promote normal hemispheric functioning [21].

Of note, many imaging studies compare samples of school-aged children or adults with dyslexia to healthy controls. Given the neuroplasticity of the developing brain, particularly throughout the process of learning to read, these studies are limited in their ability to draw conclusions about the neurological underpinnings of dyslexia. As such, a recent meta-analytic review was conducted of MRI studies examining brain differences in pre-reading children at risk for later reading challenges, and results revealed differences in the left temporoparietal brain region between at-risk pre-readers and controls [74]. This brain region is implicated in phonological processing, which provides further evidence in support of the phonological model. Further, early deficits were also apparent in auditory perceptual domains, though less consistently. Taken together, studies of brain structure and functioning provide strong evidence for neurological risk factors.

Early Signs, Symptoms, and Patterns of Weakness

The Preschool/Early Elementary Years Although reading disorders can only be diagnosed after a student enrolls in formal education, early symptoms such as language weaknesses can be identified during the preschool years [24, 60]. Of note, early identification is becoming increasingly important, as longitudinal research has shown that later remediation is less effective than early intervention [75]. Specifically, parents and preschool teachers may notice challenges with basic rhyming skills or learning simple nursery rhymes, recognizing letters, as well as mispronunciations of common words. Further, these early weaknesses are especially important to note if there is a family history of language-based difficulties (i.e., reading/writing disorder). Upon transitioning to kindergarten and first grade, reading challenges may become more apparent (e.g., difficulty sounding out basic words), and the student may verbalize their dislike for reading or avoid tasks that involve reading altogether. Further, the errors that students make while attempting to read may appear unrelated to pictures or the words on the page [60].

Second Grade and Beyond Although reading disorders often go undiagnosed through first grade, weaknesses may become more apparent in second grade and beyond as learning/reading demands increase. Academically, teachers and parents may notice limited progress in reading development, including slow reading rate and oral reading that is riddled with errors [60]. Weaknesses in decoding also become more recognizable as students have not developed an effective strategy for reading and spelling unfamiliar words, and they often make random or “dysphonetic” guesses (e.g., errors that are unrelated to letters in the word). Additionally, there may be other weaknesses in speech such as difficulties with word retrieval (e.g., naming a specific object), accurately pronouncing longer words, mixing up similar sounding words, and difficulty following conversations or responding in an appropriate time frame [60]. Children may also dislike and avoid reading out loud in the classroom and have trouble finishing tasks in the same time frame as peers, remembering rote or fact-based material, and learning a second language. Over time, these challenges may negatively impact self-esteem, academic self-competence, and peer acceptance [54], particularly when academic instruction shifts from "learning to read" to "reading to learn."

Importantly, despite the host of difficulties associated with reading disorders and dyslexia, students may show strengths in other areas that must be considered when developing an intervention plan. For example, many dyslexic readers have the ability to make sense of written material and comprehend text despite weaknesses in word reading [60], as well as show strong skills in other subjects (e.g., math) or areas of interest. Still, not all individuals with reading disorders show the same patterns of strengths and weaknesses, which has contributed to the complexity and controversy related to diagnosis. As noted above, Shaywitz et al. [63] highlighted that dyslexia appears to occur along a continuum of normal reading development and students with dyslexia fall at the lower end of that distribution. As such, there is no specific cut point or inclusion/exclusion criteria, which may impact how dyslexia is identified, treated clinically, and conceptualized within the current special education guidelines. Taken together, early identification of symptoms is critical in buffering future learning difficulties, as students' learning profiles may change overtime as a result of school- and community-based intervention and other psychosocial factors. A child may make progress within one aspect of their reading profile (e.g., improved word reading/decoding), while they experience ongoing difficulty within other domains (e.g., fluency and comprehension). This represents a shift from stringent "all-or-nothing" definitions of learning disabilities and acknowledges the fluid nature of challenges over time. Still, it is important to note that in addition to specific academic weaknesses, students may present with a host of other cognitive and social-emotional difficulties that warrant assessment (see sections "Assessment Process and Tools" and "Comorbidity" below).

Assessment Process and Tools

Different professionals, including school psychologists, clinical psychologists, and neuropsychologists, may assess children of reading age, older children and adolescents, and adults for the presence of dyslexia. Dyslexia can be identified in the context of a school evaluation or a private evaluation. There is no single test that can determine whether someone has dyslexia. Instead, the assessment procedure should include a thorough background interview, as certain signs of dyslexia often present early in life, and testing with a variety of standardized measures with established psychometric properties. While dyslexia, at its core, is a disorder of accurate and fluent reading, it frequently occurs alongside other academic and learning issues, certain neurocognitive features, and psychiatric conditions. Thus, dyslexia assessment should occur in the context of a comprehensive evaluation, in which multiple domains of academic achievement, cognitive functioning, and emotional and behavioral symptoms are assessed (see Table 2.1 for a review of assessment tools).

Obtaining Background History As discussed above, children are not typically diagnosed with dyslexia until they reach reading age; however, many children show "warning signs" of this disorder well before receiving a formal diagnosis. These may include difficulties learning the letters of the alphabet and the sounds that go with each letter, repeatedly mispronouncing certain words (e.g., saying *frackers* instead of *crackers*), difficulty understanding and generating rhyming words, and showing a limited range of expressive vocabulary [60]. Having a parent or sibling with dyslexia is a widely established risk factor for dyslexia (e.g., [67]), as are the presence of speech and language delays during early childhood (e.g., [55]). Thus, when evaluating an individual for dyslexia, it is important to obtain a thorough background and developmental history.

Assessing Aspects of Reading and Spelling Dyslexia is associated with weaknesses in efficient decoding, or the ability to link letters to corresponding word sounds, or phonemes, to read the whole word. Decoding skills are measured through tests of word recognition, which require the examinee to read printed words

Table 2.1 Commonly used tools in the assessment and diagnosis of dyslexia

Measure	Age/grade range	Key subtests	Domains assessed with key subtests
Boston Naming Test, 2nd Edition (BNT-2)	5:0–12:5 years, 18–79 years	n/a	Single-word expressive vocabulary
Comprehensive Test of Phonological Processing, 2nd Edition (CTOPP-2)	4:0–24:11 years	Blending nonwords, blending words, elision, memory for digits, nonword repetition, phoneme isolation (7–24), rapid color naming (4–6), rapid digit naming, rapid letter naming, rapid object naming (4–6), segmenting nonwords (7–24), sound matching (4–6)	Phonological awareness, phonological memory, rapid symbolic naming, rapid non-symbolic naming (4–6)
Delis-Kaplan Executive Function System (D-KEFS)	8–89 years	Verbal fluency test	Rapid word generation/retrieval
Differential Abilities Scales, 2nd Edition (DAS-II)	2:6–17:11 years for full measure; 5:0–12:11 years for phonological processing subtest	Phonological processing, rapid naming	Phonological processing (including rhyming, sound blending, phoneme elision, and phoneme segmentation), rapid automatic naming
Expressive One-Word Picture Vocabulary Test, 4th Edition (EOWPVT-4)	2–80+ years	n/a	Single-word expressive vocabulary
Expressive Vocabulary Test, 2nd Edition (EVT-2)	2:6–90+ years	n/a	Single-word expressive vocabulary
Gates-MacGinitie Reading Test, 4th Edition (GMRT-4)	K.7 – post high school	Comprehension (most levels), vocabulary (most levels); different subtests for pre-reading, beginning reading, and levels 1 and 2	Reading comprehension, word knowledge, early reading concepts (e.g., letter knowledge, letter-sound correspondence, word decoding) in lower levels
Gray Oral Reading Test, 5th Edition (GORT-5)	6–23 years	n/a	Oral reading rate, oral reading accuracy, reading comprehension
Lindamood Auditory Conceptualization Test, 3rd Edition (LAC-3)	5:0–18:11 years	n/a	Phonemic processing, syllabic processing
Nelson-Denny reading test (NDRT)	9–12th grade, 2-year college, 4-year college	Comprehension, vocabulary	Silent reading comprehension, silent reading speed, word knowledge
A Developmental NEuroPSYchological Assessment, 2nd Edition (NEPSY-II)	3–16 years	Phonological processing, speeded naming, word generation	Phonological processing, rapid automatic naming, rapid word generation/retrieval
Oral and Written Language Scales, 2nd Edition (OWLS-II)	3:0–21:11 years	Listening comprehension, oral expression, reading comprehension, written expression	Auditory comprehension, oral expression/fluency, reading comprehension, written expression
Test of Word Reading Efficiency, 2nd Edition (TOWRE-2)	6:0–24:11 years	Phonemic decoding efficiency, sight word efficiency	Word reading/recognition speed, phonemic decoding speed

Table 2.1 (continued)

Measure	Age/grade range	Key subtests	Domains assessed with key subtests
Test of Written Language, 4th Edition (TOWL-4)	9:0–17:11 years	Vocabulary, spelling, punctuation, logical sentences, sentence combining, contextual conventions, story composition	Sentence generation, auditory dictation at the sentence level, editing, sentence combining, written expression at the short story level
Wechsler Individual Achievement Test, 3rd Edition (WIAT-III)	4:0–50:11 years	Oral reading fluency, pseudoword decoding, reading comprehension, spelling, word reading	Oral reading rate and accuracy, phonemic decoding, reading comprehension, spelling, word reading/recognition
Woodcock-Johnson Tests of Achievement, 4th Edition (WJ IV ACH)	2–90+ years	Letter-word identification, oral reading, passage comprehension, reading recall, sentence reading fluency, spelling, spelling of sounds, word attack, word reading fluency	Word reading/identification, oral reading rate and accuracy, reading comprehension, silent reading speed and accuracy (for individual words and sentences), spelling, grapheme-phoneme correspondence, phonemic decoding

Note: The reader is referred to Dyslexia Help at the University of Michigan for a comprehensive list of assessment tools for dyslexia (http://dyslexiahelp.umich.edu/dyslexics/learn-about-dyslexia/dyslexia-testing/tests)

out loud. Individuals with dyslexia may struggle with this task, as they do not benefit from surrounding text to identify the target word. Commonly used word recognition tests include the Word Reading subtest of the Wechsler Individual Achievement Test, 3rd Edition (WIAT-III; [82]), the Letter-Word Identification subtest of the Woodcock-Johnson Tests of Achievement (WJ IV ACH; [56]), and the Sight Word Efficiency subtest of the Test of Word Reading Efficiency, 2nd Edition (TOWRE-2; [72]). Decoding skills are further assessed through tasks that require the examinee to apply phonics rules and grapheme-phoneme correspondence (i.e., letter-sound correspondence, or the understanding of which sounds go with which letters) to reading "nonwords" (e.g., *flisk*, *tiphur*). While some individuals with dyslexia perform within normal limits on tests of word recognition skills, they often show weaker performance on phonemic decoding tests, where it is impossible to identify the nonwords by sight. On such tests, common errors include lexicalizations (i.e., substituting a visually similar real word for the pseudoword, like *stripe* instead of *stipe*), phoneme sequencing errors (e.g., *pilk* instead of *plik*), phoneme insertion errors (e.g., *dal-ig* instead of *dalg*), phoneme deletion errors (e.g., *tras* instead of *trasp*), and vowel sound errors (e.g., *frek* instead of *frak*). Commonly used phonemic decoding tests include the Pseudoword Decoding subtest of the WIAT-III, the Word Attack subtest of the WJ IV-ACH, and the Phonemic Decoding Efficiency subtest of the TOWRE-2.

In addition to decoding weaknesses, dyslexia is associated with weaknesses in encoding, or the ability to match letters to phonemes to spell words correctly. Dysphonetic errors while spelling are particularly indicative of dyslexia (e.g., *becaud* instead of *because*, *gril* instead of *girl*). Spelling at the single-word level is often assessed with the Spelling subtest of the WIAT-III and the Spelling subtest of the WJ IV ACH, both of which require the examinee to write a series of individual words that the examiner presents aurally. Arguably, *how* the examinee attempts to spell the words is as important as whether the words are spelled correctly or incorrectly.

Dyslexia often impacts both oral reading and silent reading fluency. When reading orally, individuals with dyslexia often show a slower, halting pace compared to typical readers. They are also more likely to skip words while reading, to make visual word recognition errors (e.g., *bat* instead of *boat*), to misread short words (e.g., confusing *when* and *then*), to omit word endings, and to show difficulty decoding longer or unfamiliar words [6]. Tests of oral reading speed and accuracy include the Oral Reading Fluency subtest of the WIAT-III, the Oral Reading subtest of the WJ IV ACH, and the Gray Oral Reading Test, 5th Edition (GORT-5; [84]). Individuals with dyslexia similarly struggle with speed when reading silently too. Tests of silent reading speed and efficiency include the Word Reading Fluency and Sentence Reading Fluency subtests of the WJ IV ACH.

Some researchers have noted that despite difficulties with decoding and reading speed, dyslexic readers can show intact reading comprehension skills [60]. It has been suggested that individuals with dyslexia are very good at interpreting context clues while reading and at being able to take away the main point even in the absence of reading each word accurately [60]. However, severe decoding weaknesses may interfere with one's ability to read at grade level and to adequately comprehend while reading, and a tendency to skip short words while reading (e.g., *not*, *or*) can interfere with comprehension too. Especially when reading orally, individuals with dyslexia may focus intensely on reading carefully and accurately, but at the expense of paying adequate attention to the content of what they are reading. Commonly used reading comprehension tests include the Reading Comprehension subtest of the WIAT-III, the Passage Comprehension subtest of the WJ IV ACH, the Comprehension scale of the GORT-5, the Gates-MacGinitie Reading Test, 4th Edition (GMRT-4; [39]), and for individuals in high school and college, the Nelson-Denny Reading Test (NDRT; [8]).

Assessing Other Academic Skills While dyslexia is a reading disability, individuals with this disorder may experience weaknesses in their written expression too. Specifically, individuals with dyslexia frequently struggle with spelling, which can interfere with the intelligibility of their writing. Further, they may have difficulty producing concise, organized text in a timely and efficient manner; these issues are compounded when attention and executive function issues are also present. Shorter, focused tests of written expression include the Sentence Composition subtest of the WIAT-III and the Writing Samples and Sentence Writing Fluency subtest of the WJ IV ACH. Lengthier writing assessments include the Oral and Written Language Scales, 2nd Edition (OWLS-II; [9]), the Essay Composition subtest of the WIAT-III, and the Test of Written Language, 4th Edition (TOWL-4; [27]).

In addition to writing, a dyslexic profile can produce math difficulties too. For instance, individuals with dyslexia may struggle to read and comprehend math word problems, which can interfere with their ability to demonstrate the true range of their math reasoning skills. An aspect of dyslexia, discussed in the section below, involves weaknesses in the rapid, efficient retrieval of verbal information, including simple math facts. Math facts retrieval is commonly assessed with the math fluency subtests (addition, subtraction, and multiplication) of the WIAT-III and with the Math Facts Fluency subtest of the WJ IV ACH.

Assessing Language Functions Although there are 26 letters in the alphabet, there are 44 unique sounds, or phonemes, that make up words in the English language. Phonological processing refers to the ability to detect and manipulate these component sounds or "building blocks" of words. As highlighted in previous sections of this chapter, weaknesses in phonological processing are widely recognized as one of the central features of dyslexia (e.g., [78]); these weaknesses may or may not occur in the context of other language impairments [53]. Commonly used standardized measures to measure auditory phonological processing skills, in the absence of reading demands, include the Comprehensive Test of Phonological Processing, 2nd Edition (CTOPP-2; [79]), the Lindamood Auditory Conceptualization Test, 3rd Edition (LAC-3; [37]), the Phonological Processing subtest of the NEPSY-II [33], and the Phonological Processing subtest of the

Differential Ability Scales, 2nd Edition (DAS-II; [18]). Tests of phonological processing generally involve matching alike phonemes, producing rhymes, phoneme segmentation and identification, phoneme blending, phoneme manipulation and/or, in the case of the LAC-3, symbolically representing phonemes.

Word retrieval skills are known to be an area of weakness for many individuals with dyslexia, and these can manifest in several ways. For example, individuals with dyslexia often struggle with rapid naming skills, including the ability to quickly and accurately name different letters, digits, objects, and symbols. These skills are commonly assessed with the Rapid Non-Symbolic Naming subtests (for young children) and the Rapid Symbolic Naming subtests (for young children through young adults) of the CTOPP-2, the Speeded Naming subtest of the NEPSY-II, and the Rapid Naming subtest of the DAS-II. Further, individuals may show difficulty on tasks requiring efficient word generation, or rapid retrieval of nonspecific words. These skills are commonly assessed with the Verbal Fluency subtest of the Delis-Kaplan Executive Function System (D-KEFS; [14]) and the Word Generation subtest of the NEPSY-II. Finally, individuals with dyslexia may show weaknesses in their expressive vocabulary skills, including the ability to identify and retrieve the correct word for a given object or situation. Indeed, many individuals with dyslexia experience a "tip of the tongue" phenomenon. Expressive vocabulary skills at the single-word level are often assessed with the Expressive Vocabulary Test, 2nd Edition (EVT-2; [87]) and the Expressive One-Word Picture Vocabulary Test, 4th Edition (EOWPVT-4; [40]). The Boston Naming Test, 2nd Edition (BNT-2; [30]) is another test of expressive vocabulary skills at the single-word level; however, it is unique in that it permits the provision of phonemic cues (i.e., initial sound or sounds), which can help examinees with dyslexia identify the target word.

Assessing Cognitive Functioning Previously, dyslexia was conceptualized as unexpected reading difficulty that occurred in the context of average to above average intelligence [20]. More recently, professionals have moved away from this "discrepancy model" as it delayed the identification of dyslexia in many children, and it all together prevented the identification of dyslexia in others – namely, those with low cognitive functioning and, arguably, the most severe reading weaknesses [20]. Nonetheless, when a highly intelligent individual demonstrates reading skills that are significantly below expectations for their level of cognitive functioning – even if their achieved reading scores are within normal limits for their age – it may indicate a reading disability. Further, working memory weaknesses and other cognitive features are understood to be risk factors for dyslexia [61]. Thus, it remains helpful to consider one's reading skills in the context of general cognitive functioning, including verbal skills, nonverbal reasoning skills, visual-spatial skills, auditory and visual working memory skills, and information processing speed. Cognitive functioning is commonly assessed with well-established batteries including the Wechsler Intelligence Scale for Children, 5th Edition (WISC-V; [83]); the Wechsler Adult Intelligence Scale, 4th Edition (WAIS-IV; [81]); the Woodcock-Johnson IV Tests of Cognitive Ability (WJ IV COG; [57]); the Kaufman Assessment Battery for Children, 2nd Edition (KABC-II; [31]); and the Differential Abilities Scale, 2nd Edition (DAS-II; [18]).

Assessing Emotional and Behavioral Functioning As discussed in the following section, individuals with dyslexia are at increased risk for anxiety, depressive, and other psychiatric symptoms. When conducting dyslexia evaluations with youth, clinicians are strongly recommended to include one or more broad screening measures of socioemotional and behavioral functioning, such as the Child Behavior Checklist (CBCL; [1]). It can be helpful to obtain ratings from different observers, including parents and teachers, who observe the examinee across different contexts. Elevations in any of the subscales of the broad measures can inform further psychological assessment.

Dyslexia and Co-occurring Disorders

Dyslexia commonly occurs alongside other psychiatric disorders; an estimated 50% of individuals with dyslexia meet criteria for another diagnosis [23]. Attention-deficit/hyperactivity disorder (ADHD), a brain-based, neurodevelopmental disorder characterized by significant inattentive symptoms (e.g., difficulty sustaining attention, forgetfulness in everyday activities) and/or hyperactive and impulsive symptoms (e.g., exhibiting a high level of motor activity, difficulty sitting still and remaining seated in situations where it is expected, difficulty waiting one's turn), is one of the most frequently comorbid disorders with dyslexia. A sizeable minority – estimates range from 15% to 40% – of individuals with dyslexia are also diagnosed with attention-deficit/hyperactivity disorder (ADHD), and comparable yet slightly higher rates are estimated for children with ADHD who are also diagnosed with dyslexia (e.g., [3, 58, 85]). Differentially diagnosing ADHD and dyslexia, especially in younger children, is made challenging by the fact that some cognitive features, including weaknesses in verbal working memory and processing speed, are common to both disorders.

Dyslexia is associated with weaknesses in certain neuropsychological functions, including working memory (i.e., the ability to retain information in the very short term and to perform mental operations on that information) and information processing speed (i.e., the ability to quickly and accurately ascertain and make decisions about novel information). Weaknesses in these areas are not unique to dyslexia; indeed, they have been associated with math disabilities [86] and with ADHD too. However, working memory and information processing speed are broad constructions, and certain weaknesses within these domains have been observed among individuals with dyslexia. Specifically, auditory working memory weaknesses are most prominent in individuals with dyslexia; these have been linked to phonological processing weaknesses [78]. Further, weaknesses in rapid automatized naming – an aspect of verbal processing speed – are most implicated in dyslexia; broader information processing speed may be intact for individuals with dyslexia [25].

Dyslexia and other reading disabilities are frequently comorbid with other learning disabilities; it is estimated that comorbid reading and math disabilities are present in 30–70% of individuals with either disorder [4, 34]. Moll et al. [42] advocate for understanding learning disorders as different yet related constructs, which likely share genetic, neurobiological, and cognitive risk factors. When learning disorders do occur, they are associated with increased risks. Specifically, children with concurrent reading and math disabilities, compared to children with either disorder alone, appear to be at increased risk for functional impairment, including higher internalizing symptoms, greater academic problems, and weaker neuropsychological functioning across multiple domains, compared to children with either disorder alone [86]. Children who experience difficulties across academic domains likely have more challenging and less rewarding school experiences than children who have dyslexia but do well in other academic areas, like math or science. Thus, children with concurrent learning disabilities appear to be at increased risk for negative outcomes and should be monitored carefully.

Some existing research suggests that individuals with dyslexia are at higher risk for internalizing problems (e.g., anxiety symptoms, depressive symptoms) and externalizing problems (e.g., oppositional and defiant behaviors, conduct-related behaviors), compared to those without dyslexia [44, 69, 85]. However, other studies do not support these findings (e.g., [41]). Most of the existing research on dyslexia and comorbid psychiatric symptoms is based on children's experiences, and a small body of adult-focused literature suggests that college students and adults with dyslexia, or learning disabilities more broadly, may not experience higher rates of anxiety and depressive symptoms [43]. Further, some researchers have suggested that increased rates of externalizing behaviors among children with dyslexia may be partially, if not fully explained, by a concurrent ADHD diagnosis and symptoms

[85]. While it is prudent to screen all children with dyslexia or suspected dyslexia for concurrent internalizing and externalizing problems, there is evidence to suggest that these are not issues for all individuals with dyslexia, especially as they mature.

"Best Practices" for Educational Programming

Importantly, research has shown that environmental factors (e.g., early identification; intervention; high-quality programming) can influence later educational and developmental outcomes for individuals with reading disorders and dyslexia. The National Center for Learning Disabilities (NCLD) highlighted in their recent position paper that early and accurate identification of learning challenges can alter students' path for success [13]. Given that students spend the majority of their time at school, many of these services should be delivered by the public school district based on legal mandates outlined in the Individuals with Disabilities Education Act (IDEA). While more detailed information regarding IDEA and special education laws are outlined in Chap. 13 (Special Education Law and Procedures), school-based intervention and accommodations are typically provided through an individualized education program (IEP). The IEP is a written document that outlines a student's strengths and weaknesses, specific and identifiable educational goals, as well as the types of services that will be provided to meet these goals. Of note, students have the right to access services whether they are enrolled in a public or independent school setting. Although the intervention plan may look somewhat different for each student, some of the most commonly used evidence-based interventions for students with reading disorders/dyslexia are outlined below and in Table 2.2.

Developing the Intervention Plan In order to develop an effective educational plan, data must be gathered through a comprehensive assessment process as described above. Assessments may be conducted by school staff, outside evaluators, or both, and the information generated from this assessment is used to inform the IEP goals and services. Further, it provides evidence to determine the *type of classroom setting* that is appropriate (e.g., general education/full inclusion, partial inclusion, or a substantially separate language-based classroom), the *types/frequency of direct interventions* delivered (e.g., reading instruction; speech-language therapy), appropriate *learning accommodations* (e.g., preferential seating; extended time), and *ancillary supports* (e.g., consultations between team members) that are necessary for the student to make effective progress.

Direct Services for Dyslexia Although every IEP may look somewhat different given the model of *individualized* learning, a large body of research has reviewed the most effective evidence-based interventions for dyslexia, and results overwhelmingly suggest the strongest support for multisensory phonics-based interventions [16, 22]. This type of instruction is called multisensory structured language education (MSLE; i.e., learning through more than one sense), and examples include Orton-Gillingham (OG), Lindamood-Bell, and the Wilson Program of reading. Peterson and Pennington [52] also indicated that instruction must explicitly target phonological awareness and word analysis, as well as focus on reading fluency and comprehension. Further, Galuschka et al.' [22] meta-analytic review of 22 randomized controlled trials found that phonics-based instruction was the only approach whose efficacy is statistically confirmed to improve reading and spelling skills among children with reading disorders.

In addition to the *specific types* of intervention, research has also shown that instruction is most effective when delivered intensely (e.g., several times/week to daily), in a small group or one-to-one setting [76], and when delivered by a reading specialist certified or trained in the methodology (i.e., quality/fidelity of implementation). Further, teaching should be scaffolded (e.g., taught step-by-step) and explicit (e.g., clear and

Table 2.2 Beneficial direct services and accommodations in the classroom

Direct services	Accommodations and additional supports	
Multisensory phonics-based instruction in a 1:1 or small group setting delivered by a certified reading specialist (e.g., Orton-Gillingham, Lindamood-Bell, or Wilson Program)	Ongoing consultations between providers (i.e., reading specialist, speech and language pathologist, occupational therapist)	Slower, multisensory instruction with the use of visual aids
Access to technology driven interventions (e.g., Lexia) to promote reading fluency	Regular communication between home and school so parents/caregivers can provide reading experiences at child's level	Scaffold understanding through explicit instruction and by contextualizing information as much as possible (i.e., connecting concepts to everyday life)
Teaching of active reading strategies to improve fluency and comprehension	Extended time on all assignments and tests, including standardized testing	Take special care when asking students to read aloud in class – only called on if volunteers or prepared in advance
Intervention to support written expression (e.g., spelling, organization of ideas in essay writing)	Preferential seating during testing (e.g., quiet location)	Add structure to the day and tasks with routines and predictable transitions
Access to a learning center to receive additional training in executive function skills and strategies	Preferential seating throughout the day in order to receive	Give frequent feedback and 1:1 check-in time
Speech and language therapy focusing on the development of phonological skills or other aspects of language processing that underlie the automaticity of reading	Assistive technology (e.g., speech-to-text; text-to speech)	Breaking tasks up into smaller components
Occupational therapy to improve visual-motor and writing skills	Dictate responses to a scribe and note-taking support	Use of visual aids for reminders, as well as visual checklists to support task completion
Regular access to a counselor/school psychologist	Access to a word processor or computer for written work with spell-check enabled	Graphic organizers
Extended school year services (to prevent regression in learning)	Access to books on tape	Use graph paper to help keep numbers lined up and an extra piece of paper to cover up most of what's on a test so student can focus on one problem at a time
Vocational training	Advanced notice for large reading assignments	Have student repeat and rephrase instructions to confirm understanding of tasks presented
Transition planning into college or workforce	Use of a placeholder or word highlighter device to help isolate each word while reading	Encourage the use of verbal rehearsal strategies to enhance the meaningfulness of material
	Preview/review questions of chapters in assigned reading to target key information while reading	Allow for frequent breaks as needed
	Reduced or modified workloads and flexible deadlines	
	Modified testing format (e.g., multiple choice)	
	Pre-teaching of upcoming unit material and frequent review of previously learned material	

direct) to fully meet the student's needs [70]. Of note, based on the severity of reading challenges, students may remain in the general education setting and receive pullout reading services, or they may require substantially separate placement in a classroom that infuses these multisensory and phonics-based techniques throughout the entire school day (i.e., language-based classroom).

Further, other direct services may be warranted, including speech-language therapy to enhance underlying language weaknesses, occupational therapy to improve visual-motor skills and handwriting, or executive function skills training (e.g., planning/organizing skills; study strategies). It is also important to note that many students will require these direct services in an extended school year (ESY) program. ESY services can help students gain literacy skills and close the gap between same-aged peers, as well as prevent regression in learning that often occurs over the summer months.

Although many studies have examined the efficacy of high-quality reading instruction, most research in this area has shown that reading challenges are easier to remediate in younger as compared to older children [52]. That is, early intervention was found to be more effective than later remediation [75], particularly considering the impact of cumulative negative school experiences and reading failure. Further, reading interventions, in general, appear to be better able to improve basic reading skills (i.e., word recognition; decoding skills) than reading fluency [71]. Still, technology or computer-based interventions (i.e., Lexia; Read Naturally) have been shown to be somewhat effective in improving fluency when used to *supplement* multisensory and direct teaching [38, 73]. However, the benefits of these programs are less robust than phonics-based instruction according to the What Works Clearinghouse (WWC) from the US Department of Education. Of note, various other therapies have been developed to treat symptoms of dyslexia, but research of non-phonics-based interventions have been equivocal or shown to be ineffective and, as such, are not considered gold standard approaches [50]. Examples include treatments that focus mainly on rapid naming, visual therapy, or activity-based (e.g., exercise; sensory) intervention. Further, hybrid multisensory models such as Project Read were also found to be ineffective by the WWC.

Direct Services for Reading Comprehension Finally, while phonics-based instruction has the most research support for addressing foundational weaknesses associated with dyslexia, other interventions have been developed to address reading comprehension impairments. For individuals who have developed age-appropriate word reading skills but demonstrate specific comprehension weaknesses, the focus of remediation is different [16]. Still, the authors highlighted that reading comprehension is a complex process, and deficits may be related to a variety of underlying cognitive and language factors (e.g., listening comprehension, vocabulary, making inferences, metacognitive skills). While the field continues to gather more information related to effective comprehension interventions, there is some evidence that has shown benefits of vocabulary training [17] and verbalizing/visualizing programs (i.e., making mental movies of read information; [45]). Importantly, students may present with symptoms of dyslexia and reading comprehension impairment, highlighting the importance of a comprehensive assessment process to determine a treatment plan.

Reading Accommodations In addition to direct intervention, general learning/reading accommodations are critical. Accommodations are designed to make the classroom more accessible and even the playing field between students with reading disorders/dyslexia and their typically developing classmates [60]. While a full summary of potential accommodations can be found below in Table 2.2, key accommodations include allowing *extra time* on in-class work, assessments and standardized tests, as well as various *assistive technologies*. Additionally, a student may benefit from preferential seating near the teacher, the option to take tests in a quiet/separate location, or having test items read aloud to them. Further, a reduced or modified workload and special spelling/writing considerations may be discussed by the school team.

Before choosing a technology program, an evaluation should be completed by a specialist to determine which supports might benefit a student. A variety of audio recording devices (e.g., Smartpen) and text-to-speech (e.g., Dragon NaturallySpeaking) and speech-to-text (eReading) software are available to minimize challenges with reading, writing, and note-taking. There are also a number or websites that provide access to books on tape (e.g., Learning Ally; Bookshare), as well as word processing programs that can be implemented within the classroom. Once the appropriate assistive technology is identified, the student should work with the specialist to learn to use the programs independently.

"Best Practices" for Interventions at Home

The Early Years While developing an effective school plan is an essential component of intervention, students may also benefit from supplemental community and home-based supports. In line with the discussion of early intervention, parents and caregivers should seek regular checkups with their child's pediatrician to monitor early speech-language development. If a parent or physician has concerns for early language skills, a free evaluation can be requested through the state to determine eligibility for early intervention (EI) services from birth to 3 years old. Given the link between language development and later reading challenges [24], early speech-language therapy may serve as a protective factor that can mediate future risks, as well as other services that support literacy skills (e.g., occupational therapy for fine motor/written expression).

School-Age Services As described in Chap. 14 (Special Education Law and Procedures), children may begin accessing special education services through an IEP upon turning three. In addition to services provided through the public school district, families may seek private support depending on the intensity of IEP services. Just as comprehensive assessment is the foundation for determining appropriate school-based services, this data should also inform which community interventions are warranted. In general, families may consider the following support services:

- Private multisensory phonics-based tutoring to supplement school-based interventions. Tutors can be located by referral from medical providers, school reading specialists, or national websites (http://www.childrensdyslexiacenters.org).
- Intensive summertime multisensory phonics-based reading instruction/camps; tutoring in the interim between summer school instruction and the start of the new academic year.
- Ancillary services:
  - Speech-language therapy to enhance weaknesses that may be related to language-based academic challenges (e.g., phonological processing; rapid naming; expressive/receptive language; word retrieval)
  - Occupational therapy to address potential visual-spatial or motor weaknesses that negatively impact visual tracking for reading or manual dexterity for writing

Parent/Caregiver Strategies Finally, it is also important to support reading development at home. Parents can encourage the use of audio books or reading aloud together with their child, alternating passages and choosing books with pictures to facilitate reading fluency and comprehension (e.g., the *Wimpy Kid* series, illustrated editions of classics). Further, children may benefit from an age-appropriate discussion of learning differences, and there are a number of resources to facilitate this conversation (e.g., *Hank Zipzer* series of books by Henry Winkler or the *Phoebe Flowers* series by Barbara Brown). Parents may also wish to learn more about reading disorders/dyslexia through various educational resources and websites. Lastly, families should continue to encourage their child's engagement in activities he or she enjoys that are not centered on school.

Further, they should continue to make attempts to focus on their child's achievements and accomplishments to promote a sense of mastery and self-confidence. Although every child demonstrates areas of challenge that may require some level of support, identifying strengths will improve the impact of interventions and facilitate progress.

Conclusion

Taken together, reading disorders/dyslexia represents a complex neurodevelopmental disorder with multidimensional factors that contribute to symptom presentation. Although there have been challenges related to defining the specific weaknesses associated with reading disorders and developmental dyslexia, the most robust evidence lies within phonological deficit model. That is, dyslexia is best characterized as a language-based learning disorder with underlying weaknesses in phonological processing. Given that the nature of reading challenges can vary greatly between individuals, as well as that reading challenges commonly occur with several other psychiatric disorders, a comprehensive assessment is critical in order to develop an effective intervention plan. Further, the evaluation process should serve as a guide for identifying a child's strengths/weaknesses, as well as connecting families to evidence-based interventions.

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Mathematics Disorders

3

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The DSM-V [4] label for mathematics disorder (MD) is specific learning disorder – with impairment in mathematics. Alternative terms include developmental dyscalculia, dyscalculia, and math learning disability (MLD). Acalculia is a separate term used for acquired delays in mathematics due to neurological injury or disease and is excluded by the DSM criteria that a specific learning disorder is "not better accounted for by intellectual disabilities…or other mental or neurological disorders" (p. 67). According to the DSM, a mathematics disorder is defined by a pattern of difficulty or impairment in processing numerical information (number sense or accurate math reasoning), learning (memorization of) arithmetic facts, and/or accurate or fluent calculation. Examples given include "poor understanding of numbers, their magnitude and relationships; counting on fingers to add single-digit numbers instead of recalling math facts as peers do; and gets lost in the midst of arithmetic computation and may switch procedures" (p. 66).

Like all learning disabilities, the DSM specifies that weaknesses in math have to have been present and persistent for a minimum of 6 months despite intervention targeting the child's specific difficulty, a failure to respond-to-intervention definition. Difficulties need to begin during school-age years, though they may not fully emerge until demands on a specific skill area increase and surpass the child's skill. The child's skills in math have to be "substantially and quantifiably below those expected for the individual's chronological age, and cause significant interference with academic or occupational performance, or with activities of daily living, as confirmed by individually administered standardized achievement measures and comprehensive clinical assessment," an ability-achievement discrepancy definition. A documented history of impairments in math can be used in place of standardized assessment for diagnosing individuals who are over 17 years old or past high school education. As with other specific learning disorders, deficits in mathematics cannot be due to lack of or inadequate educational instruction.

The DSM-V criteria for math skills that are "substantially" below age expectations and cause "significant" interference in academic or occupational performance or activities of daily living are left vague. A significant discrepancy between math achievement scores on standardized tests (e.g., the Wechsler Individual Achievement Tests, WIAT-III) and intelligence scores (e.g., on the Wechsler Intelligence Scales for Children, WISC-V) can be used as a criterion. The definition of math disorder using performance substantially below age expectations is even less clear.

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Some clinicians and researchers will use a score on a standardized math test that is lower than the 20th or 25th percentile to diagnose a math disorder, while others may hold to a stricter <16th percentile criterion [21]. Math performance that is 2 or more years below grade expected level is a less often used criterion by clinicians and in schools given the somewhat controversial method of deriving grade equivalents on standardized tests.

Each of these definitions of math disorder has drawbacks, and the definition used may in fact be capturing different subtypes of or pathways to math disorder. The aptitude achievement discrepancy criterion may capture exceptionally bright children whose math achievement does not match their intellectual potential. In that case, consideration needs to be given to whether or not the child is excluded from diagnosis of a math disorder because of lack of instruction in advanced mathematics skills that would need to be mastered to match their intelligence. However, if a child with superior nonverbal reasoning and intelligence performs in the lower end of the average range on a mathematics test that draws on conceptual math reasoning rather than learned procedures, this may in fact signal a math disorder. Hale et al. [24] outline other critiques of an ability-achievement discrepancy definition including a lack of clarity over which IQ score should be used to establish a discrepancy, difficulty distinguishing between children with specific learning disability and low achievers, inconsistent application of the approach across school districts and states, overidentification of students from diverse backgrounds, and measurement problems that lead to poor decision-making.

Similarly, depending on the content of a standardized math test and whether or not it is presented in a truly step-wise manner of increasing difficulty, using a percentile cutoff may over- or under-identify children with math disorders. Furthermore, this approach is even less sensitive to differences in math instruction across local and national regions. It is much more difficult to account for possible lack of exposure to certain math concepts when a simple cutoff criterion is used. And a definition of math disorder that relies on a failure to respond-to-intervention approach risks waiting to identify students in need of special education services beyond the point at which such remedial or substantially separate/different instruction would be most effective.

Hale et al. propose that neither an ability-achievement discrepancy definition of specific learning disability nor a failure to respond-to-intervention definition is sufficient. They propose "a 'third method' approach that identifies a pattern of psychological processing strengths and weaknesses and achievement deficits consistent with this pattern of processing weaknesses" (p. 228). The best approach to diagnosing any individual child with a math disorder is a comprehensive neuropsychological and educational assessment that covers the range of skills and abilities that may contribute to different pathways to unique subtypes of math disorder. The research on the cognitive processes underlying mathematics skills supports this approach. The DSM-V specifiers for math disorder also support this approach. Math disorder can be further specified as with impairment in number sense, memorization of arithmetic facts, accurate or fluent calculation, and/or accurate math reasoning.

A Multicomponent Model of Math Disorder

Estimates of the prevalence of mathematics disorders range from 3% to 6% across countries, a range that is similar to that of developmental dyslexia and ADHD [38]. Unlike other learning disabilities, the gender distribution in math disorder is consistently female > male. This may in part be explained by environmental factors but not entirely. Math disorders are heritable with a tenfold increase in prevalence among first-degree relatives of children with math disorder compared to the general population [39] and an identified candidate gene [15]. However, basic numerical understanding is only modestly heritable (32%, [42]) pointing both to environmental influences and to other factors besides number sense that contribute to math disorder. For example, the messages girls receive regarding math achievement are often different from those boys receive

([14, 18]). Girls' math difficulties are more often attributed to a lack of ability while boys' difficulties are more often attributed to a lack of effort. The latter leaves room for improvement and often leads to intervention (and improved skills) where the former does not.

There is no agreed-upon core deficit in mathematics disorder, and prevalence estimates may vary because studies capture different subtypes of math disorder. A multicomponent understanding wherein number processing and mathematical problem solving are based on multiple neurocognitive components and skills and are implemented by distinct but overlapping neural pathways better describes mathematics disorder than a core deficit model. Mathematics disorder is currently understood to be a somewhat heterogeneous brain-based learning disability in children of otherwise overall average intelligence.

Attempts to distinguish between different types of math disorder date back at least to 1926 with Berger's proposal that acalculia (a loss of numerical concepts and an inability to perform even simple mathematical calculations) was different from math disorder related to deficits in attention, memory, language, reading, writing, or spatial abilities [46]. This distinction persists in the separation of acalculia from developmental dyscalculia. In the 1960s, Hecaen and colleagues proposed that Berger's second, undefined, category could be further divided into (1) alexia and agraphia for digits and numbers and (2) spatial acalculia [46]. In the early 1980s, Boller and Grafman proposed a difference between developmental dyscalculia due to weaknesses in calculation and that due to weaknesses in knowledge of mathematical concepts and operations [46].

In the 1990s, researchers used new experimental methods combined with advanced neuroimaging (e.g., fMRI) to articulate different pathways to unique math weaknesses in support of a multicomponent model. Weaknesses in an innate number sense of magnitude; in pairing symbols with conceptual understanding of quantity; in working memory, self-monitoring, and other executive functions; and in motor and spatial planning all relate in slightly different ways to weaknesses in math calculation or problem solving. For example, executive functions and spatial reasoning predicted 70% of the variance in later mathematics performance in a sample of 3-year-olds [44]. The nature of the deficits associated with math disorder may be related to (1) facts (semantic memory subtype), (2) procedures (procedural subtype), or (3) concepts (visuospatial subtype) [21].

It is also increasingly clear that no one region of the brain governs mathematic reasoning but rather that math skills depend upon interactions within and between large-scale neural networks. Dehaene et al. [9–12] have proposed a "triple-code model" of brain functioning in math disorders where analog number and magnitude representation for number processing (i.e., numerosity) is governed by the parietal lobe, a verbal-phonological number representation that supports verbal counting and math fact retrieval is governed by the left perisylvian areas, and the ability to pair number representation with symbols (i.e., Arabic numbers) is governed by the ventral visual stream. The "verbal code" formats numbers in the brain as sequences of words in a particular order and deficits in this region (the left perisylvian areas and temporal lobes) relate to difficulty naming digits and retrieving basic math facts. The "procedural code" represents numbers as fixed symbols and allows for visual representation on an internal number line governed by the left and right occipital-temporal regions. Weaknesses in this code may manifest, for example, as difficulty with regrouping and long division. The "magnitude code" refers to representations of analog quantities and allows for comparison and estimation and may also be apparent in weaknesses in solving geometric proofs and working with fractions. This type of numeric code representation occurs mainly along the horizontal inferior parietal sulcus in both cerebral hemispheres and facilitates more complex calculation.

Within this system, the intraparietal sulcus (IPS) is responsible for simple number processing including enumeration, estimation, subitizing, and comparison. With time and experience, the IPS becomes specialized in the left and right hemispheres. There is also a shift over development from math processing in frontal brain regions to anterior regions reflecting increased automaticity of math processing [26]. However, other areas of the brain in the subcortical and neurocortical regions, including the inferior frontal gyrus, anterior cingulate gyrus, left angular gyrus, insula, prefrontal cortex, and cerebellum have also been found to relate to math problem solving and point to impairment in other functions associated with math disorders.

This latest wave of research led to the general acceptance of a multicomponent model of math disorder. The multicomponent view of skills deficits and neural pathways also helps to explain the significant heterogeneity of math disorders and the high degree of comorbidity of math disorders with other learning disabilities (e.g., ADHD and dyslexia). A distillation of the research into a multicomponent model suggests that weaknesses in the left perisylvian region and temporal lobes are associated with an "aphasic" math disorder, right hemispheric weaknesses are associated with "spatial" math disorders, and fontal region weaknesses are associated with math disorder due to weaknesses in "planning and perseveration." Lastly, "semantic dyscalculia" is a primary or true acalculia caused by a pure deficit in understanding of numerical quantity.

The Approximate Number System (ANS) and Semantic Math Disorder

Math disorders seem to relate at least in part to deficits in number representation or the ability to develop and use mental representations of numbers or magnitude on a sort of internal mental number line. The approximate number system (ANS) refers to an innate number representation system that allows primates including people to approximate and differentiate between numbers of objects [8, 19]. In studies of the ANS, participants are often presented with groups of dots or objects on identical backgrounds, and their number acuity is measured by mean accuracy, by time to identify the larger quantity, or by calculating distance or ratio effects. The width of this internal number line and the distance between distinguishable quantities or an individual persons' number acuity can be measured by the "internal Weber fraction." Weber's fraction is calculated as the proportional difference between numbers of objects (rather than the absolute difference) that is reliably detected by an individual. The smaller the Weber fraction, the better is an individual's approximate numerosity/number acuity or ability to detect approximate differences in numbers of objects.

Evidence for this innate ability to perceive and differentiate number or quantity has been found in studies of selective attention in infants and toddlers and of Amazon tribes with limited number vocabulary or precise calculation skills who nevertheless show very good approximate skills for comparing quantities up to about "fivish" [23, 34]. There is evidence that number sense exists before development of language (preverbal) or of a symbol system for calculation. The ANS is considered responsible for representing approximate numerosity up to and including four at birth. Piazza et al. [35] review evidence that babies can discriminate between quantities of objects as soon as 3 h after birth on selective attention tasks and that numerosity discrimination improves from a ratio of 1:2 to 2:3 in the 1st year of life. Infants and toddlers have also been shown capable of treating a collection of objects as a set and treating them as a single unit [8]. And there is some evidence that even very young, preverbal, children have the ability not only to discern but also to summate basic quantities [17]. Typically developing children show increasingly precise ANS processing over time.

Weaknesses in the ANS were initially proposed as a core deficit in mathematics disorders. The fact that so much of mathematics is built on the ability to manipulate sets of objects would seem to imply the importance of the ANS. Butterworth [8] explains a model suggested by Carey whereby a child uses inductive skills ("bootstrapping") to infer and apply what he knows about small numbers processed by the ANS to larger numbers and more complex problems. Carey later introduced "enhanced parallel individuation" where the ANS is used as a base number system of knowledge or set to build upon. By this process, the innate ability to discriminate between small quantities with larger distances leads to the ability to discriminate between larger quantities at smaller distances, which in turn leads to the ability to subitize (i.e., recognize a number of objects without counting). Higher-order math calculation and reasoning skills are built on this foundation.

Research supports the connection between number sense and performance on math tasks and the idea that the development of number acuity is delayed in young and older children with math disorders [31, 35]. However, there is a lack of research to support approximate numerosity as the only or even primary skill underlying mathematics ability. The concepts of the ANS and bootstrapping/parallel individuation would suggest that deficits in subitizing are the primary feature of math disorder, but this does not seem to be the case. Instead it is likely just one skill underlying mathematics ability and as such may be related to one subtype of math disorder.

Language Processing Deficits and Aphasic or Verbal Math Disorder

Language is critical not only for comprehending mathematical word problems but also for retrieval of overlearned basic math facts, and weaknesses can result in a verbal dyscalculia. Shalev et al. [38] reported a significant comorbidity of math disorder and delays in overall language development skills. Children who exhibited weaknesses in both expressive and receptive language showed deficits in number reasoning and in calculation for arithmetic problems. Children with expressive language deficits only seemed to have delays in counting skills.

Research points to different but often overlapping pathways to deficits in nonsymbolic (e.g., using dots) numerical magnitude processing compared to symbolic mathematical processing (i.e., using digits) [13]. While nonsymbolic math reasoning may be innate, symbolic processing is dependent upon language and the ability to pair concepts and symbols. Butterworth [8] points to research indicating that children with speech and language impairments show slower and less accurate verbal counting but perform as well as age-matched peers without language deficits on tests of nonsymbolic number comparison and number reasoning and better than language-matched but younger children. As noted above, deficits in the ANS and especially in numerosity coding do not fully explain delays in conceptual math reasoning. And this research points to a role for language processing.

It has also been proposed that children may present with intact approximate numerosity but with weakness in automatically mapping symbols to their internal magnitude representations. The neural network in charge of this is referred to as the numerosity code [8]. The idea is that symbols (e.g., Arabic numbers) become paired with mental concepts of number ("oneness" or "twoness"). This skill would also be a precursor for one-to-one correspondence counting. Support for this model comes from Gerstmann's syndrome, where damage to the left angular gyrus is associated with finger agnosia, acalculia, left-right disorientation, and apraxia. Weaknesses in numerosity coding would be akin to the difficulty some children with dyslexia have in mapping symbols to phonemes.

Working Memory, Executive Functions, and Procedural Math Disorder

Working memory skills and related executive functions have emerged as a key component of math ability. Working memory performance correlates with math performance [41]. Both working memory and math tasks activate similar frontoparietal networks. It makes sense that working memory relates to math skill. For problem solving, it is necessary to keep intermediate steps and results in mind while moving on to subsequent steps. Working memory involves the ability to mentally sequence and shift the temporal or spatial order of information, a skill intimately connected to math calculation and reasoning (see [20] for a more comprehensive review of the connection between working memory and mathematics). Notably, visuospatial working memory seems to be particularly impaired in math disorders [5, 37, 40].

Feifer [16] points to Baddeley's 1998 model of working memory to explain its role in math disorder. In Baddeley's model, working memory consists of (1) a "phonological loop" that allows for verbal rehearsal of information (e.g., basic math facts) as well as for automatic retrieval of information stored in a verbal format and (2) a "visual spatial sketchpad" that allows for visual imagery and mental rotation that facilitate math reasoning (e.g., magnitude comparisons). Thus, deficits in working memory alone or combined with weaknesses in language or visual-spatial processing could lead to more or less severe weaknesses in aspects of mathematical calculation, retrieval, and reasoning.

Geary [21] reviews research indicating that many children with math disorders have difficulties with math fact retrieval that persist into adulthood even with intensive instruction in basic facts. This would seem to suggest that a retrieval deficit resistant to remedial intervention is a useful indicator of an executive function/aphasic type of math disorder. Memorization of math facts relies on verbal working memory and executive functions as well as on the verbal ability to "translate" quantities into a verbal representation/symbol and back again.

Weaknesses in other aspects of executive functioning including attention, inhibition, and self-monitoring have also been identified as related to math disorder. Children with math disorder may undercount or overcount due to weaknesses in attention as well as working memory that lead them to lose track of where they are in the counting process [21]. Compared with controls, children with math disorder have been found to show poorer performance on computerized tests of the ability to sustain and regulate attention (the Conners' computerized continuous performance test (CPT); [30]). Children with math disorders may be unable to inhibit inappropriate solutions and mental processes leading to intrusion errors. A combination of weaknesses in attention and self-monitoring may lead to careless and missed/uncorrected errors. Difficulties with planning and organization will impact performance on multi-step math problems.

Spatial/Nonverbal Reasoning and Visuospatial Math Disorder

Interestingly, while there would intuitively seem to be a clear connection between spatial/nonverbal reasoning and mathematical reasoning, there is considerably less research available on the connection between visuospatial processing impairments and math disorder than, for example, on the correlation between working memory deficits and math disorder. The triple-code model groups deficits in nonverbal and spatial reasoning together with deficits in executive functions to describe the procedural subtype of math disorder.

The fact that a mental representation of number (quantity and serial position) would seem to rely on visuospatial skills was recognized early. Galton proposed in 1880 that for some people numbers have a visuospatial representation or "number form" and also found that this is heritable [7]. Visual-spatial processing supports math skills including geometry, solving complex word problems, ability to use a mental number line, and the associated ability to make accurate estimations of quantity. However, math disorders have historically been associated with left parietal processing weaknesses, whereas weaknesses in spatial and nonverbal reasoning are more often associated with right hemispheric processing. That said, the increasing recognition that math processing depends on neural networks more so than on single hemispheric processing suggests more research is needed in this area.

There is a high coincidence of math delay in children with genetic syndromes associated with weaknesses in right hemispheric processing (i.e., patterning, sequencing, inferencing, deductive/inductive reasoning) including Turner's and

Noonan syndromes [47, 48], but this would technically be considered different from a pure specific learning disorder in mathematics. It is likely more relevant to study children with developmental coordination disorder (DCD) or the somewhat controversial pattern of verbal > visual-spatial processing skills that characterizes the unofficial diagnosis of nonverbal learning disability (NLD) to understand the potential link between visuospatial processing and math disorder.

Children with DCD often have comorbid learning disability including math disorder. Research on the indirect neurocognitive processing links between DCD and math disorder suggests that children with DCD have problems with both working memory and short-term memory that are associated with numeracy [1–3]. Other research suggests that deficits in the cerebellum lead to problems with both balance and automatization in children with DCD and that deficits in automatization in turn explain the comorbidity of DCD with math disorder [32, 45]. Pieters et al. [36] found that children with DCD performed significantly worse for number fact retrieval and for procedural calculation in comparison with age-matched controls with more significant delays in children with severe compared to mild DCD. However, the study did not control for other processes such as working memory to determine if motor or visual-spatial deficits explained differences in the severity of math delay.

Venneri et al. [43] did find evidence, though, that math delays in children with NLD are explained by weaknesses in visuospatial abilities that govern calculation rather than in generalized problems with calculation or number manipulation per se. The fact that children with NLD have less difficulty with oral calculation compared to written calculation than do matched controls is cited as evidence that, in children with NLD, visuospatial deficits might interfere with their acquisition of those aspects of mathematical calculation that rely on visuospatial processing (e.g., borrowing for subtraction or carrying for addition on written calculation tests) but not with the acquisition of other aspects of calculation. Notably, in the Venneri study, children were provided with gridded graph paper to facilitate aligning numbers on the page, but those with NLD still had greater difficulty on written compared to oral tasks than did controls. Thus, we may have yet another subtype of math disorder related to visual-spatial processing weaknesses. For now, however, spatial weaknesses are thought to contribute to a semantic math disorder in conjunction with executive function weaknesses.

Table 3.1 outlines Feifer's [16] explanation of a triple-code model of math disorders. However, it is important to note that clinically a child could present with deficits in more than one of the three coding or processing systems. There is also inherently some overlap between them.

Table 3.1 Subtypes of math disorder based on the triple-code model [16]

Verbal math disorder (left perisylvian region)	Deficits in counting, rapid number naming, retrieval of basic facts May have comorbid reading/writing disorder	Intact understanding of numeric qualities, comparisons between numbers, understanding basic concepts and visual-spatial skills
Procedural math disorder (bilateral occipital-temporal lobes)	Deficits in writing numbers from dictation, reading numbers aloud, math computation procedures (e.g., division, regrouping), and rules for problem solving (e.g., order of operations)	Intact math fluency (i.e., fact retrieval), comparison between numbers, magnitude comparisons
Semantic math disorder (bilateral inferior parietal lobes)	Deficits in magnitude representations, transcoding math operations, higher-level math proofs, conceptual understanding of math and estimation skills	Intact reading and writing numbers, computational procedures, and math fluency (i.e., fact retrieval)

Developmental Trajectory of Math Disorders

When assessing and then supporting any individual child with a math disorder, it probably makes the most sense to consider a multi-pathway model in the context of typical versus atypical development of math skills. What does typical development of particular math skills look like? How does an individual child's skill development map on to typical development? Then, an understanding of the specific skills deficits in an individual child with math disorder can clarify the subtype of math delay and guide intervention. This is the model implied by the specifiers provided in the DSM.

Geary [21] provides a useful overview of a typical pattern of delayed math skills development. First, in very young children (preschool to kindergarten), basic numerical competencies such as identifying Arabic numerals and comparing the magnitudes of numbers may be delayed but are often mostly intact for the processing of simple numbers. Furthermore, the range of typical development for basic numerical knowledge in early childhood is wide, similar to the range in other academic skills prior to about age 7 (e.g., letter/sound recognition and reading). Thus, a kindergartener who does not yet know all of his numbers need not be diagnosed with a math disorder; but difficulties with counting and estimating or differentiating between quantities might be a flag for early intervention. However, in preschool children, difficulty learning to count, to recognize numbers, to see groups of objects as more and less, and to count to 10 by rote and avoidance of basic math (e.g., counting games) may be flags for possible math delays. Delays in math skills development that may indicate a math disorder are most likely to begin to emerge around age 5 years with one-to-one correspondence counting. Geary [21] describes Gelman and Gallistel's [22] five implicit principles in children's development of math skills. The five principles are outlined in Table 3.2. By age 5, most children know and have achieved these essential features of counting, though they may also erroneously believe that in order to count correctly, counting must start at one of the endpoints of a set (a concept called standard direction) and that objects must be counted consecutively and contiguously (adjacency). However, children with MD will persist in making counting errors based largely on working memory deficits into the first and second grades. They will not have mastered order irrelevance and will continue to believe in the adjacency rule. They will count the first or last item in a set twice. They are particularly likely to label double counts of the first item in a set as correct, suggesting difficulty holding information in working memory while also monitoring the act of counting (executive functions). They may also continue to have difficulty consistently recognizing number symbols or show weaknesses in understanding patterning, sorting, and grouping items (Table 3.2).

The next stage in the development of math skills includes a shift from using one-to-one correspondence counting (*finger counting strategy* or *verbal counting strategy*) for *counting all* to *counting on* (e.g., "5, 6, 7, 8" to solve 5 +3). Following the shift from *counting all* to *counting on*, comes increased memorization and direct *retrieval* of basic math facts; over time this also reduces demands on working memory and allows for increased speed and automaticity of basic facts that underlie more complex computations and procedures. In order to move to computations of double- and triple-digit numbers, children in elementary grades will begin to use a

Table 3.2 Gelman and Gallistel's (1978) five implicit principles in counting

1. One-to-one correspondence	One and only own word label is assigned to each counted object
2. Stable order	The order of word labels is invariant across counted sets of objects
3. Cardinality	The value of the final word label represents the total number of items counted
4. Abstraction	Objects of any kind can be collected and counted together
5. Order irrelevance	Items within a given set can be arranged and counted in any sequence

Adapted from Geary [21]

strategy of *decomposition* to arrive at an answer by breaking a problem into component parts or partial sums (e.g., 6+7=6+6=12+1=13). Elementary school-aged children with math disorder often use the same types of strategies as typically developing children but shift from simpler to more complex strategies later and even then continue to differ in their strategy mix. They may also persist in struggling to identify +, −, and other signs and to consistently use them correctly. They may have trouble coming up with a plan to solve even simple multi-step problems, show a poor sense of direction, and have difficulty telling and estimating time. Difficulties with rapid retrieval of basic math facts and remembering their phone number or address may also be present.

By middle and high school, math disorder is likely to have an even greater impact on achievement in school. Math builds on itself over time, and the child who has not mastered basic skills (e.g., math fluency/fact retrieval) will struggle with higher-order skills. Weaknesses in math reasoning will be apparent in poor problem solving and difficulty learning new concepts. A particular challenge for older students with math disorder is difficulty both learning and coming up with alternate means of solving similar problems. Procedural, spatial, and executive function weaknesses may result in seemingly careless errors. Older children and adults with math disorder may also have difficulty applying math in everyday life. They may struggle with money (e.g., budgeting and estimating sale prices based on percentages or calculating a tip), telling and estimating time, and with directions.

Children with math disorders may present with delays in one, several, or all of the skills areas outlined above. They may show impairments in innate number sense (the ANS), difficulty estimating quantities, a reduced subitizing range, impairments in their ability to pair number symbols with mental representation of quantities, counting weaknesses including sticking to immature counting strategies (e.g., counting on fingers), difficulty understanding place values, impaired development of or access to the mental number line, limited retrieval of basic math facts, a lack of understanding of how to break complex multi-step problems down into simpler ones, or a lack of understanding of calculation procedures and concepts [28]. Neurologically, they may show differences in pattern of brain activation, gray and white matter volume, and fiber connections [28]. They may also continue to pull on and overly rely on other areas of brain functioning such as working memory, attention, monitoring, and quantity finger representation in an attempt to compensate for weaknesses in innate math skill. In other words, they fail to show the shift from anterior to posterior processing of math tasks typical in brain development.

Assessment of Math Disorders

Weaknesses in math will usually be identified first in the classroom. Other times, a child may perform poorly on standardized school or district-wide assessments of math and be flagged for further assessment. Usually, an assessment to diagnose a math disorder will include standardized measures of paper-and-pencil math calculation skills, math problem solving (often orally administered tests), and math fluency (i.e., rapid retrieval of math facts). The key areas of math reasoning to be assessed are computation skills, math fluency, mental computation, and quantitative reasoning. In addition, a comprehensive evaluation will include assessment of areas of cognition related to math reasoning such as working memory, executive functions, and visual-spatial/nonverbal reasoning. Some of the most widely used standardized math tests for assessment and diagnosis of math disorder are outlined below in Table 3.3.

Performance on these tests yields standard scores with corresponding percentiles and often age or grade equivalents that can be used to diagnose a math disorder. However, it will be of greatest benefit to the child if a process-oriented approach to assessment and diagnosis is used. A process-oriented approach will include both observations of a child's strengths and weaknesses in different math skill areas as well as measures of cognitive functions related to math

Table 3.3 Standardized math assessments

Test and features	Norms and scaling	Subtests
Wechsler Individual Achievement Tests, 3rd Ed. (WIAT-III)	Ages 4.0–50.11 Age- and grade-based norms available Standard scores with percentile as well as age and grade equivalents Ability achievement discrepancies available with Wechsler Intelligence Scales for Children, 5th Ed (WISC-V)	*Numerical Operations* – paper-and-pencil assessment of calculation skills *Math Problem Solving* – items read aloud covering counting, graph reading, problem solving, and geometry *Math Fluency* – 3 individual 1 min tests of fluency for addition, subtraction, and multiplication
Test of Early Math Ability, 3rd Ed. (TEMA-3) *Includes teaching guidelines for specific items to address lagging skills*	Ages 3–8 years Can be used as norm referenced (age) measure or as diagnostic instrument to identify strengths and weaknesses Standard scores with percentile as well as age and grade equivalents	Single math ability score Skill areas covered include numbering skills, number-comparison facility, numeral literacy, master of number facts, calculation skills, and understanding of concepts
Woodcock Johnson Tests of Individual Achievement, 4th Ed. (WJ-Ach IV)	Ages 2–90+, grades K.0–18.0 Age- and grade-based norms available Standard scores with percentile as well as age and grade equivalents Ability achievement discrepancies available with Woodcock Johnson Tests of Cognitive Abilities 4th Ed. GAI score	*Applied Problems* orally administered items measuring ability to analyze and solve math problems using appropriate calculations *Calculation* paper-and-pencil numerical operations (+, −, ×, /) as well as geometric, trigonometric, logarithmic, and calculus operations *Math Facts Fluency* *Number Matrices* (in extended version) – assesses mathematics problem solving in a matrix reasoning format
Feifer Assessment of Mathematics (FAM) *Provides information on specific neurodevelopmental processes underlying math ability and for specifying subtypes of math disorder*	Ages 4–21 years Grade-based norms PK – college (with age proxies provided); age and grade equivalents for subtests	19 subtests measuring math fact retrieval, numeric and spatial memory, perceptual estimation skills, linguistic math concepts, and core number sense development *Verbal Index Score* – automatic fact retrieval and linguistic components of math *Procedural Index Score* – measures ability to count and order numbers or mathematical procedures *Semantic Index Score* – visual-spatial and conceptual reasoning including magnitude representation, patterns and relationships, higher-level mathematical problem solving, and number sense
Academic Achievement Battery (AAB)	Age- and grade-based norms for ages 4–85 years Ability achievement discrepancies available with Reynolds Intellectual Assessment Scales, 2nd Ed (RIAS-2)	*Mathematical Calculation* – oral and written responses for grades Pre-K to 3 and increasingly difficult paper-and-pencil math calculations in a timed task for upper grades *Mathematical Reasoning* – requires examinee to apply mathematical reasoning to real-life problems through oral response

Table 3.3 (continued)

Test and features	Norms and scaling	Subtests
Kaufman Test of Educational Achievement, 3rd Ed (KTEA-3)	Ages 4:0–25:11 Age- and grade-based standard scores, age and grade equiv., percentile ranks, normal curve equiv. (NCE's), stanines, and Growth Scale Value (GSV)	*Math Concepts and Applications* orally administered items covering number concepts, operation concepts, time and money, measurement, geometry, fractions and decimals, data investigation, and higher-math concepts *Math Computation* written calculation test assessing counting and number identification, +, −, ×, /, fractions and decimals, square roots and exponents, and algebra *Math Fluency* 1 min timed tests of +, −, ×
Wide Range Achievement Test, 4th Ed. (WRAT-4) *Fifth edition to be released soon*	Ages 5–94 years Age-based standard scores, percentile ranks, stanines, normal curve equiv., grade equiv., and Rasch ability scaled scores	*Math Computation* measures ability to count, identify numbers, solve simple oral math problems, and calculate written math problems
Peabody Individual Achievement Test *Multiple choice answers with option to point to choice – allows for use with children who have trouble communicating verbally*	Age range 5–22.11; grades K-12 Age-based norms, percentile ranks, and grade equiv.	*Mathematics* multiple choice format assessing math concepts from recognizing numbers to solving geometry and trigonometry problems; does not require paper and pencil but given option
Mathematical Fluency and Calculation Tests (MFaCTS) *Three forms allow to measure change in math fluency and calculation and tracks progress; allows for individual or group administration*	Ages 6–18:11 years; grades 1–12 Both age and grade-based norms w/ percentile ranks	*Calculation* paper-and-pencil calculation problems of increasing difficulty *Fluency* 5 min for grades 1–2 (+, −) and 3 min for grades 3–12 (+, −, ×, /)
Comprehensive Mathematical Abilities Test (CMAT) *Based on state and local curriculum guides*	Ages 7–0 to 18–11 Age- and grade (3–12)-based norms	6 core subtests Basic calculations: 1. *Addition*, 2. *Subtraction*, 3. *Multiplication*, 4. *Division* Mathematical reasoning: 5. *Problem solving*, *Charts*, 6. *Tables and Graphs* 6 supplemental subtests Advanced calculations: 1. *Algebra*, 2. *Geometry*, 3. *Rational Numbers* Practical applications: 1. *Time*, 2. *Money*, 3. *Measurement*

disorder. It stresses the importance of monitoring a child's approach to math problem solving and calculation and his or her consistent (or inconsistent or nonexistent) use of more or less effective and age-appropriate strategies. A process-oriented approach is also likely to lead to the most effective interventions.

The WIAT-III is one of the most widely used tests of academic skills including math and includes a variety of subtests that provide us with a good example to use to describe what a process-oriented approach to assessing math disorder might look like. The Math Problem Solving subtest is for students in prekindergarten through grade 12+ and progresses from recognizing small quantities, shapes, and numbers through concepts of more and less, sequential order, graph reading, addition and subtraction in word problems to telling time, place values, word problems requiring fractions, and multi-step problem solving using formulas. A process-oriented approach will take note of both the particulars and themes in a child's approach to problem solving. Does a first grader recognize three fingers without one-to-one counting? Does a fourth grader struggle with fractions? Does a high school student do well on math problems but struggle with geometry or vice versa?

The Numerical Operations subtest of the WIAT-III is for students in kindergarten through grade 12+ and is a paper-and-pencil test. For younger children, problems are read aloud, and the child is asked to write or circle his answers. Counting, number and symbol recognition, and grouping and sequencing skills are assessed. Paper-and-pencil problems then progress from single-digit addition/subtraction to multiplication, division, order of operations, summing fractions, algebra, geometry and eventually trigonometry, limits, and logarithms. Notably, the child is given scrap paper to use as needed to work out problems. Here, a process-oriented approach will include looking at the strategies a child uses to solve problems in addition to the concepts and procedures she is able to successfully complete. Does she count or carry when solving multi-digit subtraction problems? Does he use logic or algebraic reasoning to solve for X? It is also important for this test to ask about concepts the child has/has not been exposed to in school as this test relies more on knowledge of procedures compared to concepts on Math Problem Solving. A process-oriented approach will also look for error patterns. Does a child know how to solve problems but consistently make errors due to inattention (e.g., to signs) or spatial weaknesses (e.g., incorrectly lining up numbers)?

Lastly, the WIAT-III and other tests of academic achievement (e.g., the Woodcock Johnson (WJ-IV)) often include tests of math fluency (i.e., rapid retrieval of single-digit addition, subtraction, and multiplication facts). Some tests like the WIAT separate operations into different tasks, while others like the WJ combine them into one task. On combined tasks, it may be important to look at a child's pattern of errors to see if difficulties are specific to one operation. It may not be the one expected. For example, often, older children will do better on multiplication fluency than on addition fluency because it is a more recently learned and practiced skill. Fluency tasks are important to mention because they are often overlooked for being simple with most children doing as well as expected on them. However, as noted above, research suggests that, for children with math disorder, math fluency skills often remain impaired even with intensive instruction and remediation of difficulties with higher-order math. Children with math disorder often show error and reaction time patterns that differ from younger, typically achieving children when tested on math fact retrieval [21]. Impairments in math fluency may be one of the most sensitive and reliable indicators of math disorder.

The multicomponent nature of and multiple pathways to math disorder necessitate a comprehensive assessment including more than standardized assessment of math skills alone. A comprehensive assessment for diagnosing math disorder will include intelligence testing with measures of verbal and nonverbal/spatial processing as well as working memory and processing speed. Additional assessments of executive function skills including both verbal and visual working memory, shifting attention, inhibition, and planning and organization can elucidate the specific deficits contributing to an individual child's weaknesses in math. It may be necessary to include additional measures of visual-spatial perception and processing to better understand a child's cognitive strengths and weaknesses contributing to math processing. Tests of symbol recognition and phonological decoding may reveal weaknesses in symbolic processing that contribute to aphasic math disorder. A list of possible measures that may be included in a comprehensive neuropsychological assessment of math disorder and the domains of functioning they address is outlined in Table 3.4.

Comorbidities of Math Disorders

Certain neurological and genetic conditions such as epilepsy and Turner's and Noonan syndromes carry with them a higher risk for math disorder. The most common comorbidities of

Table 3.4 Additional measures of cognitive processes associated with math disorder

Verbal skills	Tests of rapid naming from NEPSY-II, CTOPP, DAS, and others DKEFS Color-Word Interference (also assesses inhibition)
Working memory	WISC-V Digit Span, Letter-Number Sequencing, Picture Span DAS-II Recall of Digits, Recall of Objects, Recall of Sequential Order DKEFS Trails Test WRAML2 Verbal Working Memory and Symbolic Working Memory subtests
Attention/ inhibition	WISC-V/DAS-II and other Digits Forward tasks Conners' Continuous Performance Test (CPT-3) Test of Everyday Attention for Children (TEACh)
Planning/ organization	Rey Complex Figure Test DKEFS Tower Test Wisconsin Card Sorting Task
Visual-spatial skills	WISC-V Block Design, Visual Puzzles, Matrices DAS-II Matrices, Recall of Designs, Pattern Construction, Matching Letter-Like Forms WJ-IV Spatial Relations, Visual Matching Beery Visual Motor Integration Test (VMI) Test of Nonverbal Intelligence (TONI-3 and C-TONI) Wide Range Assessment of Visual Motor Ability (WRAVMA)

math disorder are attentional problems (ADHD), dyslexia, anxiety, visuospatial deficits, and working memory and other executive function weaknesses. Language-based learning disabilities also often co-occur with weaknesses in math (particularly symbol recognition and fluency). About 56% of children with reading disorder also have poor math achievement, while 43–65% of children with math disorder have poor reading skills [6].

In some cases, it may be difficult to determine if a child has a separate learning disability in math or simply shows weaknesses in aspects of math because of another disorder. For example, a child with ADHD may make careless errors on math testing that disappear and significantly change his performance and score when his ADHD is treated with a stimulant and behavioral support. As discussed above, a comprehensive neuropsychological assessment is often critical to identifying cognitive strengths and weaknesses that either support a diagnosis of a separate math disorder or in some cases do not and instead point to math weaknesses that are really the result of a different skills deficit or learning disability.

Children who do meet criteria for a math disorder with an attention deficit or other learning disorder seem to be at particular risk for problems in learning and adjustment. Children with a dual diagnosis of math disorder and dyslexia have been found to be more significantly impaired on arithmetic skills and to have overall poorer performance on neuropsychological tests than children with math disorder alone or children with math disorder and ADHD [38].

Math disorders also carry with them a high risk for not only attention problems but also for internalizing problems. Math anxiety is very real and significantly impairing for many children and especially for those with a math disorder. Students with higher levels of math anxiety perform more poorly than students with lower levels of anxiety across all areas of math reasoning and regardless of whether or not they have a diagnosed math disorder [27]. It is therefore important to determine to what extent math delays are due to deficient skills underlying math reasoning versus anxiety. This is best accomplished with a comprehensive assessment that includes measures of anxiety and where math achievement and its underlying skills are assessed in a setting that minimizes or accounts for the possible impact of anxiety.

Math anxiety can also contribute to an inability to apply strategies learned in remedial or intensive instruction on testing. Executive functions, in particular, tend to shut down when anxiety is high as part of a fight or flight response and this in turn further limits flexible problem solving [25]. Even worse, math anxiety very often leads to math avoidance. Children with math disorders may be reluctant to engage in intensive instruction and fall further behind their peers as a result. A comprehensive assessment to diagnose math disorder will include measures assessing general and possibly even math-specific anxiety such as the Behavior Assessment Scales for Children (BASC), Multidimensional Anxiety Scale for Children (MASC), or the Math Anxiety Rating Scale.

Prognosis and Interventions

Probably because of the variability in type of and pathways to math disorder and the relatively recent contribution of cognitive neuroscience to understanding math disorder, there is a relative lack of good data on the longitudinal outcomes of and prognosis for math disorder. Shalev [38] point out that many children in younger grades (e.g., from 1st to 2nd) show improvement in math skills with remedial and intensive instruction. Of course, this raises the unanswered question of what predicts which children flagged in younger grades would go on to develop math disorder and which would not even without intervention.

There is less improvement among children at older ages. For example, 95% of children 10–11 years old with math disorder who were re-evaluated 2 years later continued to score in the lowest quartile of their school class and half continued to meet criteria for math disorder (Shaley 2000). In this age group, risk factors for persistence of math disorder included the severity of math impairment and having a sibling with math disorder, while SES, gender, and the co-occurrence of another learning disability were *not* significantly related. These results would seem to suggest that more significant and neurobiologically based math disorders carry a worse prognosis.

A variety of studies have found the effect of math disorder on a person's short- and long-term adjustment, and achievement is significant, including a serious negative impact on professional careers [33]. There is no question that it is important to address math disorder given the impact on employment and economic status, particularly in an increasingly technology- and engineering-focused society. The early identification and diagnosis of delays in math is important for intervening early and intensively with children with math disorder. Given the multiple pathways to and presentation of math weaknesses, effective interventions will also rely on an accurate and specific understanding of an individual child's mathematics strengths and weaknesses.

Interventions that are individualized, structured and hierarchically built, and repetitive and that address anxiety and avoidance of math are likely to be most effective [28]. Furthermore, interventions should ideally draw on what we know about math disorder from an interdisciplinary perspective including psychology, neuroscience, and education. For example, Kucian et al. [29] found a computer-based training program (*Calcularis*) to be effective for improving number representations and strengthening the link between numbers and spatial processes on the internal mental number line in children both with and without math disorder. The computer training was also found to modulate brain functioning with increased activity in the IPS and a shift from frontal to anterior processing.

Perhaps more so than other learning disorders, math disorder is a moving target. Each change in grade comes with a new math topic (or several) to master. The child who struggles with geometry will not necessarily struggle with calculus, again depending on the nature of and cognitive pathways to his particular math disorder. Furthermore, approaches to math instruction seem to change between teachers and over relatively short periods of time. A child may be taught math using two or even three different approaches or curricula in a single year. Geary [21] points out that math instruction varies in its focus on mathematics as an applied domain where conceptual understanding is more important than learning procedures and facts and instruction that approaches mathematics as a field to be mastered where procedures take precedence. Depending on whether an approach to math instruction is more conceptual or procedural, numbers- or language-based, computer-based, or hands-on, a child with math disorder will struggle more or less. Again, understanding an individual child's pattern of cognitive and math weaknesses is key to determining how best to support him.

Unfortunately, there are few evidence-based interventions for children with math disorder, especially when compared to interventions for reading disorder/dyslexia. However, a well-done assessment for math disorder can guide the math special education teacher in choosing interventions that address the particular areas of weakness for that child, not just in math skills but also in the *processes* underlying the math skill. The research on interventions that does exist suggests that structured multisensory approaches are likely to be most effective. A structured approach breaks math down into smaller skills and builds on them over time using frequent review and preview. A multisensory approach uses physical manipulation of objects, body movements, and visual and auditory tools to engage sight, hearing, touch, and proprioception for learning. Particularly for children with language strengths, an approach that "talks through" problem solving can also be helpful. One math program with some empirical support that uses such an approach is Stern Structural Arithmetic. Some tutors are also successful in adapting the multisensory approach to reading of the Orton-Gillingham program to math. The Lindamood-Bell approach has been similarly adapted for math disorder.

With a lack of many empirically supported programs for addressing and remediating math disorders, it is generally up to math educators to determine specific supports and accommodations to remediate math disorders in schoolchildren. It is beyond the scope of this chapter to review all of the approaches to math curricula and remedial intervention available. A list of often-recommended interventions and accommodations for children with math disorder is outlined in Table 3.5 but cannot be considered exhaustive or even relevant for every child with a math disorder. However, a comprehensive neuropsychological assessment of the child struggling with math disorder can be a guide. In their white paper response to the IDEA 2004 law defining specific learning disabilities [24], a group of leading

Table 3.5 Accommodations and supports for math disorder

Primary interventions:
Intensive, remedial multisensory instruction (using movement, manipulatives, music, etc.) in areas of math calculation and reasoning identified as weaknesses
Use of computer software as appropriate (e.g., to improve math fluency)
Address other contributing factors
Medication and/or behavioral supports for attention
Medication and/or therapy to address anxiety
Occupational therapy for visual-motor/spatial processing weaknesses
Speech and language therapy for executive function and language weaknesses
For severe math disorder in older students, focus instruction on applied skills (e.g., money, measurement, telling time)
Accommodations:
Access to graph paper, calculator, math facts sheet, number line
Extended time for math tests
Slower pace of instruction with frequent preview and review – concepts build on each other
Have child complete fewer problems (e.g., every other item of worksheet that covers a single topic)
Present math in simplified form – problems presented vertically instead of horizontally, fewer items on a worksheet
Teach multiple ways to solve problems
Supports at home:
Play board games that support math learning or the skills underlying math reasoning (e.g., Hi-Ho Cherry Oh!, Shoots and Ladders, Uno, Monopoly, Qwirkle, Rush Hour)
Verbalize and model everyday math (e.g., telling and estimating time, money management, calculating tips, miles per hour, etc.)
Help your child use visual aids for math homework (e.g., cutting up fruit for fractions)
Work on reducing math anxiety by setting up homework routines and minimizing pressure to achieve in math

experts in learning disabilities noted that "children with specific learning disabilities need individualized interventions based on specific learning needs, not merely more intense interventions designed for children in general education." To that end, they recommended that assessment of cognitive and neuropsychological processes be used not only for identification of learning disabilities but for intervention as well.

Case Examples

Megan: A 20-Year-Old College Student on Academic Probation

Megan is a 20-year-old college student referred for assessment by her psychiatrist. Megan has a history of anxiety beginning early in middle school. She is enrolled in a private university and is studying sociology. She is currently on academic probation in spite of apparently high-intellectual ability and generally good (if somewhat inconsistent) effort. Megan previously attended a bilingual charter school in a large city for elementary and middle school where she generally did very well. She was more of an average student in her large city high school. She and her parents note that math has historically been one of her weaker subject areas, but they also note she did not seem to get very good math instruction in high school. She also struggles some with organization for writing. While she completes tests quickly, she has a harder time completing longer-term assignments. Megan has never received supports in school and has never been previously evaluated. Her psychiatrist is wondering about the possibility of ADHD and/or a specific learning disability and about the impact of anxiety on Megan's academic performance.

Megan's scores on key measures are presented in the table below. She demonstrated many strengths including general intellectual abilities in the high average to superior range with particular strengths in verbal knowledge and reasoning. While her abstract nonverbal inductive reasoning skills and her visual-spatial processing skills were less well developed than her verbal skills, she still scored in the high average range for her age. While not reported in the table here, her ability to sustain and regulate her attention was intact in spite of weaknesses in initial rote attention and learning on a list-learning task (possibly due to anxiety). In spite of initial weaknesses in attending to and encoding a list of words, she went on to score in the overall high average range for auditory verbal learning and memory.

While testing did not support a formal diagnosis of primary ADHD, Megan did demonstrate relative personal weaknesses in aspects of executive functioning including working memory and mental processing speed on intelligence testing and in organization and planning on the Rey Complex Figure copy task. She showed slower processing speed when required to shift her attention between competing demands compared to her performance on more rote tasks, even though her scores were consistently average on standardized measures. By her own self-report, Megan had difficulty on everyday tasks with shifting her attention between tasks, initiating tasks and assignments, and managing multiple demands at once. She also noted some difficulty inhibiting impulses. In light of ongoing concerns for anxiety, it was assumed her relative weaknesses in aspects of executive functioning were both related to and exacerbated by anxiety.

Most notable in her scores below is Megan's performance on tests of math achievement. She showed strengths in basic reading and reading comprehension but personal and normative weaknesses in math calculation and basic fluency. We can see that her performance on Numerical Operations was both in the low average range (<16th percentile) compared to her same-age peers and significantly below aptitude expectations (predicted score based on FSIQ = 115). Her math fluency skills for single-digit addition, subtraction, and multiplication were even weaker and significantly below age and grade expected level. Taken together, Megan's performance on neuropsychological assessment suggests a math disorder related to weaknesses in aspects of executive functioning that also impact her academic performance in other areas (e.g., completing long-term projects and assignments, testing well). Megan also shows comorbid anxiety typical of many individuals with math disorder.

Megan and her parents were somewhat surprised to see how poorly she performed on math compared to her abilities in other areas and compared to her peers. They questioned whether weak math instruction in her public high school might explain her performance. However, her particularly weak performance on fluency is strongly suggestive of an underlying math disorder, and when this was explained, it was compelling evidence for Megan and her parents. Megan was at a point in her academic career where she had completed math course requirements for a college degree and remedial math instruction did not seem to be a good use of her time or resources. However, it was recommended she share the report of testing with her university student services office to document a math disorder so she could receive accommodations in courses that might relay heavily on math (e.g., science or statistics). It was also recommended that addressing weaknesses in executive functioning through tutoring and accommodations might help her to succeed overall academically.

Intellectual functioning WAIS-IV	**Standard score**	**Percentile rank**	**Qualitative**	
Full scale IQ	117	87	High average	
Verbal Comprehension Index (VCI)	127	96	Superior	
Perceptual Reasoning Index (PRI)	113	81	High average	
Working Memory Index (WMI)	108	70	Average	
Processing Speed Index (PSI)	105	63	Average	
Rey Complex Figure Test (RCFT)	**Raw score**	**Percentile rank**	**Qualitative**	
Copy	31	<1	Extremely low	
Copy time	120	>16	WNL	
Math achievement	**Standard score**	**Percentile rank**	**Qualitative**	
WIAT-III Numerical Operations	84	14	Low average	Predicted score = 115
WJA-III Math Fluency	76	6	Borderline	GE = 6.8

Michael: An 8-Year-Old Boy in the Third Grade

Michael is an 8-year-old, left-handed, boy referred for evaluation by his pediatrician. Michael has a history of concerns for fine motor skills, sensory processing issues, and attention at home and school. He has difficulty with transitions and completing tasks with multiple steps. Academic testing completed through his school when he was in the second grade indicated delays in early math skills and was suggestive of concerns in writing. Michael has also been noted to have difficulties with attention and sitting still in the classroom. His desk is very messy and he often forgets to bring home work that needs to be completed. Michael's strengths are in reading and science.

Michael was adopted from Honduras to the USA at 10 months old, and information about his birth history is limited, but he has generally been healthy since his adoption. He did receive services through early intervention due to slight motor and speech/language delays. His mother notes he caught up quickly with supports, and Michael is now described as quite talkative. An occupational therapy evaluation completed when he was 6 years old identified issues with strength, endurance, sensory processing, gross motor skills, visual motor skills, bilateral integration, and sequencing skills. Michael received 1 year of vision therapy to address ocular divergence and weaknesses in visual tracking and his ability to read and participate in physical activity improved significantly, though he still does not enjoy team sports where his participation is limited by vision weaknesses. He wears glasses and participates in ice skating and swimming. While he gets along well with his siblings and with adults, Michael is described as often the "odd one out" with peers and is socially somewhat immature.

Michael's scores on key measures are presented in the table below. Michael's intellectual ability, including both verbal and nonverbal reasoning skills, was assessed in the average range for his age on the WISC. He showed particular strengths in verbal abstract reasoning and verbal fluency. However, he did show personal and normative weaknesses on the WISC Matrix Reasoning task, a measure of understanding patterns. Michael showed additional weaknesses in rote attention, working memory, and mental processing speed as well as in other aspects of executive functioning including logical and flexible problem solving, shifting attention, and self-monitoring. Notably, though, his weakest performance on the DKEFS Trails task was for speed of sequencing numbers as opposed to letters. Weaknesses in sequencing were also apparent in his difficulty retelling stories immediately after hearing them on the WRAML Story Memory task but good recognition memory when he was asked about details from the stories later.

Michael also showed weaknesses in visual-spatial perception, visual tracking, and visual-motor integration. His skills in written expression were assessed on the OWLS-II and were age- and grade-appropriate but notable for poor handwriting with weak planning and spacing. Michael's scores on tests of reading and language skills were consistently in the high end of the average range for his age or better. In contrast, his scores for math calculation, reasoning, and fluency were within the low end of the average range for his age. His pattern of performance on testing was consistent with a semantic math disorder with underlying weaknesses in visual-spatial reasoning and processing as well as executive functions. Michael's difficulties with attention were noted by parents and teachers on the BASC and ADHD symptoms checklist to be interfering for him in general and accompanied by symptoms of hyperactivity/impulsivity, and he met criteria for a comorbid diagnosis of attention deficit hyperactivity disorder, combined type (ADHD-CT).

Multisensory teaching, supports for attention in the classroom, extended time for tests and assignments particularly in math, and occupational therapy were recommended for Michael. Additional supports for math included access to a calculator, math facts sheet or number line, and ability to use graph paper. It was recommended that worksheets be simplified and Michael be presented with as few math problems at a time as possible. Computer programs were recommended for building math fluency in addition to frequent preview and review. Individualized instruction in math and tutoring in executive function skills were also recommended. Michael's parents chose for the time being to address his attentional problems with behavioral supports but noted they might consider medication in the future if issues with attention and hyperactivity became more interfering for him.

Michael's was a case where his math disorder clearly mapped onto underlying weaknesses in spatial reasoning and executive functioning, but his math disorder was at risk of being overlooked and attributed instead to attention problems or vision weaknesses. Having a comprehensive evaluation of more than simply intellectual skills and academic achievement allowed his parents to better advocate for him for the specific types of supports and intervention he needed.

Intellectual functioning WISC-IV	**Standard score**	**Percentile rank**	**Qualitative**
General Ability Index (GAI)	102	55	Average
Verbal Comprehension Index (VCI)	106	66	Average
Perceptual Reasoning Index (PRI)	96	39	Average
Matric Reasoning Scaled Score = 6, 9th %tile			
Working Memory Index (WMI)	74	4	Borderline
Processing Speed Index (PSI)	83	13	Low average
Language tests	**Standard score**	**Percentile rank**	**Qualitative**
NEPSY-II Comprehension of Instructions	9	37	Average
FAS – animals	126	96	Superior
DKEFS Letter Fluency	14	90	High average
DKEFS Category Fluency	11	63	Average
DKEFS Fluency Switching	16	98	Very superior

Visuospatial tests	**Standard score**	**Percentile rank**	**Qualitative**
NEPSY-II arrows	5	5	Borderline
Beery VMI	85	16	Low average
Attention and executive functions	**Standard score**	**Percentile rank**	**Qualitative**
Rey Complex Figure Copy	N/A	<1	Extremely low
DKEFS Trails Visual Scanning	12	75	Average
DKEFS Trails Number Sequencing	1	<1	Extremely low
DKEFS Trails Letter Sequencing	11	63	Average
DKEFS Trails Letter-Number Switching	3	1	Extremely low
Conners' Continuous Performance Test (CPT-2)	50/100 chance of significant attention problems		
TEA-ch Score! Test	10	50	Average
Children's category test	$T = 20$	<1	Extremely low
Learning and Memory Tests	**Standard score**	**Percentile rank**	**Qualitative**
Story Memory Immediate Recall	5	5	Borderline
Story Memory Recognition	10	50	Average
Math achievement	**Standard score**	**Percentile rank**	**Qualitative**
WIAT-III Numerical Operations	87	19	Average
WIAT-III Math Problem Solving	85	16	Low average
WIAT-III Math Fluency	89	23	Average

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4

Disorders of Written Expression

Ellen H. O'Donnell and Mary K. Colvin

The DSM-V [1] description of specific learning disorder with impairment in written expression includes delays or weaknesses in spelling accuracy, grammar and punctuation accuracy, and/or clarity or organization of written expression. Diagnosis with a specific learning disorder in writing does not require that all or even most of these criteria be impaired. Thus, there is considerable heterogeneity in the clinical presentation of writing disorders and overlap with other clinical syndromes. Further complicating diagnosis is that the term *dysgraphia* is often used to describe writing difficulties. We will reserve dysgraphia to describe illegible handwriting or printing due to weaknesses in visual-motor coordination, as the term was initially used to describe such difficulties following neurological impairment.

Like all learning disabilities, the DSM specifies that weaknesses in written expression must be present and persistent for a minimum of 6 months despite interventions targeting the child's specific difficulty, a failure to respond to intervention definition. Difficulties need to begin during school-age years, though they may not fully emerge until demands on written expression skills increase and surpass the child's skill. The child's written expression skills must be "substantially and quantifiably below those expected for the individual's chronological age, and cause significant interference with academic or occupational performance, or with activities of daily living, as confirmed by individually administered standardized achievement measures and comprehensive clinical assessment." These diagnostic criteria are a slight weakening in the stringency of prior DSM criteria that required a statistically significant discrepancy between ability (typically assessed as IQ) and academic achievement and are consistent with a move toward diagnosing learning disabilities based on a pattern of weaknesses in core skills that contribute to the specific learning difficulty [48]. A documented history of impairments in written expression can be used in place of standardized assessment for diagnosing individuals who are over 17 years old or past high school education. As with other specific learning disorders, deficits in written expression cannot be due to lack of or inadequate educational instruction.

The DSM-5 symptom severity criteria for specific learning disabilities (i.e., "substantially" below age expectations and causing "significant" interference in functioning) is perhaps harder to define for writing than for reading and math.

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While there is some agreement about the typical development of specific writing skills such as spelling, grammar, and punctuation (often referred to as *conventions* of written expression), there is far less objective agreement around the development of skills in written *composition*. We do, though, know quite a bit about deficits in specific skills such as executive functioning and visual-motor processing that contribute to challenges and weaknesses in written expression.

In this chapter, we identify and describe key components of written expression skills, arguing that a thorough assessment of writing disorders should address each of these areas. Children whose skills in any of these components are assessed below developmental or age expectations should be automatically considered at risk for a writing disability. This will include many children who have neurodevelopmental or neuropsychiatric conditions, but the manifestation of the writing disability will vary depending on the nature of the condition, as not all components will be impacted equally across the populations. This theoretical framework allows one to predict and better characterize the different manifestations of a writing disability within different populations and to identify specific targets for intervention.

Incidence and Impact of Disorders of Written Expression

Research into the incidence and prevalence of Disorders of Written Expression dates back only about 20 years. In 2009, Katusic et al. used a population-based birth cohort between 1976 and 1982 in Rochester, Minnesota, to estimate the prevalence of Disorders of Written Expression in the general US population. They found that written language disorders were at least as frequent as reading disorders and similarly significantly more frequent among boys than girls. Depending on three different formulas used to define specific learning disability, cumulative incidence rates of written language disorder varied from 6.9% to 14.7%. Boys were two to three times more likely than girls to be affected by written language disorders [31].

In a separate study of unreferred middle school students recruited from three regions of the United States, prevalence rates similarly ranged from 6% to 22% [29]. In 2011, the National Center for Education Statistics [45] reported 58% of fourth graders wrote at "basic" level, 14% wrote "below basic" level, and 26% wrote "at proficient" level. Numbers were similar for eighth graders (54% at basic level, 20% below basic, and 24% at proficient level) and 12th graders (52% at basic level, 21% below basic, and 24% at proficient level).

Written language skills have been proven to be an important predictor of a child's overall development and impact their overall academic achievement and long-term social and economic standing [25, 28, 42]. This is not surprising given the importance of written language skills to academic success across the curriculum, particularly as students advance in school. In a school-based sample of 326 middle school students, written expression skills significantly predicted students' GPA above and beyond the effect of IQ and reading abilities [43].

It may also be that Disorders of Written Expression have a significant impact on overall academic achievement because of their frequent comorbidity with other learning disorders. In the Katusic et al. study, only 25% of the children identified as having writing problems had only a written language disorder [31]. In other words, three quarters of students with a Disorder of Written Expression in a population-based sample also had another identified learning disability. The most frequent comorbidities with Disorders of Written Expression are ADHD, language-based learning disability, and autism spectrum disorder. Understanding the specific skills deficits underlying Disorders of Written Expression in each of these populations provides a window into understanding written language disorders in general.

Typical Development of Written Expression Skills

While written expression is dependent upon oral language, it follows its own developmental trajectory and generally requires much more explicit instruction to be learned. The development of written expression skills is dependent upon several distinct but interrelated cognitive processes, some of which become more automatic over time but all of which continue to be equally important to the task of writing. A delay in the acquisition or meaningful use of any of these skills can lead to persistent weaknesses in written expression. Delays in written expression in turn can impact a child's ability to demonstrate knowledge across all academic areas, and the impact of such delays may become compounded over time.

Broadly speaking, the first task of the very early elementary student learning to write is to master transcription skills, beginning with letter formation, followed by words and followed by copying/combining and ultimately generating sentences. Transcription skills depend on visual-motor integration, fine motor dexterity and control, working memory, and phonological encoding for spelling. Transcription skills and working memory are most predictive of writing skills in early elementary school [23].

Once transcription skills become automatic, oral language skills including pragmatic skills become more critical for written expression. Productivity relies on transcription skills and on a well-developed vocabulary [24]. Text quality depends on structural language skills such as grammar and morphology [40, 63] and also on higher-level pragmatic skills including tone, meaning and metaphor, and targeting language to one's audience [67]. These skills tend to emerge later in formal schooling, during middle or high school.

Throughout the development of written expression, skills emerge along two dimensions: *text quality* (accuracy and complexity) and *productivity* [8]. Text quality might refer to conventions including spelling, grammar, and punctuation or to word choice and vocabulary. It might also refer to the organization and sequence of writing as well as to its expression or sophistication. Productivity refers to the amount or length of written text and can be measured by character count, word count, paragraph count, or number of correct word sequences. In the section below, we outline the key cognitive components in written expression that support its development.

Key Neuropsychological Components of Written Expression

Mastery of written expression is an ongoing and iterative process that relies on the ability to simultaneously engage language abilities and multiple other cognitive and motor skills, including attention, organization, planning, working memory, and graphomotor skills [73]. From a neuropsychological perspective, these components are dissociable; they rely on different brain networks and can be differentially impacted within different neurodevelopmental conditions. Identifying which components are impacted in a given child is important in characterizing the writing disorder and in developing an effective remediation plan.

Graphomotor Skills By age two, most children can hold a crayon or pencil and make meaningful marks on the page (e.g., vertical strokes). Over the course of the next several years, this process becomes more refined and complex, with letter formation beginning in the preschool years [17, 69], During early elementary years, handwriting gradually becomes smaller and less variable and automatic by age 10 [47]. Thus, handwriting is a motor learning process that involves the integration of visual perception, kinesthesia, and motor planning. As with most motor tasks, there can be difficulties with accuracy (legibility) and speed, and these two dimensions can be dissociable [69]. Delayed fine motor skill acquisition would be expected to negatively impact writing, and historically, the term developmental dysgraphia has been associated with this type of writing impairment.

Phonological Processing and Auditory Working Memory The smallest units of sound comprising words are called phonemes. The first step in writing often involves hearing a word and then identifying the individual phonemes that have been blended to form that word. These sounds are thought to be held in a temporary auditory working memory buffer known as the phonological loop [3]. While in auditory working memory (phonological loop), the writer can map phonemes to graphemes, implementing orthographic rules that are usually acquired gradually and with repeated practice. Deficits in phonological processing typically manifest as both reading and writing difficulties. Children who have core deficits in phonological processing should be assessed for difficulties with both grapheme-to-phoneme conversion (ability to decode (read) unfamiliar words; phonological decoding) and phoneme-to-grapheme conversion (ability to spell unfamiliar words; phonological encoding). Decoding difficulties are the core deficit in developmental dyslexia. Because of this relationship, children with developmental dyslexia should be assessed for comorbid writing (spelling) difficulties, which may be under-recognized [6]. Higher-order writing skills should also be assessed in those who have weaknesses in phonological processing and/or auditory working memory. Reduced auditory working memory may limit the ability to transcribe spoken language (e.g., taking notes during a lecture), the ability to transcribe written material (e.g., taking notes from the board), and the ability to hold internal thoughts in mind while writing.

Semantic and Syntactic Processing Higher-order writing skills parallel those that support oral expression. Beyond the single-word level, writing requires access to vocabulary and to an understanding of the meaning that can be created by using a word in context (semantics). For example, the word "cold" means something different in the sentence "It is cold outside" than it does in the sentence "She was very cold to him." Syntax is also critical in supporting meaning. Within a sentence, the order of words can lead to very different interpretations. "The man who wore the hat chased the dog" is different from "The man chased the dog who wore the hat." Syntax is enhanced through use of punctuation and sequencing of sentences within paragraphs.

Pragmatics Effective writing also requires an understanding of how the text will be interpreted and used by others. This process requires the writer to take the perspective of the reader. The writer needs to accurately assess the reader's level of knowledge and then choose to share their own knowledge at a level that is appropriate for the intended audience. The writer also needs to monitor how word choice, tone, and semantics may influence the interpretation of written text, adjusting as needed to preserve clarity and intention [18, 67].

Attention and Executive Functions Given all the motor and linguistic components above, it is not surprising that writing is a cognitively demanding task that requires executive functions. Executive functions involve developing and implementing an approach to performing a task and are defined as "the ability to maintain an appropriate problem solving set for attainment of a future goal" (p. 201, [72]). In addition to working memory, executive functions include fluency (generating words or novel ideas/solutions under time pressure), planning for problem solving, inhibition, and set-shifting (the ability to move from one thing to the next or to alternate between complementary but competing demands on attention). Executive functions have been found to contribute to the writing process in students with and without specific learning disabilities [30], and the fact that executive functions are not fully mature until a person is in their mid-20s helps to explain the long trajectory of developing skills in written expression (into college and beyond).

Comorbidities Reflecting Specific Skills Deficits in Disorders of Written Expression

Disorders of Written Expression very often co-occur with other specific learning disorders and developmental disorders. We will describe how the manifestation of the writing disability may vary depending on which of the key components are impacted by the learning or developmental disorder. We outline several common comorbidities of Disorders of Written Expression to emphasize the point that, when any of these are present, assessment of written expression skills

Table 4.1 Neuropsychological framework for conceptualizing and assessing Disorders of Written Expression

	Neuropsychological components of written expression				
	Graphomotor skills	Phonological processing/ auditory working memory	Semantics and syntax	Pragmatics	Attention and executive functions
Dysgraphia	X				X
Dyslexia		X			
Autism spectrum disorder	X		X	X	X
ADHD	X	X			X
Language disorder		X	X	X	
Nonverbal learning disability	X			X	X
Writing anxiety					X

is strongly recommended. We also propose a framework for conceptualizing and assessing writing difficulties in different neuropsychiatric conditions in Table 4.1. This is based largely on clinical experience, and our aim is to emphasize that only through a comprehensive assessment can Disorders of Written Expression be diagnosed and understood so that interventions can be tailored to the specific skills deficits impacting a given students' writing skills. This framework may also drive future clinical research to differentiate between different types of writing disorders.

Developmental Dysgraphia

The term dysgraphia has historically been used to describe acquired difficulties with handwriting following a known neurological insult. It is now also commonly used to refer to idiopathic difficulties with handwriting that emerge during development but is also sometimes also used interchangeably with a specific learning disorder with impairment in writing. For the purposes of this chapter, we define dysgraphia as a difficulty with graphomotor output, or the integration of visual perception, kinesthesia, and motor planning to support the act of writing. Dysgraphia is not included in the DSM-V but, as defined, may manifest as part of what is now defined as Developmental Coordination Disorder (DCD) or by the clinical construct of DAMP (Deficits in Attention, Motor Control, and Perception) [70, 74]. To date, it is unclear whether dysgraphia and DCD are dissociable; one recent study found that children with isolated handwriting difficulties (dysgraphia) performed similarly to children with DCD on handwriting tasks, with both groups performing worse than typically developing controls [53]. Children with DCD have also been shown to produce less written text than their peers [54] and to have poorer handwriting quality than children with learning disabilities alone [14]. Interestingly, executive function weaknesses have been described in pediatric DCD patients [36, 74], which may compound their vulnerability to developing a specific writing disorder.

Dyslexia and Reading Disorders

Teasing apart the research on comorbidity of reading disorders and Disorders of Written Expression is challenging. It was only within the past two decades that orthographic weaknesses (encoding for spelling) were considered separable from phonological reading problems (decoding). Until the publication of the DSM-V, reading and writing disorders were generally diagnosed as one and the same. While there is some research evidence that orthographic processing for spelling and reading are separate processes and that it is possible to show weaknesses in encoding for spelling but not in decoding for reading [27], these findings tend to be based on very small samples and largely on case studies.

What we do know is that individuals with dyslexia are on average poorer writers when compared to same-aged peers, and these differences are in part but not entirely explained by weaknesses in spelling [66]. The difficulties that students with dyslexia have with writing may begin at the word or sub-word level (i.e., coding phonological information into orthographic codes – written phonemes or words), but those word-level deficits seem to contribute to a cascading effect of weaknesses in processing at higher levels of written language. To put it simply, getting "stuck" at the level of encoding for spelling leaves little capacity remaining for generation, translation, and elaboration of ideas into meaningful, well-developed text.

Further complicating the comorbidity of reading and writing disorders is the high comorbidity of each with other learning disorders and with weaknesses in cognitive processes that contribute to written expression. There are generally much higher rates of ADHD, dysgraphia, and executive dysfunction among students with reading disorders which may contribute to more widespread difficulties with writing, even if higher-order auditory comprehension and spoken language skills are intact. A study using fMRI data suggests related but independent neurological and behavioral evidence for dysgraphia, dyslexia, and Disorders of Written Expression [7].

While many students with phonological processing weaknesses will show both reading and spelling difficulties, some show only one or the other. Looking at research exploring how weaknesses in writing present in students with and without reading disorders – both in phenotype and in the likely underlying neurocognitive weaknesses contributing to their difficulties – can help us to understand the different paths to Disorders of Written Expression. For example, students with dyslexia show particular weaknesses in automatic letter writing and naming, impaired inhibition and verbal fluency, and spelling but do not necessarily show graphomotor weaknesses [5]. Students with weaknesses in reading comprehension also show weaker written expression skills marked by poorer quality of writing, and these weaknesses seem in part to be explained by working memory difficulties [11]. Additionally, students with dyslexia may read less, leading not only to weaknesses in comprehension but to a dearth of vocabulary for written expression.

Problems with written expression may be under-recognized and undertreated in students with reading disorders. Adults with dyslexia report that writing, not reading, is their biggest problem [9, 44], possibly because they have benefitted from compensatory strategies and explicit instruction in phonetic decoding for reading without ever having received the same level of support for writing. Hopefully, with the separation of specific learning disorders in reading and written expression, more students with dyslexia will also be evaluated for writing disorders and receive additional supports.

As with the other comorbidities outlined here, it is crucial that students with dyslexia not only be evaluated for written expression but that they have a comprehensive assessment to identify the specific skills deficits contributing to weaknesses in reading and writing. A study of high-achieving university students with dyslexia showed differences only in spelling compared to same-aged peers when writing essays (i.e., there were no differences in essay organization and coherence) [13]. For these students, compensatory strategies and accommodations for poor spelling may be enough to improve their skills in written expression, while students with weaker language or executive function skills may need a different level and type of intervention for writing.

Autism Spectrum Disorder

Handwriting weaknesses are common among students with autism spectrum disorders (ASD), and many will need assistive accommodation for writing because of poor legibility [34]. More interesting, though, is the impact of impairments in pragmatic language on written expression. Students with high-functioning autism spectrum disorder generally have intact (or even superior) expressive and receptive verbal knowledge skills. However, they still produce generally briefer, less complex texts with fewer uses of mental state terms in comparison to matched peers [4, 10]. Weaknesses in executive functioning that accompany ASD also impact writing. Students with ASD are less focused on the main topic in their writing and make fewer smooth transitions between ideas [10].

It is also notable that, in a study comparing the writing skills of students with language impairments to those of students with ASD, a significant minority of students with autism did not produce written text [15]. This is certainly consistent with our own clinical experience and suggests that difficulties with understanding directions for complex tasks, task initiation, generating ideas, and/or low frustration tolerance that often characterize students with ASD impact written expression. The study authors note that children with ASD have been found to have difficulty generating ideas [46] and have difficulty talking about events [32]. Thus, impairments in fluency and mental sequencing as well as pragmatic language likely impact written expression.

In the Dockrell study, the students who failed to produce any written work tended to be younger and rated higher on autism symptomatology but did not show any more significant difficulties with handwriting or transcription that would explain their inability to write. The nonwriters were, also, on average about 8 years old, just the age when typically developing children begin producing longer, more complex, and more spontaneous texts.

Attention Deficit/Hyperactivity Disorder

Based on population estimates, approximately 60% of children diagnosed with ADHD will meet criteria for a written language disorder by age 19, compared to about 12% of those without ADHD [31]. Prevalence rates of Disorders of Written Expression among individuals with ADHD are similarly estimated at about 60% [41]. Other studies of school-based samples estimate rates of written language disorder closer to 20% among students with ADHD [43]. Regardless, as a result of this quite high coincidence, the American Academy of Pediatrics recommends that children with ADHD be evaluated for coexisting Disorders of Written Expression.

Students with ADHD tend to generate less organized written work, write less, and make more errors of grammar, spelling, and punctuation compared to peers without ADHD beginning around age 9 years [12, 57]. These differences hold even when students with and without ADHD have received the same level of instruction in written expression and have equivalent knowledge of the basic rules of writing [81]. Looking at patterns of performance on tasks of written expression among students with ADHD tells us something about the skills deficits that contribute to difficulties with writing.

Deficits in visual-motor integration and motor coordination often accompany ADHD, with up to 50% also meeting diagnostic criteria for Developmental Coordination Disorder (DCD) [22]. Children with ADHD often show poor handwriting [33, 50, 55, 58]. Weaknesses in working memory, planning, and organization also impact the quality and production of written language among children with ADHD [56, 76].

Even otherwise intellectually gifted students with strong verbal skills who also have ADHD often struggle with the demands placed on planning and organization for writing. Stewart [65] argues that writing typically requires "top-down delivery of ideas" – a main idea or thesis statement followed by supporting ideas or details. But she points out that individuals with verbal strengths and relative weaknesses in executive function tend to be "bottom-up" thinkers whose cognition is more associative and detail oriented, providing insight and connections between ideas but lacking organization. Clinically, students with written language disorders often show poorer than expected performance on tests of planning and organization (even for visual information).

Consistent with this, a study of 14 gifted students (Verbal IQ of 120 or above) with specific learning disability of written expression (based on an ability-achievement discrepancy) found that most students' scores for executive functions including working memory and processing speed were significantly lower than their scores in other skill areas [2]. While only some students had spelling difficulties, more than half had weak writing fluency (considered an executive function-mediated process). Stewart suggests that, to become better writers, individuals with superior verbal intellectual ability can be encouraged to pull on their strengths in language processing to learn a way of organizing their ideas for writing by "gather(ing) their ideas, label(ing) them, and plac(ing) them into the system of language (p. 30)."

Language Disorder

As discussed above, the development of spoken and written language are interdependent but unique processes. That said, longitudinal studies of preschool age children with speech and language difficulties suggest that 50–75% of them go on to have academic difficulties, including Disorders of Written Expression [37]. Young children who show weaknesses in higher-order language skills such as expression, abstraction, and comprehension seem to be at greater risk for learning disabilities than those with speech-sound disorders alone.

Research on the connection between language-based learning disability and Disorders of Written Expression suggests that language impairments particularly impact written syntax and vocabulary. In a study of children ranging in age from 7 to 14 years identified as having a language-based learning disability (either phonology alone or phonology + language impairment) and their siblings without LD, those with phonological and language impairments fared worst [37]. Their writing samples were marked by weaker thematic maturity, contextual vocabulary, syntactic maturity, and contextual spelling. Even the children with histories of phonological impairments alone used shorter and less complex sentences in their writing. There were no group differences, however, in students' use of written mechanics such as capitalization and punctuation, suggesting these aspects of writing are mediated by processes other than language.

Interestingly, in the Lewis study, measures of spoken syntax and semantics were not significantly correlated with measures of written syntax and semantics. Children who struggled with writing did have lower scores on language measures including receptive vocabulary (PPVT-R) and spoken language (CELF-R). The study authors suggest an indirect relationship between language-based learning disabilities and Disorders of Written Expression. Their findings support language and writing development as distinct but overlapping processes. Nonetheless, in our clinical practice, assessment of oral expression and auditory comprehension are important to determine the extent to which the writing disorder is isolated or embedded within a broader language disorder.

Nonverbal Learning Disability

Nonverbal learning disability (NLD) was first proposed to describe patients who presented with intact language-based skills (e.g., reading) and deficits in visuospatial and constructional skills, as well as math difficulties. Rourke and colleagues then hypothesized that this learning style was associated with selective weaknesses in right hemisphere functioning and linked it to many different neurodevelopmental conditions. The construct remains highly controversial. There are no clearly established diagnostic guidelines for NLD, and the reliability, descriptive validity, and predictive validity have not been adequately tested [48, 64]. Nonetheless, Rourke and colleagues described difficulties with graphomotor skills in this population, as well as difficulties with the hierarchical organization of knowledge. Clinically, we see that children who have similar patterns often struggle with the physical aspects of writing but also may adopt a bottom-up or detail-oriented approach to writing that may result in a mismatch between the intention of the writing assignment and what is produced (e.g., the written work may become too broad or too narrow). Problems with tone and pragmatics may also be present.

Writing Anxiety

Actual rates of co-occurring anxiety, depression, and Disorders of Written Expression are unknown, but writing anxiety (a fear and avoidance of writing) is reasonably well-studied. When a student presents with both anxiety and avoidance around writing, as well as apparent weaknesses in written expression, it can be near impossible to determine which came first. Even assessing the cognitive processes underlying Disorders of Written Expression may provide few clues as anxiety is associated with weaknesses in attentional regulation and executive functions that contribute to cognitive inefficiency (e.g., processing speed, shifting perspective). These skills may be important in writing.

There may well be subgroups of students who struggle with writing anxiety. Some may avoid writing because of the effort involved in putting words to paper. These students probably suffer from a primary Disorder of Written Expression. But there is good evidence from social cognitive theory that students' writing self-efficacy predicts their writing performance, even in the absence of a specific learning disability in writing [60, 75]. Students for whom anxiety is primary may have extremely rigid rules about writing, procrastinate starting writing projects, and be overly perfectionistic in how they evaluate their written products. When this is the case, screening for obsessive compulsive disorder (OCD) is important. In its most extreme form, students with OCD may be unable to put pen to paper because of perfectionistic compulsions regarding letter formation or the placement of words and sentences on the page or because of rewriting compulsions.

What we do know is that addressing writing anxiety is very often a key component of remediating Disorders of Written Expression. The most effective approach seems to be one that addresses symptoms of writing performance anxiety by a cognitive behavioral approach with simultaneous writing process instruction (i.e., instruction in how to write discussed in more detail below under interventions) [59]. The goal of both is to increase students' flexibility around writing to alleviate anxiety and improve the written product. However, there is also evidence that even addressing writing alone can have a positive effect on reducing writing anxiety. For example, fifth grade students who were taught prewriting activities such as brainstorming and outlining showed improved scores for written expression *and* a decrease in self-reported writing anxiety [61].

A Neuropsychological Framework for Disorders of Written Expression

In this section, we have discussed some of the neuropsychiatric conditions with known high rates of Disorders of Written Expression. This is by no means an exhaustive list; clinically, we have commonly seen writing disorders in other neurological (e.g., Tourette syndrome) and psychiatric (e.g., depression) conditions. By identifying the dissociable motor and cognitive components involved in the development of written expression, one can predict the nature of a writing disorder in any given condition, as well as develop targeted interventions to remediate it. Table 4.1 illustrates this framework for the conditions discussed above. For example, in children who have ADHD, writing disorders will be most likely to result from deficits in graphomotor skills, phonological processing/auditory working memory, and attention and executive functions. This framework may also serve as a way to organize clinical investigations about writing disorders in different developmental conditions.

Assessment of Disorders of Written Expression

A review of the research suggests there is little evidence for a specific pattern of cognitive deficits that is associated with Disorders of Written Expression. In particular, the aspects of cognition assessed on standardized measures of intelligence such as the Wechsler scales (WISC-V) show limited if any correlation with specific learning disorders of writing [51]. The Learning

Disabilities Association of America [35] discourages using any cognitive assessment for diagnosing a Disorder of Written Expression. Instead, a comprehensive neuropsychological assessment can help to define the individual profile of cognitive strengths and weaknesses contributing to a particular student's learning disability in writing and to guide intervention. Table 4.2 outlines measures of related and underlying skills for written expression.

While there are a number of standardized measures of writing skills and written expression, the subjective evaluation of what makes for good writing, especially at the higher levels, makes their administration, scoring, and norms much less reliable than assessments of more objectively evaluated skills such as math or reading. For this reason, it is particularly important that assessments of written expression be administered and scored by appropriately credentialed professionals or by psychometricians who have had extensive training and supervised practice. Even then, we find that measures of written expression often seem to overestimate students' skills and that providing teachers and tutors with actual examples of writing, in addition to scores, is useful.

Tests of writing for the youngest students focus on transcription skills such as copying or generating

Table 4.2 Measures of cognitive processes associated with written expression

Vocabulary and verbal fluency	Tests of verbal fluency from NEPSY-II, COWAT, D-KEFS, and others
	Receptive vocabulary: Peabody Picture Vocabulary Test (PPVT) and Receptive One-Word Vocabulary Test (ROWPVT)
	Expressive vocabulary: Expressive Vocabulary Test (EVT) and Expressive One-Word Picture Vocabulary Test (EOWPVT)
	WISC-V vocabulary or DAS-II word definitions
Syntactic and semantic processing	CASL-2
	TACL-4
	CELF-5 sentence comprehension, formulated sentences, understanding spoken paragraphs, semantic relationships, sentence assembly
	Narrative memory tasks from the WRAML-2, CMS
	OWLS-2: oral language, receptive processing, and expressive processing composites
Pragmatic language	NEPSY-II Theory of Mind
	D-KEFS proverbs
	CASL-2
	CELF-5 pragmatics profile
Phonological processing/auditory working memory	Tests of phonological processing such as the CTOPP-2 and pseudoword decoding (WIAT-III)
	WISC-V digit span, letter-number sequencing
	DAS-II recall of digits, recall of sequential order
	WRAML2 verbal working memory subtests and sentence memory
Attention and executive functioning	Rey Complex Figure Test
	D-KEFS Tower Test
	Wisconsin Card Sorting Test
	D-KEFS Color-Word Interference Test or Stroop Color-Word Interference Test
	D-KEFS verbal fluency switching; D-KEFS Trail Making Test
	Conners Continuous Performance Test – Third Edition (CPT3)
	Test of Variables of Attention (TOVA)
Graphomotor skills	Beery Visual Motor Integration Test (VMI) – Sixth Edition
	Wide Range Assessment of Visual Motor Ability (WRAVMA)
	NEPSY-II visuomotor precision
	Grooved Pegboard Task
	Purdue Pegboard task
	Fine motor tasks from the BOT-2 or MABC

letters of the alphabet under time pressure. Later, students may be asked to combine multiple sentences into one complete sentence that means the same thing and/or to compose sentences using one or a few key words, either under time pressure or not. Identifying more challenging writing tasks that will appeal to a range of students and that stimulate enough written text to be analyzed for productivity, grammatical accuracy, and quality can be problematic. Students who struggle with writing are often prone to shutting down when faced with a blank page or pressure to write a lengthy piece.

Writing to a short probe (e.g., "Write about your favorite food including three reasons why you like it.") or picture has proved to be successful with a wide range of students [20] and is often used in standardized assessments of writing [71]. Some standardized tests of written expression include a sample essay that is read to the student first as an example. Most include a prompt for students to spend a set number of minutes brainstorming or outlining ideas for what they will write, though they can choose whether or not to do so, and students with Disorders of Written Expression often spend little if any time on the planning stage. Tests of essay or story writing generally allow a total of about 10–15 min to write with prompts of time remaining. It is important to note that some students will respond better to a creative writing prompt, while others will respond better to an expository prompt. Both are available but not within the same test or measure.

Scoring tests of written expression for *productivity* typically relies on total word count but might also include a count of correct versus incorrect word sequences (CWS), which adds a measure of grammatical accuracy [19]. Additional measures of grammar might include accurate use of capitalization, punctuation, and paragraph structure. Many measures of written expression include scores for use of specific vocabulary or more complex grammatical structures (e.g., using conjunctions other than "and"). When complemented by more subjective measures of text *quality* (usually scored by comparison to examples provided by the test developers or based on a template of introduction/theme, elaboration, and conclusion), such tasks can provide a reasonably comprehensive measure that captures the complexity of a student's writing [16]. Table 4.3 outlines a number of measures of written expression skills, both simple and more complex that are appropriate for students of different ages and abilities.

Accommodations and Interventions for Disorders of Written Expression

Accommodations

Students with Disorders of Written Expression can benefit from a number of accommodations. Many will need extended time on tests and assignments to allow more time for planning and proofreading. Some, particularly those with developmental dysgraphia, will need access to a scribe for writing and use of low-tech assistive technology such as pencil grips and slant boards. Having access to teachers' or peers' notes and outlines can ease the burden of note-taking for lectures. Teachers can be required to evaluate students' writing for content without penalizing for spelling and grammatical errors, for those students for whom mechanics are the primary problem. Word banks have proven effective for helping students to construct written work [49]. Particularly at the high school and college level, we often recommend that students be allowed priority registration to customize a course schedule that does not overly burden them with classes heavy on writing requirements. Taking a reduced course load is another alternative.

Assistive technology is often of particular benefit to students with Disorders of Written Expression. The most basic example is having access to word processing software with grammar and spelling check. The "cut and paste" option of a word processing program can be used to address issues of text organization and theme development. Speech to text software or voice recognition software such as *Dragon NaturallySpeaking* is often a useful tool. Even for students without access to these programs, many will have access to a phone with audio

Table 4.3 Standardized measures of writing skills and written expression

Test and features	Norms and scaling	Subtests
Wechsler Individual Achievement Tests, 3rd Ed. (WIAT-III)	Ages 4.0–50.11 Age- and grade-based norms Standard scores with percentile as well as age and grade equivalents Ability achievement discrepancies available with Wechsler Intelligence Scales for Children, 5th Ed. (WISC-V)	Spelling Sentence combining Sentence composition Essay composition
Woodcock-Johnson Tests of Individual Achievement, 4th Ed. (WJ-Ach IV)	Ages 2–90+, grades K.0–18.0 Age- and grade-based norms Standard scores with percentile as well as age and grade equivalents Ability achievement discrepancies available with Woodcock-Johnson Tests of Cognitive Abilities 4th Ed. GAI score	Spelling Writing fluency Writing samples Punctuation and capitalization Spelling of sounds Editing
Detailed Assessment of Speed of Handwriting (DASH)	Ages 9:0–16:11 (DASH-17+ also available) Standardized subtest and composite scores based on a sample of over 500 children collected across the United Kingdom in 2006	Copy best Copy fast Alphabet writing Free writing Graphic speed
Oral and Written Language Scales, Second Edition (OWLS-2)	Ages 3:0–21:11 (LC/OE) Ages 5:0–21:11 (RC/WE) Age- and grade-based standard scores plus five composite scores: oral language, written language, receptive processing, expressive processing, and overall language	Written expression – progresses from alphabet writing fluency to transcription to sentence and paragraph composition
Test of Written Language, 4th Edition (TOWL-4)	Ages 9:0–17:11 Subtest scaled scores and composite standard scores for overall writing, contrived writing and spontaneous writing; two forms (A and B) for progress assessment Age- and grade-based norms provided Based on normative data from 2006 to 2007	Vocabulary – the student writes a sentence that incorporates a stimulus word Spelling and punctuation – the student writes a sentence from dictation following correct spelling and use of capitalization and punctuation Logical sentences – the student edits illogical sentences to correct grammar and syntax Sentence combining – contextual conventions and story composition – the student writes a story in response to a stimulus picture and is given points for correct use of orthographic and grammatic conventions as well as for quality of composition (e.g., plot, prose, development of characters, interest to the reader)
CELF-5	Ages 5:0–21:11 Scaled scores and age equivalents	Structured writing – the student completes a short story by completing a sentence and adding one or two sentences

recording app that they can use to verbalize and record ideas. By playing back and then transcribing the audio, they have the ability to use oral language abilities to compose printed text. Other technologies available to students with Disorders of Written Expression include outlining software programs such as *Inspiration* that are flexible for students with top-down or bottom-up preferences for brainstorming and organizing a composition. The software allows more visually inclined students to literally draw connections between ideas in complex maps that the program then translates into an outline.

Unfortunately, there is very little data to prove the benefit of these sorts of accommodations for students with Disorders of Written Expression. A review of empirical studies looking at the impact of assistive technologies on college students' completion of courses requiring writing, grades in those courses, and writing fluency showed that (at least in some studies) tools such as word processors and speech to text software were effective in helping with proofreading for mechanical errors, grammar, spelling and outlining ideas [38]. There is no guidance on which accommodations best fit which underlying deficits of written expression, nor do any studies address the effectiveness of different assistive technologies relative to different writing genres such as expository, narrative, or persuasive [39].

Interventions

A comprehensive neuropsychological assessment is critical to identify the key weaknesses underlying a student's Disorder of Written Expression. Once this has been done, then the appropriate interventions can be put in place to target these weaknesses. This may require a team of specialists, including occupational therapists (OTs), speech and language therapists (SLPs), reading specialists, and special educators.

Younger children who have dysgraphia may benefit from occupational therapy to improve fine motor and visual-motor integration skills. Older children with dysgraphia may also benefit from assistive technology, which should ideally be taught through formal instruction rather than as an accommodation. Students with developmental dysgraphia will benefit from learning keyboarding or from technology that provides feedback for improving motor control and handwriting.

Speech and language therapy (SLP) may be important in addressing weaknesses in language-based skills important for writing. SLPs have the unique training to address skills deficits in language, vocabulary, syntax, and morphology that impact writing. SLPs also increasingly have training in strategies to address the deficits in executive functioning that can impact written expression. Price and Jackson [52] outline a variety of ways SLPs can elicit writing samples from students that can then be used to scaffold improvement in written expression for different genres of writing. Unfortunately, a 2012 survey of more than 2000 school-based SLPs indicated that less than one third of them regularly served students in the areas of reading and writing and that this reflected a decline from 40% in 2004 (ASHA).

There is less research on writing interventions aimed to teach executive function skills. Children with specific learning disorders of written expression need to be explicitly taught the purpose, form, and nature of written expression and need to master procedures for planning, drafting, editing, and error identification [20, 82]. Students who are provided with models of how to use specific strategies for planning, writing, revising, and editing text, and then practice using those strategies until they can do so independently, have shown improved writing quality in grades 1 through 12 [79]. The emphasis is on teaching strategies for planning and revising as such skills predict positive writing performance [80]. Without strategy instruction, students with Disorders of Written Expression typically complete minimal planning but when taught to brainstorm and sequence ideas will spend as much or more time planning as writing [25, 68].

One evidence-based teaching approach to strategy instruction, developed by Graham [77], is self-regulated strategy development (SRSD) [62].

Students are provided with multiple strategies for improving writing including explicit instruction, mnemonics, and prewriting strategies such as brainstorming and graphic organizers. Most of the approaches to tutoring in written expression we are aware of follow a similar approach. Like SRSD, they emphasize development of executive function skills for self-regulation for writing (e.g., goal setting, self-monitoring, self-reinforcement). They provide opportunities to practice these skills as applied to different types of writing, across the curriculum. Some teach skills that contribute to written expression via strategy game playing (e.g., *Mastermind*). Hetzroni and Shrieber [78] found that, among a small group of seventh and eighth graders with learning disabilities, emotional and behavioral disorders, ADHD, and autism spectrum disorder, use of a computer-based graphic organizer developed for Microsoft Word improved both written production and quality of writing. These improvements persisted even when students were subsequently asked to write again without using the graphic organizer.

Case Study

Brief Background

Meg was 12 years old and at the beginning of her seventh grade year in public middle school when her parents requested an evaluation due to concerns that her spelling, grammar, and skills in written expression were below grade level, in spite of strong reading comprehension skills. Meg reportedly seemed apathetic about schoolwork and had difficulty meeting deadlines. It often took her much longer than it should to complete assignments.

The history provided by Meg's parents indicated that she was generally healthy, except for wearing glasses for nearsightedness and suffering from seasonal as well as food allergies. Meg had met all early speech and language, social, and fine and gross motor developmental milestones within normal limits. Family history was notable for depression and anxiety, but there was no known history of attention or learning problems.

Meg's parents noted that she seemed to lose interest in and motivation for school beginning in the sixth grade. Her grades ranged from As to Ds with strengths in math and weaknesses in writing and anything requiring independent research. Meg reported that she most enjoyed art and reading. Weaknesses in spelling were noted in the third grade but became more concerning when Meg's poor performance for writing on standardized testing brought down her whole score. Since beginning middle school, Meg had been having difficulty completing homework on a regular basis, even with oversight from her mom. Meg had never received any kind of formal supports in school.

Socially, Meg was reportedly a "mix of shy and friendly" but mostly introverted. Her mother noted that it was difficult to gauge how things were going socially for Meg at school. In the sixth grade, she had only one friend contact her all year and didn't meet up with any friends but would text with them. Meg was an avid reader of fantasy novels and often reread books over and over again. Her mother expressed some concern that reading had become a social escape for her. Meg also enjoyed camping, sewing, art, and writing fan fiction online. Meg had no previous testing.

Assessment Procedures and Observations

The comprehensive evaluation included administration of the WISC-V as well as academic testing using the WIAT-III and WJ-IV fluency tests. Tests of visual-motor skills included the VMI-6 and Rey Complex Figure Test. The CTOPP-2 was administered as a test of phonological processing, and the CVLT-C was used to assess verbal learning and memory. Tests of executive function from the D-KEFS and the CPT-3 computerized test of attention were also administered. Finally, Meg and her mother completed rating forms of emotional and behavioral functioning (BASC-3) as well as executive functions (BRIEF-2).

Meg presented as a polite and personable young girl who appeared her age. She presented as socially somewhat young for her age but was well related. She easily engaged in conversation with the examiner and showed good eye contact as well as wide-ranging and congruent affect and nonverbal gestures and communication. Meg was easily engaged in tasks and appeared to put forth her best effort throughout a long day of testing. She did at times retreat to the fantasy novel she had with her, sometimes reading for even the brief time that the examiner paused between tasks or tests. During difficult tasks that she worked on independently, Meg was sometimes observed to talk or sing to herself. Her oral reading was impacted by her tendency to rush through or past words requiring phonetic decoding. Similarly, Meg tended to rush through encoding for spelling.

Results and Discussion

The results of this evaluation illustrate how a comprehensive evaluation can document both significant strengths and weaknesses in a student's cognitive and learning profile. Meg's individual scores on the assessment tell us relatively little. However, when viewed together as a cognitive/learning profile, we see evidence of weaknesses in phonological processing impacting her reading decoding as well as her writing and weaknesses in visual-motor integration and executive function further impacting her written expression skills. Furthermore, including a sample of her writing better illustrates the significant discrepancy between Meg's superior verbal intellectual ability and her skills for written expression than do her standard scores on a measure of written expression alone. Key findings from the evaluation were as follows:

1. The WISC-V results revealed that Meg exhibited very high verbal intellectual abilities (VCI = 127, 96th percentile). She also showed strengths in visual-spatial processing (VSI = 122, 93rd percentile), and in nonverbal/fluid reasoning (FRI = 126, 96th percentile). However, her rote attention and working memory skills as well as her processing speed abilities were significantly weaker, though still within the Average range for her age (WMI = 103, 58th percentile; PSI = 105, 63rd percentile).
2. Additional tests of language skills revealed weaknesses in phonological processing. Meg scored in the Low Average range for verbal fluency when given phonemic (initial letter) cues but in the Very High range for her age when given semantic (category) cues (D-KEFS Letter Fluency 9th percentile; Category Fluency 97th percentile). She scored within the Average range for her age on a test of auditory phonological processing where she was required to repeat nonsense words, but her score was significantly lower than would be expected based on her very strong verbal intellectual ability (CTOPP-2 Nonword Repetition 37th percentile).
3. Meg also showed a significant discrepancy between her superior spatial processing ability on intelligence testing and much weaker performance on tests of visual-motor integration. She scored in the Low Average range for her age on the VMI when instructed to copy a series of increasingly complex figures (VMI = 87, 19th percentile). Meg worked carefully on the task but struggled with overlapping and three-dimensional figures. She had more significant difficulty on the copy task of the RCFT (performance at less than the 1st percentile). Meg showed weaknesses in planning and organization when approaching this complex multistep visual task. She was unable to step back to appreciate how the individual pieces contributed to the design and subsequently had difficulty integrating the details of the figure. In contrast, Meg scored in the High Average range for her age on the D-KEFS Tower Test (84th percentile), a step-by-step test of planning and impulse control without an organizational demand.
4. On additional tests of executive functions, Meg showed good ability to sustain and regulate her attention to a computer task (CPT-3). Her weakest performance was on a test of rapid naming, inhibition, and set-shifting (D-KEFS Color-Word Interference Test) – an equivalent to the classic Stroop test. Meg

made more errors than expected on the task and her scores ranged from the Low to High Average range for her age. Her performance suggested possible weaknesses in orthographic processing (a phonological process of automatically pairing sounds with symbols). On the BRIEF-2 rating form, Meg's mother reported that Meg had difficulty independently starting tasks. Meg reportedly showed planning and organizational difficulties and often had good ideas but lacked the follow-through to translate those ideas into her work. She also had difficulty with task-monitoring – checking her performance on tasks mid-way through or shortly after completion to make sure she accurately met her goal.

5. Finally, the results of academic testing were revealing, but only when viewed in the context of Meg's comprehensive evaluation. She showed strengths in Math Problem Solving on the WIAT-III (87th percentile, >12th grade equiv.) and average math calculation skills (Numerical Operations 58th percentile, seventh grade equiv.). But her Math Facts Fluency skills on the WJ-IV were low average for her age, at just the 14th percentile.

Meg's scores on tests of reading, indicated average reading comprehension (55th percentile, tenth grade equiv.) and word reading (58th percentile, eighth grade equiv.) but with a subtle personal weakness in phonetic decoding of nonsense words (pseudoword 34th percentile, fifth grade equiv.). Her phonetic encoding skills for spelling were similarly weak (19th percentile, fifth grade equiv.). A closer look at her general strong skills in oral reading fluency revealed that Meg sacrificed accuracy for speed (oral reading accuracy 16th percentile and fourth grade equiv.; oral reading rate 82nd percentile and 12th grade equiv.).

Finally, Meg scored in the Average range for her age and above grade level overall on the WIAT-III essay composition task (68th percentile, ninth grade equiv.). However, this was due mostly to her writing a long essay (word count 82nd percentile) but one with average use of grammar and mechanics (61st percentile, eighth grade equiv.) and weaker theme development and text organization (45th percentile). As seems often to be the case when looking only at standardized scores on a test of written expression, a look at Meg's actual essay makes it clear that her skills for written expression fall well below what would be expected based on her verbal intellectual ability. See Box 4.1.

Box 4.1 Case Study 1 Sample Essay in Response to WIAT-III Essay Composition Prompt

My favorite game is Mine Craft. I like it beause 1: you can build anything you want. I've seen people create the most amazing things like a working computer, TV Xbox, etc you name it Someone has built it. 2: I love the severs where you can play with other people and play games others have thought up and created. 3: the vidieos people do for it some people will role play with minecraft and they put so much time and work into them and its amazing to see. 4: the maps people make people have made theme parks with amazing roller costers, carosels and other amazing things. 5: the skys the limit, literaly! Anything you want to do with it you can its amazing to think up something and then do it its amazing to watch your creations come to life

Conclusions and Recommendations

In sum, Meg's performance on a comprehensive assessment revealed significant strengths in several areas, including overall intellectual skills in the very high range for her age (93rd percentile) and strong verbal knowledge and reasoning, verbal learning and memory, and semantic (category) fluency skills. She was well able to sustain and regulate her attention, and she showed academic skills in the average or better range for her age with particular strengths in math problem solving. However, she also showed weaknesses in aspects of executive functioning, including organization and in her ability to efficiently break down complex information.

While she was an avid reader and scored in the Average range for her age on tests of basic reading, reading comprehension, and fluency, Meg's reading skills were less well developed than would be expected based on her very strong language skills. She showed particular weaknesses in phonological processing that impacted her reading decoding and encoding for spelling. Her weaknesses in visual-motor integration, math fluency, and errors on a rapid naming task were consistent with what was a likely a missed reading disorder.

Meg had been able to rely on her strong language skills and seemed to use context for reading comprehension. As a result, while she was known to be a poor speller in early elementary school, her difficulties didn't become clearly apparent until demands increased in middle school. And, even then, her teachers generally dismissed concerns because of Meg's interest in reading and writing. It wasn't until she began to resist writing assignments and struggle to complete homework that her parents decided to seek an outside evaluation.

Meg's skills in written expression were significantly weaker than would be expected based on intellectual ability. She showed weaknesses in organization and clarity of written expression and in spelling. Her difficulties stemmed from weaknesses in phonological processing, visual-motor integration skills, and executive functions. Specific recommendations to support Meg in middle and high school included the following:

- Extended time (e.g., time and a half) on all testing, including standardized testing (e.g., MCAS, SAT's, AP exams)
- Use of an MP3 recorder to record lectures and classes for later review
- Access to a laptop/word processor for note-taking and writing for the "cut and paste" option to help her reorganize her notes/writing
- Provide both written and oral directions for tests/projects and assistance with determining a step-by-step approach to assignments
- Use of a paper or electronic assignment book/system to be reviewed daily with her teachers and to facilitate communication between home and school
- Additional time (e.g., after school or during free period) for one-to-one instruction with teachers before tests/exams and around longer-term projects
- Enrollment in an academic strategies class for study and organization skills
- Private tutoring in executive function skills as well as written expression
- Tutoring in reading fluency and in active reading strategies for improving comprehension including programs such as *Read Naturally* and *Lexia*

Conclusion

Although Disorders of Written Expression are quite common among children and adolescents and have a significant impact on overall academic achievement, they are likely under-recognized. Compared to reading and math disorders, they have been understudied, likely in part because writing disorders have been challenging to define. In this chapter, we identify the dissociable neuropsychological (motor and cognitive) components that underlie the development of written expression, arguing that knowledge of these components provides a framework to understand how writing disorders manifest differently depending on the neuropsychiatric disorder and also a way of identifying skills that should be targeted in remediation. This kind of comprehensive assessment is perhaps more important than formal assessment of writing skills, which may identify whether writing is delayed, but not why it is so. Furthermore, it is our experience that even the best available standardized assessments of written expression will often overestimate a given student's skills based on scores alone. Thus, for children and adolescents with suspected writing disorders, formal neuropsychological assessment by a pediatric neuropsychologist is recommended, especially for those children who also have neuropsychiatric conditions known to be associated with writing disorders.

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5 Language Disorders

Drew C. Coman and Nicholas D. Mian

> *Without language, one cannot talk to people and understand them; one cannot share their hopes and aspirations, grasp their history, appreciate their poetry, or savor their songs.*
>
> —Mandela, N.

Introduction

Communication is an intricate dance comprising a myriad of permutations of verbal, nonverbal, sensory, and cognitive processes between two entities. Language, which is only one branch of communication, is unique and vital to the human species, and it is fundamental to our functioning. Thus, it is not surprising that there is an array of adverse effects on the functioning of children with impairments in language. Deficits in language can ultimately lead to communication disorders, which are one type of neurodevelopmental disorder that can be a salient aspect of the clinical picture for many young individuals in need of psychiatric services. Yet, this area is poorly understood and underemphasized in medical training programs, which can in part be attributed to the complexity of language pathology and the lack of consensus among experts in the field regarding theory, assessment, and treatment pertaining to language-based conditions. Nonetheless, language impairments in youth (including language delays and those meeting formal diagnostic thresholds for language disorder) are prevalent, affecting as many as 7% of 5-year-old children; prevalence rates are even higher (11–12%) when speech disorders are included [32]. In addition, contrary to common beliefs, language-based weaknesses do not simply go away on their own, and they are highly comorbid with other vulnerabilities such as behavior problems [62]. Overall, considerations of language functioning in young patients can be vital to psychiatric care given the prevalence and far-reaching effects of language vulnerabilities. It is therefore essential for psychiatrists and related professionals to consider these factors in case conceptualization and, importantly, to refer children for further specialized evaluations of language when indicated (e.g., speech and language, neurodevelopmental, neuropsychological, or psychoeducational assessments). These evaluations can be imperative when designing quality treatment plans and assisting with educational programming for patients and their families.

To support psychiatrists and related professionals with their clinical care, provided herein is an overview of the current state of the research on two of the five primary communication disorders in youth as presented in the *Diagnostic and Statistical Manual for*

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Mental Disorders, Fifth Edition (DSM-5; [2]): *language disorder* and *social (pragmatic) communication disorder*. We also detail common comorbid conditions and provide a discussion of the early signs and symptoms of these two disorders as well as the associated impacts on learning. Additionally, this chapter offers a review of "best practices" in assessment (from a neuropsychological/neuropsychiatric standpoint), presents a case example, and reviews "best practices" for both school- and home-based interventions. While this chapter represents a developmental psychology and neuropsychological perspective, the integration of psychology, neuropsychiatry, speech and language pathology, and other specialties represents "gold-standard" clinical care for patient with language impairments.

To understand the landscape of clinical care in the setting of atypical language development, it is first helpful to review relevant terminology in this field, review the different domains of language, and describe normal language development in youth. There are many terms associated with language pathology (e.g., communication disorders, language delays, developmental language disorders/impairments, specific language disorders/impairments, primary language disorders/impairments, or language-based learning disorders), and these are frequently used interchangeably—sometimes, inaccurately. One survey found 132 different terms used to refer to language-related problems [8] leading to significant confusion and challenges with defining various conditions. Figure 5.1 is an illustration of the basic organization of the terms. As indicated here, "communication disorders" is an umbrella term that comprises disorders with deficits in *language* (defined as the form [e.g., phonology], content [e.g., semantics], and function [e.g., pragmatics] of a conventional system of symbols in a rule-governed manner for communication), *speech* (defined as the expressive production of sounds that can include articulation, fluency, voice, and resonance quality), and *communication* (defined as verbal or nonverbal behavior that influences the behavior, ideas, or attitudes of another individual) [2]. Underlying this umbrella term are the DSM-5 diagnoses of *language disorder*, *social (pragmatic) communication disorder (SoPCD)*, *speech sound disorder*, *childhood-onset fluency disorder*, and *unspecified communication disorder*. As noted above, we focus primarily on two of these conditions, *language disorder* and *SoPCD*, which will collectively be termed "language impairments (LI)" henceforth, unless otherwise specified. Language pathology is complex and can, for instance, involve broad and overt deficits in expressive or receptive vocabulary to more subtle vulnerabilities in articulation, as well as everything in between; as such, it is beyond the scope of this chapter to address *all aspects of* communication disorders. Instead, we focus on some of the most key clinical considerations and commonly presenting problems to bolster psychiatric care in the setting of comorbid LI. Some attention will be given to *specific learning disorders with impairment in reading* and *written expression* given these disorders are rooted in language (frequently referred to as "language-based learning disorders"; see Chaps. 2 and 4). For an excellent and more comprehensive review of all language pathologies, the reader is referred to Paul and Norbury [42].

One widely accepted framework for the major domains of language recognizes four domains: phonology, syntax, semantics, and pragmatics [1, 3, 12, 31]. *Phonology*, or speech sounds, and *syntax*, which means how words are organized to communicate, both underlie language. *Semantics* includes the meaning of words, phrases, and sentences [42], while *pragmatics* refers to the appropriate social use of speech (i.e., conversational "rules" and using language effectively across contexts) [3]. Youth with language disorders and SoPCD can present with weaknesses in one or all of these areas; however, SoPCD predominantly refers to impairments with language pragmatics. Typical language milestones involving these domains are depicted in Table 5.1. Guidelines like this can be helpful; however, it is important to note that there is considerable heterogeneity in developmental trajectories, even in typically developing children.

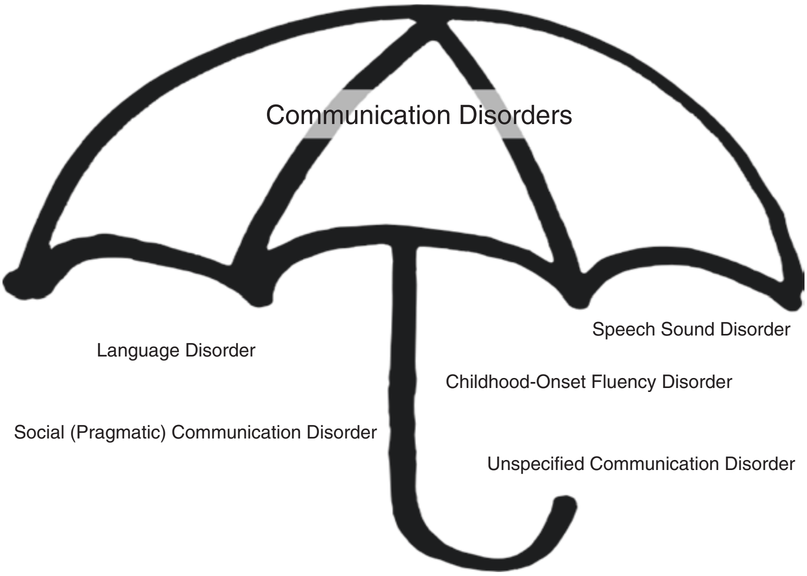

Fig. 5.1 Communication disorders: an umbrella term

Current State of the Research

Prevalence

In a systematic review of 18 studies on the prevalence of speech and/or language impairments, Law and colleagues [32] estimated the prevalence of language deficits (not including speech impairments) at 2.63% at age 3 years, 6.8% at age 5 years, 5.5% at age 6 years, and 3.1% at age 7 years. The authors noted the challenges associated with estimating prevalence due to differences in operational definition and measurement across studies. The increase from age 3 to 5 likely reflects shifts in expectations associated with maturation and, therefore, increased attention on those with delays. Language delays tend to be more common in boys compared to girls, with male/female ratios ranging from 1.2:1 to 2.3:1, although there is some discrepancy in the literature [32]. Some studies have found rates to be twice as high in boys compared to girls [26]. It is noteworthy that the studies referenced above do not include prevalence rates for the specific category of SoPCD. As this classification is new to DSM-5, there is limited information available on this condition. One South Korean epidemiological study comparing DSM-IV-TR pervasive developmental disorder (PDD) and DSM-5 autism spectrum disorder shed some light upon the prevalence of SoPCD; around one third of PDD cases (17/58, 29%) did not qualify for an ASD diagnosis when DSM-5 rules were applied; and most of these (13/17, 76%) individuals met criteria for SoPCD [28]. In addition, in a community sample of around 1300 kindergarteners, another study suggested that pragmatic language impairment occurs in about 7.5% of children and impacts more boys than girls by a ratio of 2.6:1.0 [27]. Notably, higher rates ranging from 23% to 33% have been noted in individuals with comorbid language disorders [14, 27]. As Swineford et al. [48] point out in their review, the percentage of children expected to warrant a SoPCD diagnosis may be currently unknown.

Etiology

Research on the etiology of LI suggests that there is a myriad of different factors and vulnerabilities that can lead to a similar outcome. This is consistent with findings suggesting that language difficulties are highly comorbid with a range of psychiatric conditions and are also a symptom of many developmental disorders (e.g., Down syndrome, fragile X syndrome, Williams syndrome, ASD) [34]. Research using twin studies provides

Table 5.1 Selected speech and language development milestones

Age (years)	Phonology	Semantics	Syntax	Pragmatics
0–1	Cooing, progressing into vowel-like sounds	Understands up to 50 words		Orients to faces; pays attention to caregivers’ actions
	Babbling (consonant-vowel combinations) emerges, becomes increasingly speech-like	Looks up, turns to source when hearing own name		Vocalizes in response to speech and initiates vocalizations to others
	Perception, production reflect first language’s speech sound categories			Uses gestures and vocalizes to request, refuse, and comment
				Participates in turn-taking games
1–2	Uses systematic strategies to simplify pronunciation (e.g., only pronouncing stressed syllable of word)	Understands various kinds of two-word phrases	Uses two-word, telegraphic (grammatically unmarked) phrases	Initiates joint attention by pointing or vocalizing
	At 24 months, half of speech the child produces is intelligible	Uses *no* and *more*	Uses a consistent word order of subject, verb, and noun	Acknowledges others’ speech vocally or with eye contact
	Pronounces 70% of consonants correctly	Answers yes/no and *what’s this?* questions	Refers to self using *me* and own name	Uses words to request, refuse, and comment
		By 24 months, expressive vocabulary of 200–300 words		
2–3	At 36 months, three quarters of the child’s speech is intelligible	Asks and understands simple questions with *who*, *what*, and *where* about people, objects and events	Understands person pronouns	Uses words for symbolic play, teasing, and dissimulation
			Uses *gonna*, *wanna*, etc.; later begins to use *can* and *will*	
	Continues to use simplifications and sound substitutions	Asks and understands *why* questions	Begins to use grammatical markers, e.g., /s/ for plural	Talks about objects not currently present
	Becomes aware of and can produce rhymes	Development of syntax supports semantics learning and vice versa	Over-regularizes past tense rules (e.g., *runned*, instead of *ran*)	Answers some requests for clarification of own speech
				Responds on topic nearly half the time
3–4	Intelligibility continues to improve	Understands and uses words for color, size, and kinship relationships	Expresses possession using *’s*	Uses words to express emotions, retell past events, and reason and for imaginary play
	A few simplification strategies remain (e.g., consonant blends pronounced as single consonants)	Understands and asks *when* and *how*	Produces phrases with 4–5 words, including some complex sentence forms	Begins to simplify language when speaking to younger children
		Uses vocabulary to coin a term when they do not know a word	Uses articles and irregular past tense	Narratives emerge with theme and some temporal elements

Table 5.1 (continued)

Age (years)	Phonology	Semantics	Syntax	Pragmatics
4–5	Speech becomes fully intelligible	Starts to understand numbers and counting	Produces longer sentences with more complex grammatical structure	Can express requests indirectly
				Adjusts speech based on social expectations
	Errors on some consonants may persist (particularly s, sh, r, l, v, z, zh, ch, and j)	Starts to learn letter names and sounds	Able to use and understand basic sentence forms	Narratives become sequences of events
	Begins to be able to segment words into syllables	Asks for the meaning of new words		
5–7	Almost all speech errors disappear	Expressive vocabulary size on average 3000–5000 words	Begins to use and understand passive constructions	Narratives use story form with focus, climax, and resolution
	Begins to be able to segment words into speech sounds	Receptive vocabulary larger than expressive	Continues to improve ability to produce complex sentences	Extends oral language skills to reading and writing

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strong evidence for a significant heritable component for LI, as evidenced by substantial discrepancy in concordance rates of monozygotic compared to dizygotic twins [11, 52]. One study reported that heritability estimates were higher when LI were defined by referral for speech and language services compared to when it was defined by language test scores [9]. This is likely because children with co-occurring speech problems are more likely to be referred for services. Moreover, LI are likely of polygenic origin, although specific genes such as the FOXP2 gene and markers on a handful of chromosomes (3, 6, and 19) have been identified [36]. As language delays or problems are a prominent feature in ASD, there is reason to suspect commonalties in etiology as well. Bishop has suggested that in fact ASD and language disorders likely share a common genotype [7]. Findings suggest that variants of the gene CNTNAP2, which has been associated with language delays in ASD, also appear to be associated with language acquisition and delays in young children in the general population [60].

Regarding neurodevelopmental factors, traditional models posited that language-related problems stemmed from abnormalities in cortical structures, given the prevailing wisdom of language being linked with the temporal and frontal lobes of the cerebral cortex. Indeed, research has suggested that hemispheric asymmetries are often prevalent in children with language impairments, but findings have been inconsistent [39]. More contemporary models that reflect the type of complex learning associated with language acquisition suggest that subcortical structures (i.e., the caudate nucleus of the dorsal striatum) likely play a prominent role [29]. Language disorders can also be secondary to infection or brain injury (e.g., anoxia at birth) in addition to environmental risk factors—most notably socioeconomic status (SES), neglect, and abuse [3, 36].

Comorbidity

Language is fundamental to the development of the cognitive, socio-emotional, and behavioral functioning of children. Accordingly, it is not surprising that it is comorbid with social, emotional, and behavioral difficulties in youth. In one prospective longitudinal study, 42% of children with a language impairment at age 5 years were diagnosed with a psychiatric disorder at age 12 [4]. Additionally, language disorders are more likely to be found as a comorbid condition than a single diagnosis [26], and difficulties in language (particularly receptive) in early childhood tends to increase the persistence of behavioral problems, especially among high-risk children [62]. One meta-analysis also suggested that youth with language impairments are two times more likely to exhibit heightened levels of emotional or behavioral challenges relative to controls [61]. For example, Voci et al. [53] conducted a prospective longitudinal study on children with language impairments at the age of 5 and, relative to matched controls, found that at age 19 they had 2.7 times the odds of having social phobia. Moreover, children and adolescents with LI are more likely to experience social challenges [24, 47]. As mentioned above, language disorders are also highly comorbid with ASD [7, 49]. In one study, the prevalence of ASD was found to be ten times what would otherwise be expected in a sample of adolescents with a history of LI [20].

There is substantial evidence that children with attention deficit/hyperactivity disorder (ADHD) and specific learning disorder with impairments in reading (SLD-reading) exhibit higher risk for language deficits as well. In one study, 81% of children diagnosed with *both* ADHD and reading disorder exhibited LI (by parent/teacher reports), whereas this was true for 43% of those with ADHD, 46% of those with SLD-reading, and only 5% in a control group [26]. It can be difficult to tease these conditions apart. For example, children with ADHD are expected to have difficulty with attention, which can present similarly to a child with a receptive language problem. Careful, independent assessment of both attention and receptive language is necessary to make this distinction. Similarly, since LI is exhibited across modalities (i.e., speaking and writing), children who have difficulty with reading comprehension or writing could have a language disorder or a learning deficit in either area.

Early Signs, Symptoms, and the Impacts on Learning and Development

Unlike most diagnoses in the DSM-5, a formal diagnosis of language disorder or SoPCD is largely dependent on quantifiable, developmental comparisons. That is, a child's or adolescent's language abilities or social use of language may be considered in the normal range at one age but delayed later in life. Careful consideration of developmental comparisons is particularly important given the broad range and often idiosyncratic nature in the achievement of developmental milestones for each child. In fact, the majority of children identified with late language acquisition (i.e., "late talkers") in early childhood (i.e., 24 months), which has a prevalence rate falling somewhere between 10% and 20% [36, 44], do not exhibit long-term deficits [10]. These children largely catch up to peers by age 3 [36, 44] and go on to have abilities in the normal range by late childhood or adolescence [3]. However, if the language delay is still present at the time of preschool entry (i.e., age 3), it is more likely to be predictive of long-term difficulties [32]. Grizzle and Simms [25] reported that 50–80% of preschoolers who have severe language delays and normal nonverbal intelligence continue to show language-based difficulties well beyond the initial diagnosis and into early adulthood. Thus, disentangling later language acquisition that falls within typical development from the emergence of "true" language-based difficulties can be essential, whether a psychiatric provider is assessing current functioning for a patient or retrospectively acquiring information via clinical interview. While children under age 4 years are rarely referred to psychiatrists, it is nonetheless important for providers to be able to conduct a comprehensive review of a child's past and current language development as it can be a salient factor in case conceptualization and treatment programming. Toward this end, a review of the DSM-5 diagnostic criteria for language disorder and SoPCD is provided below, along with a discussion of early signs and symptoms and potential adverse impacts on learning and development.

The DSM-5 diagnostic criteria for *language disorder* include “persistent difficulties in the acquisition and use of language across modalities (i.e., spoken, written, sign language, or other) due to deficits in comprehension or production…” [2]. These deficits can include reduced vocabulary, limited sentence structure, or impairments in use of vocabulary or sentences. To meet diagnostic criteria, the child’s language abilities must be substantially below age expectations *and* lead to functional impairments in social participation, academic achievement, or other contexts. It is important to note that deficits can be found in either expressive or receptive language use. Diagnostic criteria for SoPCD (a new diagnostic category in DSM-5) include “Persistent difficulties in the social use of verbal and nonverbal communication” [2]. To meet criteria, a child must exhibit deficits in *all* of the following areas: using communication for social purposes, changing communication to match the context, following rules of conversation (including nonverbal rules and turn-taking), and understanding what is not explicitly stated (e.g., idioms, metaphors, etc.). Weaknesses in these areas lead to functional impairments in effective communication, social participation, social relationships, or performance in other contexts. Care must be taken to distinguish each of these profiles from that of autism spectrum disorder (ASD; see Chap. 10 in this volume), of which deficits in social communication are also hallmark symptoms (other differential diagnoses include global developmental delay and hearing impairment). There are ongoing debates as to whether SoPCD is distinct from ASD; some argue that SoPCD lies on the cusp of ASD diagnostic threshold [35], while others have argued these conditions can be reliably distinguished by the severity of social communication deficits and the presence of ASD-specific behavioral symptoms (e.g., stereotyped behaviors such as excessive interests, repetitive behaviors, sensory processing abnormalities [49]).

As with most pathologies, early identification is imperative in order to establish treatments as soon as possible, which will decrease the duration and level of adverse impact that the associated symptoms will have on a child’s development and learning. It can also mitigate the risk of early language difficulties progressing and ultimately preclude symptoms from meeting the full DSM-5 criteria for language disorder or SoPCD in the future. There are some general patterns and courses that we would expect in the growth of language in youth. Many of these milestones are broadly illustrated in Table 5.1. Even in early infancy (i.e., birth to 12 months), there are detectable nonverbal and verbal indicators that may suggest when language and/or social development may be abnormal. Some of the more specific nonverbal means of communication that emerge in the first year of life, and even weeks, include eye gaze and the initiation of and response to joint attention (i.e., following others’ eyes and facial expressions when being directed to look at an object [40]) and gestures that nonverbally communicate shared enjoyment or anticipation (e.g., an infant crunching their nose and smiling as tickling hands loom above). Verbally, we would expect the emergence of cooing and laughter within 4 months along with the first use of single words and the understanding of 3–50 words at around 12 months [42]. By age 3, we would also anticipate children to be able to produce rhymes, three- or four-word phrases, and approximately 75% of their speech to be intelligible [25, 42]. From age 3 to 5, Grizzle and Simms [25] point out that we broadly expect children to be following complex instructions, producing four or more word sentences, and using complex sentence structures at the latter end of that range.

Because most patients are referred for psychiatric care during the school-aged years or beyond, we provide a review of the symptoms of an emerging or current profile of language disorder and SoPCD from ages 5 to 17 years. Table 5.2 delineates the common signs of these conditions during these periods and provides school-related “red flags” that are strong indicators for the presence of LI along with their associated impacts on academic functioning. It is important to note that any one, or even several of these characteristics, does not warrant a DSM-5 diagnosis; these are simply concerning signs that may warrant further evaluation. It is also noteworthy that many of these “red flags” could indicate a different type of psychiatric problem.

Table 5.2 Common “red flags” for language disorder and SoPCD across development within the home and school settings

Age range (years)	Common concerns for language disorder	Common concerns for SoPCD
5–7	*Home and/or school*	Relative to age mates
	Challenges with use of tenses and conjunctions (e.g., because)	Tangential or circumstantial topics of conversation impact success of play or interactions with peers
	Difficulties learning the “exceptions” to basic grammar rules	Difficulties with exhibiting their own or deciphering feelings of others through facial expressions or other nonverbal means (e.g., eye contact)
	Poorly developed expressive vocabulary	Odd attempts to initiate, sustain, or terminate social interaction or conversation
	Persisting speech errors that impact intelligibility	Tone of voice of a child does not match social context, and similarly, child experiences challenges with interpreting the tones of voice from others (e.g., a firm tone of voice is not interpreted as “serious” or important by child)
	Difficulties segmenting words into phonemes	Challenges with exhibiting self-regulatory behaviors in social contexts, despite negative social consequences
	Difficulties understanding questions or following simple instructions	Difficulties with tailoring their wants and needs in play dyad to their peers’ wants and needs
	Language organization results in poor intelligibility	Challenges with providing a narrative with some elements of a plot and coherency
	Frequent omissions of parts of words, phrases, or sentences	Challenges with to-and-fro conversation that impacts social reciprocity
	Difficulties describing sequences of events	Play dates are unsuccessful and/or friendship cultivation is impacted
	Problems repeating back sentences accurately	
	Specific to school	
	Challenges with or disinterest in learning alphabet or other school readiness skills	
	Difficulties understanding words are made up of sounds that can be represented by letters	
	Challenges with learning to decode by identifying sounds of printed letters and synthesizing to make words	
	Not learning sight words	
	Unable to identify, count, blend, segment, or manipulate sounds in words	
	Avoidance/disinterest in reading or listening to books for pleasure	
	Vulnerabilities with conventional spelling	
	Avoidance/disinterest in writing or spelling	
	Socio-emotional or behavioral difficulties present in school setting or related activities (e.g., homework time)	

7–9	Persisting challenges with areas noted above	Relative to age mates
	Articulation is not largely cleared up	Persisting challenges with areas noted above
	Frequent incorrect use of words or use of malapropisms	Literal/inflexible interpretations of the language used by others or challenges with sarcasm and jokes
	Excessive use of pronouns in lieu of nouns	Language is not used effectively to promote social success
	Despite exposure to new vocabulary, new words are not utilized in vernacular	Challenges with providing more complex narratives of stories or events
	Difficulties learning that words have multiple meanings	Failing to give context or background to their audiences for effective communication of stories
	Use of figurative language fails to emerge	Challenges with cultivating closer friendships outside of acquaintances at school or other extracurricular activities
	High frequency of grammatical or language organization errors	Poor perspective-taking of others
	Specific to school	May be perceived as "immature" or "younger" than age mates
	Not independently reading chapter books for pleasure	
	Unable to manipulate sounds within words or "play" with word sounds as in pig Latin	
	Mechanics (e.g., punctuation, capitalization) in writing fail to emerge	
	Relative to age mates, fewer words recognized by sight	
	Reading comprehension is not emerging at level of peers	
	Reading fluency is not progressing	
	Spelling errors, particularly those that are not phonologically sound, persist	
	Overall avoidance/disinterest in classes and coursework that require language-based skills including reading, spelling, and writing	
9–12	Persisting challenges with areas noted above	Persisting challenges with areas noted above
	Unable to decipher common idioms	
	Lack of flexibility in the organization of language	
	Metacognition is limited in language organization	
	Specific to school	
	School curriculum exceeds vocabulary in conversational speech	
	Knowledge of writing conventions does not progress	
	Reading and writing is dysfluent	
	Decoding is inefficient and laborious	
	Unable to "read to learn"	
	Comprehension is poor	
12–17	Persisting challenges with areas noted above	Persisting challenges with areas noted above
	Specific to school	
	Study skills and habits do not naturally develop	
	Critical thinking and reading abilities are limited	
	Unable to disentangle fact from opinion	
	Higher levels of written expression more challenging relative to age mates, such as persuasive writing	

Data from Refs. [36, 42, 64, 65]

Marked disruptions in one or more of these developmental patterns should be monitored closely by caregivers, pediatricians, school teams, and other related professionals with ongoing considerations for a referral to a specialty provider, such as a neuropsychologist or speech and language pathologist. If retrospectively obtaining this data via clinical interview, psychiatrists and related professionals should also take note of any atypical patterns. However, with all of these early childhood milestones to monitor, and the noted nuances in developmental trajectories, when should providers refer patients for language (and hearing) evaluations or retrospectively make a determination that language abnormalities may be an important factor in case conceptualization? Clinical opinions will differ, but most experts agree that the "wait and see" approach is contraindicated, as this presents risks (with very little benefit) with regard to child outcomes. While referring a child for specialized assessments when in reality a "true" LI is not present may cause some familial stress, inconvenience, time, and perhaps financial resources for families, the risks of not referring them when a LI *does* indeed exist can have exponentially higher costs for that child and family. Additionally, if a provider suspects language development may be abnormal, a referral for a formal evaluation can provide key information into understanding the child's present neuropsychiatric profile and course of psychiatric illness. In other words, we generally recommend that providers become more comfortable with making false positives (i.e., mistakenly referring a child or adolescent when a LI does not exist) and minimize the likelihood of false negatives (i.e., not referring a child or adolescent when a LI does truly exist ["wait and see" approach]) in the context of language-based concerns.

Even though very young children are unlikely to be seen by a psychiatrist, it is still important to note "red flags" when taking a developmental history. One general rule of thumb is that language development is most likely to be abnormal if *both* language comprehension and expression were delayed between 18 and 24 months [25]. If a hearing test was completed, a clinician can be more confident that language did not develop as expected. In addition, receptive language problems are generally much more challenging to identify by non-specialty providers and without formal standardized testing compared to deficits in expressive language. When taking a history, it will be helpful to note if a patient was able to follow single-step directions without gestures by 12–14 months and/or two-step directions without nonverbal assistance by 24–28 months [25]. A strong indicator for atypical language development in any toddler or preschooler is a profile comprising late language acquisition *and* one or more of the following: (a) comorbid socio-emotional or behavioral challenges or (b) a family history of LI, school-related difficulties (e.g., reports of a parent receiving academic supports, having difficulties learning to read or spell, or with completing high school), or formal diagnoses of specific learning disorders (i.e., impairments in reading, dyslexia, or written expression) within the family. Another marker is if a language delay is present or existed at the time of preschool entry (i.e., age 3), which is a strong indication that LI is part of the clinical profile [32]. As additional guidance, the literature also suggests that children with pathological patterns of late language emergence differ from non-pathological "late talkers" in that the latter group (a) is more frequently male with a paternal history of non-pathological late language acquisition, (b) utilizes more communicative gestures, (c) has better social functioning, (d) has healthier receptive and comprehensive language skills, and (e) demonstrates better recall of sentences—formally demonstrated on standardized testing [36, 50, 51]. Overall, when in doubt, psychiatrists and related professionals should always consult with well-informed colleagues across disciplines when there are questions pertaining to language atypicalities and whether a referral should be made. Moreover, becoming more comfortable with making false positives with regard to the referral process is important for providers, as the risks far outweigh the benefits—particularly at earlier stages in development.

Assessment Process and Tools

The neuropsychological assessment process for determining the presence of a language disorder and/or SoPCD is arguably one of the most complex and involved evaluations within the testing field. Even still, from a language pathology standpoint, an assessment by a neuropsychologist or related clinician is often a broader evaluation of these conditions relative to the richer evaluations conducted by speech and language pathologists; that is, neuropsychologists can be considered the radiologists, while speech and language pathologists are the surgeons. Collaboration across these professions is often warranted. Thus, the intricacies that occur in the presentation along with the heterogeneity in these syndromes usually requires a comprehensive, multi-method, multi-informant, and not uncommonly, a multi-disciplinary evaluation process. We further describe these procedures below.

Broadly, the neuropsychological evaluation should comprise a detailed clinical interview of developmental history and current language functioning, a review of family history, in vivo clinical observation, standardized assessments, and report measures. As with many disorders, the general methodology behind the assessment process, such as test battery selection, will depend on several factors, including but not limited to the following: chronological or mental age, informal or formal estimates of intellectual functioning, current language abilities (e.g., nonverbal versus verbal), behavioral functioning, and even motor development. A clinician's overarching goal during the assessment of these conditions is to determine whether the reported symptoms of concern fall within the realm of "neurotypical/normal" age-appropriate developmental expectations as delineated above and/or to differentiate these symptoms from other psychopathology or neurodevelopmental conditions. An evaluation should answer the following questions: (1) Are there currently the presence of persisting symptoms, observed across multiple settings, that are associated with language disorder and/or SoPCD? (2) Were these symptoms present in early development? (3) Do the identified symptoms result in functional impairment (such as social or academic functioning)? (4) Are these symptoms better accounted for by environmental factors (e.g., neglect) or another psychiatric or neurodevelopmental condition, such as global developmental delay, intellectual disability, autism spectrum disorder, ADHD, anxiety, and selective mutism, or medical conditions? Careful consideration of these other etiologies is essential, including ruling out hearing or sensory impairments (e.g., speech-motor difficulties), cleft palate, possible impacts of recurrent ear infections, neurological disorders associated with language regressions (Landau-Kleffner syndrome), and other medical explanations for poor language development. If any of these other medical etiologies are a concern, then referrals may be warranted to specialists such as those within neurology, audiology, genetics, and/or otolaryngology (ear-nose-throat specialty). Overall, this is not an easy task, and questions 3 and 4 noted above can be particularly challenging.

Importantly, regional, social, and multicultural considerations (e.g., dialects, limited exposure to stimuli [e.g., early school readiness curriculum] due to environmental factors, impacts of neglect/trauma, English as a second language, sequential versus simultaneous language learner, and acculturation) are also vital in the assessment procedures given the confounds that can impact individuals' performances on standardized testing. Notably, collective research strongly suggests that bi- or multilingualism does *not* lead to poorer language or literacy development; on the contrary, these are considered enriching experiences with advantages that likely assist with mastering skills and refining cognitive and other mental processes [5]. However, varying levels of exposure to a language and an individual's proficiency (as well as other cultural considerations) can lead to underestimates of a patient's "true" potential on standardized testing as many of these measures are not developed or normed on populations with confounds such as varying English language proficiencies or exposures. Simply put, a child being raised in a household in which English is not the primary language may appear delayed if tested only in English.

If this is a concern, it is important for the clinician to strongly consider a bilingual assessment, conducted by a bilingual evaluator that accesses measurement tools with appropriate normative data. At a minimum, the evaluators should have access to professional interpreter services.

The clinical interview is one of the most important tools in the assessment of LI. It should comprise a comprehensive developmental history, a review of the more recent concerns, as well as family history of LI or other related conditions. To make a formal diagnosis, concerns must be present in early development, though it is not uncommon for challenges to go under caregivers' or pediatricians' radars during that time. Additionally, these symptoms may not manifest fully until developmental and societal expectations begin to exploit a patient's weaknesses. As delineated in the sections above, there are key developmental milestones that should have been achieved, and these are essential to evaluate both from a historical and current perspective—whether a clinician is evaluating young children, school-aged children (i.e., ages 5–12), or adolescents (i.e., ages 13–17). Assessing alternative ways a child may communicate (e.g., sign language) is also important. Moreover, to assist with ruling out other conditions, clinical inquiry should involve questions specific to other conditions such as the early markers of ASD (see Chap. 9; e.g., eye contact, joint attention, stereotyped language), global development delays, and intellectual disability. If the patient is in school, clinical interview should also evaluate challenges within the school setting, such as difficulties with social interactions with peers, problems with following directions, or whether the child is falling behind their peers from an academic standpoint (e.g., difficulties learning letters and their associate sounds). Lastly, the interview should include questions pertaining to a patient's social, emotional, and behavioral functioning in attempt to ascertain possible etiological factors of any difficulties in these arenas. For example, does a child get more anxious in social settings with higher language demands or do tantrums seem to occur when the child appears frustrated with not being able to express their needs or desires? The higher the frequency of concerns, the severity of impairment, and their consistency across development and contexts, the more confident a clinician is in determining a diagnosis of LI.

Clinical observations within the assessment procedures can be a critical component as well. Clinicians need to be vigilant to identify concerning language or social pragmatic vulnerabilities and to corroborate information gleaned from the clinical interview and standardized testing. For example, in concert with standardized testing, skilled clinicians utilize "internal norms" they've developed across the years of working with all developmental stages to identify data such as a paucity in word knowledge, weak articulation, challenges with organizing language (i.e., poor syntax) for effective verbal expression (e.g., "how much difference are they"), neologisms (e.g., a 4-year-old child using a nonsense word such as "bimbap" for "balloon"), malapropisms (e.g., use of "electoral" when an adolescent meant "electronic"), word retrieval challenges, difficulties with processing verbal directions, or poor pragmatic response to or use of language. Collecting data on language-based academic performances, such as reading fluency and written expression, is also enlightening to an evaluation. Such clinical observations can provide excellent insight into a child's strengths and weaknesses.

At the heart of the neuropsychological evaluation for both language disorder and SoPCD is an array of standardized assessments and report measures. Therefore, the assessment of LI often entails many of the evaluation practices described throughout other chapters in this book and should involve (though is not limited to) measurements of the following: cognitive/intellectual potential or developmental level; expressive language, including retrieval and fluency (articulation as well, though this is often out of the scope of neuropsychological testing); receptive language or language processing; social pragmatic use of language; phonological awareness/processing; language-based academic skills (i.e., reading and writing abilities); verbal memory (e.g., narrative and rote); and socio-emotional as well as behavioral functioning. Table 5.3 lists many of the useful tools to evaluate each of these arenas.

Table 5.3 Selected instruments for diagnosing language disorder and/or social pragmatic communication disorder

Instrument	Age range (years)	Area(s) assessed	Common diagnostic utility
Preschool Language Scales (PLS; [63])	Birth to 7:11	Auditory comprehension and expressive communication	Language disorder/delays
Expressive Vocabulary Test (EVT; [59])	2:6–90	Expressive vocabulary and word retrieval	Language disorder/delays
Expressive One-Word Picture Vocabulary Test (EOWPVT; [38])	2–18:11	Expressive vocabulary and word retrieval	Language disorder/delays
Peabody Picture Vocabulary Test (PPVT; [23])	2:6–90	Receptive vocabulary	Language disorder/delays
Receptive One-Word Picture Vocabulary Test (ROWPVT; [37])	2:0–18:11	Receptive vocabulary	Language disorder/delays
Boston Naming Test (BNT; [13])	5–13; 18+	Word retrieval	Language disorder/delays
Clinical Evaluation of Language Fundamentals (CELF; [58])	5–21	Broad band assessment of expressive and receptive language abilities	Language disorder/delays and social pragmatic communication disorder
Comprehensive Assessment of Spoken Language (CASL; [17])	3–21	Broad band assessment of expressive and receptive language abilities	Language disorder/delays and social pragmatic communication disorder
Oral and Written Language Scales (OWLS; [18])	3–21	Broad band assessment that includes measures of language processing, reading and written expression, as well as pragmatics	Language disorder/delays, specific learning disorders, and social pragmatic communication disorder
Delis-Kaplan Executive Function System (D-KEFS; Verbal Fluency; [21])	8–89	Executive functions within verbal modalities (e.g., word retrieval) and language fluency	Language disorder/delays
NEPSY-II [30]	3–16	Broad band assessment that includes measures of language processing, phonological processing, verbal memory, and social cognition	Language disorder/delays and/or social pragmatic communication disorder
Comprehensive Test of Phonological Processing (CTOPP; [54])	5–24:11	Phonological processing	Language disorder and specific learning disorders (dyslexia)
Wechsler Individual Achievement Test (WIAT; [56])	4–50:11	Expressive and receptive language; language-based academic skills (i.e., reading, spelling, written expression)	Language disorder and specific learning disorders
California Verbal Learning Test (CVLT; [22])	5–89	Rote verbal learning memory	Language disorder
Hopkins Verbal Learning Test-Revised (HVLT-R; [16])	16–92	Rote verbal learning memory	Language disorder
Wechsler Memory Scale (WMS; [57])	16:0–89:11	Narrative and rote verbal learning and memory	Language disorder
Wide Range Assessment of Memory and Learning (WRAML; [46])	5–90	Narrative and rote verbal learning and memory	Language disorder
Social Language Development Test (SLDT; Bowers, [15])	6–17:11	Social language comprehension and expression	Language disorder/delays and/or social pragmatic communication disorder
Test of Pragmatic Language (TOPL-2; [43])	6–18	Social communication	Language disorder/delays and/or social pragmatic communication disorder
Children's Communication Checklist (CCC; [6])	4:0–16:11	General language and pragmatic use of language	Language disorder/delays and/or social pragmatic communication disorder

The reader is also referred to the accompanying chapters in this book to review assessment procedures for each of these areas.

Usually one of the initial steps in the standardized testing procedures is to obtain a reliable and valid estimate of cognitive functioning or intelligence. The reader is referred to Chap. 7 for a review of frequently utilized measures for cognition and/or intelligence. If a language disorder is present, this juncture in the evaluation process can identify this by way of delineating discrepancies between a patient's verbal and nonverbal abilities. For example, an adolescent who performs within the 10th percentile on the Verbal Comprehension Index of a Wechsler Intelligence Scales for Children (WISC; [55]) and in the 82nd percentile on the Fluid Reasoning Index may be experiencing a language-based issue. On the other hand, if all the cognitive abilities assessed fall markedly below expected levels, it can be (not always) suggestive of more global impairments in functioning that are related to other clinical explanations (e.g., intellectual disability, unspecified neurodevelopmental disorders). Importantly, and more specific to language disorders rather than SoPCD, existing language challenges can lead to underestimates of a patient's "true" potential given these tests are highly confounded by language functions—even subtests that are considered measurements of nonverbal abilities. Assessments of nonverbal intellectual potential in the context of LI can be key, as an estimate of nonverbal intellectual potential may be a more accurate representation of a patient's "true" cognitive abilities and/or can be assistive in better profiling strengths and weaknesses. While global estimates of cognition or intelligence are not diagnostic indicators for SoPCD, a measurement of cognition can also be essential in further understanding what may be at the etiology of a patient's social functioning weaknesses. For example, if there is a patient presenting with struggles within the social arena, obtaining estimates of their cognitive abilities relative to age mates can be helpful in providing more data in determining whether a diagnosis of SoPCD is warranted or if the root of the social difficulties can be better explained by cognitive challenges.

One reasonable next step is to obtain a more detailed assessment of an individual's language profile, including expressive and receptive language, phonological awareness/processing and memory, verbal memory, and pragmatic use of language. There is a myriad of these abilities and sub-abilities that could be assessed, and the data collected up to this point in the evaluation often dictates the procedures that are taken by a clinician. While by no means an exhaustive list, Table 5.3 outlines several measures that assess these functions. Expressively, neuropsychological testing should obtain a measurement of a patient's single-word expressive and receptive language, effortful word retrieval, and language fluency, which can, respectively, be captured by using one or more of the following: EVT, EOWPVT, PLS, BNT, WIAT-III, OWLS, DKEFS, NEPSY-II, CASL, and CELF. From a receptive language standpoint, it is also important to evaluate single-word receptive language and language comprehension. The PPVT, ROWPVT, PLS, WIAT-III, NEPSY-II, and CELF all afford good measures of these skills. Phonological processing/awareness, a hallmark cognitive ability often impaired in specific learning disorders with impairment in reading, more specifically dyslexia (see Chap. 2), is frequently an important area to assess as well and can be accomplished with the CTOPP, WIAT (Pseudoword), or NEPSY-II. In addition, evaluating a patient's academic skill set can be essential in identifying language-based issues that impact learning, including reading, spelling, and written expression. The reader is referred to the accompanying chapters for a review of the useful tools to this end. Narrative and rote verbal memory can be important to evaluate as well to assess a patient's ability to encode/learn, retrieve, and recognize types of verbal information. The WRAML, CVLT, NEPSY-II, HVLT, and WMS are measurement means to this end. More specific to an assessment of SoPCD, measurements of a patient's social pragmatic use of language are essential, including (but not limited to) the use of verbal and nonverbal means to communicate, understanding of verbal and nonverbal communication, theory of mind/perspective-taking, spontaneity in communication, conversation skills, use and understanding of abstract or figurative language, and comprehension of verbal or nonverbal discourse. This can be accomplished via the NEPSY-II, TOPL, SLD, Autism Diagnostic Observation Schedule Second Edition (ADOS-2; [33]), as well as parent or teacher report measures available including the CELF Pragmatics Profile; Social Responsiveness Scale, Second Edition (SRS; [19]); Social Communication Questionnaire (SCQ; [45]); and the CCC-2. Chapter 9 provides further details of the ADOS-2, SRS, and SCQ measures. Finally, assessments of a patient's emotional and behavioral functioning can be important as well to evaluate possible secondary challenges to LI, such as anxiety, poor self-esteem, or depression (see Chaps. 10 and 11).

Case Study

Provided here is a case example that highlights important features of the evaluation process along with the testing results that were utilized in making a diagnostic determination of language disorder for a girl referred for several concerns. Information was obtained through a neuropsychological evaluation comprising a clinical interview and observation, collateral with a referring pediatrician, standardized testing, and parent and teacher reports on standardized measures.

Reason for Referral *Sarah was an 8-year-, 5-month-old, right-handed, monolingual (English), girl of Hispanic descent referred for a comprehensive neuropsychological evaluation by her pediatrician, Dr. Bruce Smith, and her biological parents. In the context of her prior diagnosis of attention-deficit/hyperactivity disorder, combined presentation (ADHD-C), all parties were seeking further diagnostic clarification due to longstanding concerns regarding socio-emotional and behavioral challenges* (e.g., *hyperactivity and tantrums/outbursts), academic struggles, and an array of executive dysfunctions* (e.g., *inattention, distractibility, and poor self-monitoring). Her parents were also seeking assistance with treatment and educational planning.*

Early Development *Sarah was reported to be a product of an uncomplicated, full-term, 41-week gestational pregnancy, weighing 8 lb, 1 oz via induced labor. Reportedly, Sarah experienced significant delays in her speech and language development as she did not utilize single words until approximately 2 years of age and simple sentences/phrases until around the age of 3. In addition, her motor development was also delayed as she did not walk until the age of 2. She received early intervention services comprising speech and language therapy, occupational therapy, and play therapy up until the age of 3.*

Medical History *Medical history was reported to be largely unremarkable, except for ear infections and enuresis. Medical workups for these issues were reported to be unremarkable. Sarah was followed by her pediatrician, Dr. Smith, who prescribed her stimulant medication for ADHD management. Hearing and vision were reported to be within normal limits. Family neuropsychiatric history was remarkable for ADHD and dyslexia.*

Psychosocial/Psychiatric History *Eye contact, response to joint attention, and response to name were all reported to be largely within normal limits in Sarah's early development. There were no atypical and/or stereotyped behaviors or excessive interests indicated, with the exception of some sensory sensitivities to tolerating food textures. However, as noted above, Sarah experienced delays in her early development, some of which may have resulted in a low frustration tolerance and tantrums at a young age per the parent's report. Sarah was also reported to exhibit a history of learning and social challenges during her early development in the context of hyperactivity, inattention, distractibility, and poor self-monitoring.*

At the time of the evaluation, Sarah was reportedly struggling with restlessness and other executive functions (e.g., *sustained attention, organization, and time management). In addition, she reportedly exhibited daily tantrums triggered by parents setting limits or making requests* (e.g., *homework completion). Socially, she was* *reported to have friends at school and to be well-liked; however, there were some inconsistencies in her social successes. In addition, Sarah was reported to frequently exhibit limited insight into certain social situations and/or the impact of her behaviors within these contexts. Symptoms of depression and anxiety were denied by all parties. However, Sarah self-reported distress pertaining to homework completion.*

Educational History *Sarah's academic tenure was reported to be marked by the concerns regarding hyperactivity and other executive dysfunctions. She was retained in preschool reportedly due to delays in her learning and social development. At that time, she was placed onto an Individualized Education Program (IEP). At the time of the evaluation, Sarah was enrolled into the second grade in a regular education classroom (*i.e., *full inclusion). According to her IEP at that time, Sarah was receiving pull-out/direct services for language arts (3x/30 min/week), in-class language arts supports (4x/45 min/week), and consult services from all services providers. Despite these services, Sarah was reported to continue to struggle across all academic subject areas.*

Key Clinical Observations *Eye contact and social reciprocity fell largely within normal limits; however, Sarah's social interactions were hindered by difficulties with hyperactivity, sustained attention, and self-monitoring. These challenges were prominent throughout the testing session; however, Sarah was easily redirected and responded favorably to positive reinforcement and verbal praise. Speech and language difficulties were notable; Sarah exhibited challenges at times with efficiently retrieving and organizing her thoughts for effective verbal expression, evidenced by latency in her response patterns. This impacted her pragmatic language at times. Moreover, malapropisms were indicated (*e.g., *used the word "Pictionary" when she intended "dictionary"). Hearing and vision appeared to be within normal limits. Sarah also exhibited marked difficulty across most academic areas, particularly reading fluency, which was noted to be slow and laborious. Phonological processing/awareness difficulties were exhibited across most reading, spelling, and writing tasks. The results of testing were deemed a valid representation of her abilities at that time.*

Key Neuropsychological Test Results *Sarah was administered the Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V;* [55]*). The overall estimate of Sarah's intellectual functioning (*i.e., *Full Scale IQ) fell within the low average range (SS = 84; 14th percentile). While discrepancies were noted among her performances on subtests that comprise the FSIQ, the level of intersubtest scatter was not uncommon within the normative sample. Sarah's profile was nonetheless best understood by an individual examination of each of the five composite scores. More specifically, her visual organization and spatial reasoning (SS = 100; 50th percentile) and her nonverbal reasoning and problem-solving abilities (SS = 91; 27th percentile) fell within the average range and were considered a relative strength for her in comparison to her verbal and information processing abilities. Her verbal reasoning and knowledge (SS = 86; 18th percentile) fell below expected levels within the low average range. Her working memory (SS = 79; 8th percentile) and processing speed (SS = 77; 6th percentile) fell markedly below expected levels, within the borderline range, and were considered significant weaknesses.*

Separate measures of Sarah's language functioning reflected low average single-word expressive language on the Expressive One-Word Picture Vocabulary Test, Fourth Edition (EOWPVT-4; SS = 85; 16th percentile), though average receptive skills on the Receptive One-Word Picture Vocabulary Test (ROWPVT-4; SS = 94; 34th percentile). Moreover, weaknesses in effort word retrieval and language fluency were evidenced on the Delis-Kaplan Executive Function System (DKEFS; Letter Fluency ss = 7; 16th percentile; Category Fluency ss = 6; 9th percentile). On the Comprehensive Test of Phonological Processing, Second Edition (CTOPP-2), a measure of phonological processing, various challenges were exhibited as Sarah's performance *largely fell within the borderline to low average ranges (Elision ss = 5; 5th percentile; Phoneme Isolation ss = 6; 9th percentile). Academically, on the Wechsler Individual Achievement Test, Third Edition* [56], *Sarah's word reading, decoding, reading comprehension, reading fluency, sentence and essay composition, sentence building, as well as mathematical problem-solving and calculation all fell within the borderline to low average ranges (SS ranged from 76 to 81; 5th to 10th percentiles). On the WRAML-2, Sarah's ability to encode/learn, retrieve, and recall rote and narrative information was impaired, while she evidenced largely intact visual recognition abilities. Her sentence memory fell below expected levels as well. In addition, her visual-motor integration skills on the Beery-Buktenica Developmental Test of Visual-Motor Integration, Sixth Edition (VMI), were borderline (SS = 77; 6th percentile), which was noted to impact the intelligibility of her handwriting. Parent and teacher reports on rating scales suggested marked executive dysfunction along with several other concerns regarding hyperactivity, sustained attention, anxiety, somatization, social skills, and withdrawal in both home and school settings.*

Overview of Summary and Clinical Impression *Clinical impressions and results of testing were deemed to be consistent with a polite and kind-hearted girl who presented with primary weaknesses in her language-based abilities, including phonological processing/awareness deficits, expressive language challenges, weaknesses in language fluency and word retrieval, and difficulties in language organization/syntax (per clinical observation). Sarah's cognitive profile, with weaknesses in not only her language functions but also information processing and executive functioning (working memory, processing speed, inattention, and self-regulation), puts her at risk for academic challenges. However, all these difficulties are likely exacerbated by her prominent language-based impairments, collectively resulting in specific learning challenges (reading, spelling/writing, and math). Secondary to all of these difficulties, Sarah was also evidencing socio-emotional weaknesses, including symptoms of anxiety, social vulnerabilities, as well as periodic noncompliance and emotional dysregulation related to schoolwork within the home. Many of these behavioral and emotional difficulties likely stem in part from her language difficulties as well, which commonly increase the risk of frustration or interpersonal problems. Sarah's history of language-based challenges and the results collectively supported the following Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), diagnoses:*

- *315.39 Language disorder*
- *315.00 Specific learning disorders with impairments in reading, and more specifically dyslexia (severe)*
- *315.1 Specific learning disorder with impairments in mathematics (moderate to severe)*
- *315.2 Specific learning disorder with impairments in written expression and more specifically dysgraphia (severe)*
- *314.01 Attention-deficit/hyperactivity disorder, combined presentation (ADHD-C; moderate to severe)*

It is important to note that a quick perusal of the above scores and developmental history might lead some clinicians to jump to the conclusion that all of Sarah's symptoms are simply the result of a known diagnosis of ADHD, but more careful examination would suggest that her learning and cognitive difficulties are primarily linguistic in nature. This is apparent, for example, in the discrepancy between her performance on tasks requiring language and others that do not—her strengths were in visual organization and spatial reasoning and nonverbal reasoning and problem-solving abilities.

"Best Practices" for Educational Programming

One of the most comprehensive, effective, and often necessary treatment approaches for children, adolescents, and families impacted by LI is to access services within a patient's educational setting. More specifically, within public schools, services are mandated through the Individuals with Disabilities Education Act (IDEA), which ensures that children with all disabilities have free and appropriate public education made available (FAPE; [41]). The IDEA requires that public school districts consider the employment of an Individualized Education Program (IEP) for a student, which is a service plan that delineates educational goals and objectives as well as *how* these will be measured and achieved within the school setting (see Chap. 13 for further review). An IEP can be accessed for a patient starting at the age of 3 upon entry into preschool. Notably, early intervention (EI) services can be acquired sooner via a referral from a child's pediatrician or with the help of the public school district. This is further discussed in the section to follow.

The educational goals, objectives, and services should be illuminated by comprehensive evaluation procedures and can be conducted within the public school, independent clinics, or both. These assessments, as indicated above, profile a patient's strengths and weaknesses across an array of neurocognitive and learning abilities. In turn, this can elucidate the appropriate school and/or classroom placement (e.g., integrated preschool, full inclusion, partial inclusion, substantially separate classroom [i.e., language-based classroom]) as well as specify accommodations (e.g., testing in separate settings), direct services (e.g., speech and language therapy), and ancillary supports (e.g., consultation with a speech and language pathologist) that will fulfill that patient's educational needs. There is no "one-size-fits-all" service plan for students with LI. However, there are several principles that can help effectively guide all parties through this process in addition to specific components that should be included in their educational planning.

Broadly, for all youth, it is important that the accommodations and direct services are highly individualized, systematic, and have targeted goals and measurable outcomes. It is also important that progress is measured both relative to age mates and prior individual performances to ensure effective progress across time. A high level of communication between the family, school administration, teachers, special education support staff, and both school- and community-based treatment providers is important as well. Moreover, supports are matched according to the severity of the presenting symptoms (see Table 5.4). For example, a patient with mild LI may require only accommodations, whereas a patient with moderate LI may require both accommodations and direct services. Finally, a patient who is presenting with significant weaknesses within their language functions may also require enrollment into a separate educational setting entitled a "language-based classroom." Table 5.4 lists the key components of this type of specialized classroom, along with beneficial direct or pull-out interventions, as well as other accommodations and supports that a student with an LI may need. An important feature to educational programming is also to ensure that as patients and their families begin to think about graduation in the later academic years, there is ongoing transition planning to prepare everyone for the next steps into a college setting, employment, and/or other pathways to promote achievement of post-secondary goals.

The services and protections noted above are not mandated in private school settings by the IDEA, but private schools at times can have access to similar resources, though these are often not under the auspices of an IEP. Families can also obtain an evaluation from their local school district and have an IEP proposed even if they are not enrolled in the public school system, which they can deliver to their school team at their non-public institution. This can help inform private schools of the educational needs of a student. Lastly, there are many private schools that are specifically geared toward providing supports to children with language-based or social functioning differences. Educational consultants can be helpful in identifying such placements for families. It can also be very beneficial for families to consult other professionals, such as educational advocates or attorneys, to help them navigate this process. All of this can be far from an easy task for schools or caregivers to accomplish, but it is crucial, and it is not uncommon for psychiatrists

Table 5.4 Key components of a "language-based classroom," direct services, and accommodations for the school setting

Key components of a language-based classroom	Direct services	Accommodations and additional supports	
Substantially separate classroom setting	Speech and language therapy	Ongoing consultations with a speech and language pathologist, assistive technology specialist, or other related providers	The rate of presentation of materials and concepts altered to a slower pace
Small student-teacher ratio with no more than 6–8 students	1:1 or small group academic tutoring in reading, spelling, or writing, which sometimes requires multi-sensory, rule-, and phonics-based approaches for disorders such as dyslexia	Extra time on all tasks, tests, and standardized testing	Access to a written checklist of steps required to complete a task (also a completed work example can be beneficial)
Instruction that integrates multi-sensory (e.g., visual, auditory, tactile, and kinesthetic), rule-, and phonics-based teaching approaches across all subject areas and all aspects of the curriculum	Augmentative and alternative communication assistance	Modified workloads, testing formats, and flexible deadlines	Complete written work on a computer with spell-checking functions. The use of laptops/keyboard for all writing assignments
Visual aids, hands-on, concrete examples, and experiential learning approaches should be utilized	Assistive technology (e.g., speech-to-text devices)	Allow to take frequent breaks	Access to graphic organizers
Peers have similar profiles regarding their neurocognitive, learning, social, emotional, behavioral, adaptive, and speech and language strengths and weaknesses	1:1 or small group social skills training or a "lunch bunch"	Structure and support, consistent feedback, and frequent monitoring in classroom	Books (and textbooks) on tape to facilitate learning
A speech and language pathologist, certified reading specialist, and/or assistive technology specialist should provide direct therapeutic services and consultation to the classroom	Extended school year services (to prevent a regression)	Breaking assignments into smaller "chunks"	Have student repeat and restate instructions to confirm understanding of tasks presented
Systematic instruction with clearly defined learning objectives and systematic teaching methods	Occupational therapy to assist with handwriting development	Preferential seating in areas that minimize distractions	Use headphones in classroom to mitigate effects of extraneous stimuli
Targeted learning objectives tailored to student's functioning level	1:1 or small group executive functioning tutoring	Routine for assigning homework should be completed	Having lessons repeated on different days and engaging in the rehearsal of concepts, perhaps in condensed form, in order to ensure that information is encoded into memory

Table 5.4 (continued)

Key components of a language-based classroom	Direct services	Accommodations and additional supports	
A clear schedule and routine, one that concretely delineates expectations throughout the day	Counseling for secondary anxiety or social challenges	Assign a peer role model to assist getting student started with classroom activities and assignments, as well as to assist with social development	Avoid using a red pen to correct mistakes as this has negative connotations associated with it
		Access to teacher notes to assist in keeping up with the materials presented within the classroom	Advanced notice for large assignments or projects, which should be broken down into multiple deadlines (e.g., part I of book report is due week 1; part II is due week 3; entire project is due week 5, etc.)
		Not penalized for spelling errors when spelling is not the main area being assessed	Access to executive functioning supports across his day to assist student in taking organized and efficient approaches to learning, self-monitoring, confirming that they are keeping up with materials, planner support, and guidance with ensuring they have all the necessary materials for a lesson

and related professionals to, on some level, assist their families with this across treatment.

"Best Practices" for Home- and Community-Based Interventions

Much of the same treatment programming that is available within the educational setting is also available to patients and their families within the home and/or community clinics. While available, accessing these interventions is not always an easy process as families are often faced with the daunting task of identifying where to access such interventions as well as conducting their own research on what the science supports and what would be specifically helpful for their child's particular profile. Moreover, similar to many other conditions, families impacted by LI have considerations around logistical and financial factors. Unfortunately, it is not uncommon for families to encounter a rather unwelcoming insurance authorization process. Therefore, it is important for a family's treating psychiatrist or related professional to have a working knowledge base not only the options for treatments in their local communities but also what is supported by the science, what is "best practice," and how to assist patients and their families in locating and accessing such care. If working with a patient who is in need of services for LI, the identification of these services can often pay dividends to treatment goals that are specific to emotional or behavioral psychopathology (e.g., attenuation of anxiety by way of treating language or social delays).

Early detection and early intervention are key for all patients with or at risk for LI. At the time these delays are identified or a diagnosis has been confirmed, the next step should entail a selection of treatment(s) which is dictated by the patient's age and particular profile of strengths and weaknesses as outlined by an evaluation. For children under the age of 3, families can contact their local school district for information on the state's agency that delivers EI services. Directing families to resources such as the American Speech-Language-Hearing Association (ASHA; www.asha.org) or the Early Childhood Technical Assistance Center (http://ectacenter.org; http://ectacenter.org/contact/ptccoord.asp) can also be helpful in identifying services. Children are eligible for EI services up until the age of 3, but different states have different parameters and rules for eligibility. EI services will initiate the employment of an Individual Family Service Plan (IFSP) for the family, which is an early treatment program that mirrors an IEP. This may comprise the following: evaluations or screenings, progress evaluations, care coordination, access to specialty providers (e.g., developmental specialists), speech and language therapy, occupational therapy, physical therapy, behavioral interventions, and/or play/social groups. After 3 years of age, families can begin to access services within their local school district as described above.

Families may also access services, for all age ranges, outside of those provided by the state. Caregivers may be interested in receiving their primary interventions through hospitals or independent clinics/providers or supplementing what they might already be accessing through the state or public school districts. Services for LI, such as private speech and language therapy or social skills groups, are available through various institutions and practices. The myriad of interventions and services available, however, can be overwhelming for families. As a psychiatrist or related professional, it is important to direct families to taking a three-pronged approach with regard to treatment: (1) It should be evidenced-based, that is, supported by science; (2) it should be individualized (and informed by standardized evaluations with periodic progress monitoring); and (3) the intensity (i.e., frequency and duration) should match the severity of condition(s). These services can be located by having patients' families contact their pediatricians for referrals (if one has already not been placed), referring to a psychiatric provider's own speech and language department, or via resources such as the ASHA (www.asha.org; www.asha.org/profind/).

For social skills training (especially important for children with SoPCD), the above resources can be helpful, and caregivers can access additional information via Autism Speaks® (www.autismspeaks.org). Caregivers can also identify clinics providing evidenced-based social skills programming via Social Thinking® (www.socialthinking.com). Children, adolescents, and their families with LI may also greatly benefit from other treatments that include, but are not limited to, occupational therapy, assistive technology and/or augmentative communication supports, academic or executive functioning tutoring, psychotherapy (e.g., cognitive behavioral therapy), and behavioral parent training/coaching. It is important for families to know that common co-occurring difficulties (e.g., executive functioning issues, delayed reading fluency, comprehension, and written expression) can often times be addressed within speech and language interventions as language can be at the root of many of these vulnerabilities.

Finally, it is not uncommon for caregivers to ask their psychiatric providers after receiving a diagnosis, "What can we do today to start to help our child at home?" Certainly, initiating the acquisition of the services delineated above as soon as possible is a good start, but that answer often leaves much to be desired from a parent's perspective. Fortunately, there are practical strategies or methods that families can begin to provide within the home setting. While not exhaustive, provided below is a general list of helpful home strategies and accessible resources for families (some data listed adapted from [1]):

- Listen and respond to your child.
- Talk and play with your child. Verbally describe what you are doing and what your child is doing—allowing your child to direct the play.
- Back-and-forth conversational interchanges are key, as they promote language much better than just exposing children to words.
- Frequently verbally label objects.

- Use multiple instructional modalities. Pairing verbal explanations with visual aids, demonstrations, and hands-on tasks can be helpful.
- Read to your child as much as possible; accessing books (and textbooks) on tape to facilitate language and learning for older children may also prove beneficial (www.learningally.org; www.bookshare.com).
- Listening to music with lyrics, and having your child learn nursery rhymes or songs, can promote language development across all ages.
- Communicate with your child in the language that you are most comfortable using, and know that your child learning a second language *can* be beneficial.
- Use a lot of different words with your child.
- Use longer sentences as your child gets older.
- Have your child play with other children; engagement within structured peer activities to promote language and social development.
- Give your child time to talk; do not interrupt or stop your child while he or she is speaking.
- In a nurturing and supportive manner, require your child to practice language as much as possible.
- Consistently reward them when they use language by providing verbal praise and provide positive support when they are having difficulties expressing themselves.
- Model prosocial behaviors, both verbally and nonverbally, such as demonstrating greetings to others, pleasantries, appropriate eye contact and facial expressions, and how to appropriately end conversations or social interactions.
- Retrospectively review with your child, in a supportive manner, what went wrong socially or from language standpoint, and review possible ways to correct it in the future.
- Minimize multiple-steps commands.
- Understood: For Learning and Attention Issues (https://www.understood.org/en) provides an array of helpful information for families.
- Applications for smart phones to assist with language development and social skills, academic skill sets, and other areas of functioning can be found here: www.autismspeaks.org/autism-apps.

Conclusion

While impairments in language are not always easy to identify either currently or retrospectively, it is critical that strong considerations of language are given due to the prevalence and far-reaching effects of such vulnerabilities on patients and their families. Simply put, LIs can have a negative impact on children's experience of many aspects of childhood (e.g., academics, friendship) that are key to optimal development. A thorough and accurate understanding of language abilities can be key in generating accurate and precise case conceptualization and resulting treatment planning. Prompting patients for further specialized evaluations of language when indicated (e.g., speech and language, neurodevelopmental, neuropsychological, or psychoeducational assessments) can often pay dividends by opening an array of ameliorative services, either within the home or school settings, which can greatly assist in treating some of the primary factors at the root of mental health differences.

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6

Nonverbal Learning Disability

Nathan Doty

The term nonverbal learning disability, often abbreviated as NVLD or NLD, has been used by researchers and clinicians to characterize a constellation of cognitive and learning challenges that impact an individual's ability to process information lying outside the verbal domain. Individuals with NVLD typically show broad deficits in the nonverbal domain, which impact their ability to process spatially or visually complex information, perform visual-motor tasks, and use nonverbal problem solving. Their academic challenges also lie within the nonverbal domain, with mathematics representing the area of greatest difficulty. Verbal abilities, as well as basic reading and spelling skills, are often intact or even advanced. However, individuals with NVLD may struggle with certain aspects of written language, such as comprehension of complex or inferential material, organization of ideas, and handwriting. For many, the challenges of NVLD extend beyond the classroom, impacting their social functioning as well as their use of organization, planning, and other executive functions in day-to-day life.

While this syndrome of nonverbal cognitive deficits and associated challenges has long been recognized within the field of neuropsychology, its acceptance as a discreet clinical diagnosis remains tenuous. The current edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) does not classify it as a diagnosis, and experts continue to debate its status as a distinct diagnostic entity. Proponents of its diagnostic classification argue that NVLD provides a framework for understanding a unique group of children who show deficits in right-hemisphere brain functions, which are not well characterized by existing diagnoses. Detractors, however, have questioned whether NVLD can be considered distinct, particularly given its significant overlap with established diagnoses such as developmental coordination disorder, specific learning disorder, and high-functioning autism spectrum disorder (historically and colloquially known as Asperger's disorder). The overlap between NVLD and high-functioning autism has been a particular focus, with some theorists even describing NVLD as a "mild" form of autism. Indeed, nonverbal cognitive deficits are especially common in higher-functioning individuals on the autism spectrum. However, recent studies suggest that the social deficits seen in NVLD may be fundamentally different than those associated with autism [4]. Further, many individuals with NVLD do not present with restricted interests or repetitive mannerisms, which are necessary criteria for the diagnosis of an autism spectrum disorder.

Despite controversy surrounding the nosology of NVLD, it remains clear that learning disabilities are not exclusively language-based

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and that a student's academic progress may be impacted by deficits in the nonverbal domain. As one would expect, prevalence estimates for NVLD vary depending upon the criteria used, but the most frequently cited estimate is that 10–15% of all learning-disabled students have a profile of NVLD [12]. For the purposes of this chapter, the term NVLD is used inclusively to describe individuals with spatial or nonverbal cognitive deficits that impact their academic, social, or day-to-day functioning. A brief review of existing research is followed by a discussion of NVLD's clinical characteristics, as well as best practices for its assessment and treatment. The chapter concludes by examining the case of a 10-year-old girl with NVLD in order to highlight key facets of diagnostic decision-making, intervention, and support.

Review of Existing Research

The first published account of nonverbal cognitive deficits was authored by neurologist Josef Gerstmann, who described a syndrome of nonverbal impairments consisting of left-right confusion, finger agnosia, agraphia, and acalculia [6]. In 1967, Johnson and Myklebust introduced the concept of "nonverbal learning disabilities" as part of their comprehensive book on learning disabilities [8]. They identified a group of children whose difficulties lay beyond the more commonly recognized purview of "language-based learning disabilities," hence the term "nonverbal learning disability." In addition to the motor, math, and writing challenges described by Gerstmann, Johnson and Myklebust also noted deficits in visual-spatial processing and social perception. In the 1980s, neuropsychologist Byron Rourke identified a similar group of children that he designated as having nonverbal learning disorders [17].

Research by Rourke and his many collaborators has formed the foundation for most contemporary conceptualizations of NVLD, which hypothesize that its pervasive nonverbal deficits are the result of underlying dysfunction in the right hemisphere of the brain [17, 19]. Neurological research has lent support to this theory, demonstrating similarities between NVLD and acquired injuries in the right hemisphere of the brain. Imaging studies have also found mild right-hemisphere abnormalities in the brain scans of individuals with NLD [5]. Rourke and others have argued that these "right-hemisphere" deficits reflect dysfunction in the brain's subcortical white matter, which comprises long neuronal fibers that are especially prevalent in the right hemisphere and are critical to its functions. Whereas the processing of verbal information involves very distinct areas of the brain, complex spatial and organizational tasks require communication across many different regions of the right hemisphere. By disrupting this relay of information, deficiencies in subcortical white matter are thought to disproportionality affect the diffuse right-hemisphere functions of the brain. Underlying deficiencies in white matter may also explain why organization, planning, and other executive functions are often impaired in individuals with NVLD, since these higher-level processes also require coordination across diffuse neurological pathways. This theory, commonly referred to as the "white matter model," reflects the most widely accepted view of NVLD at this time [3].

Clinical Features of NVLD

While researchers and practitioners have yet to agree upon a formal definition and criteria for diagnosis, commonly accepted views of NVLD describe a pervasive pattern of nonverbal deficits that impacts an individual's ability to (1) process spatial information, (2) perform tasks involving motor or visual-motor coordination, and (3) use abstract nonverbal problem solving. As such, individuals with NVLD may show faulty spatial perception, poor visual memory, and difficulty on tasks that are not readily verbalized (e.g., reading maps, graphs, or charts; solving visual patterns or puzzles; grasping abstract mathematical concepts such as part-whole relationships). As noted above, executive functions are also compromised in many individuals with NVLD, particularly in areas such as organization, planning, time management, and flexible thinking. Those with NVLD may become lost among the details, rather than processing information in a holistic or well-integrated manner. Lastly, individuals with NVLD often struggle with relating to others and may show specific weaknesses in their social perception skills. Social perceptions often require the integration of many disparate observations and details, placing significant demands on right-hemisphere processing. Social interactions also rely upon a multitude of nonverbal cues, including eye contact, facial expressions, body language, and vocal intonation.

Despite their cognitive, academic, and social challenges, individuals with nonverbal learning disabilities often display specific areas of strength. Their verbal skills are generally intact and, in many cases, may be exceptionally strong. Some have suggested that children with NVLD develop superior verbal abilities as a means of coping with and compensating for their nonverbal deficits. Individuals with NVLD may also show excellent rote memory skills, particularly for verbal information. They tend to be detail oriented. Even when processing visual information, their attention to detail may help them to compensate for difficulties integrating the information with the same coherency and efficiency as their peers.

NVLD Across the Life Span

The signs and symptoms of NVLD vary across the life span, but research and clinical practice have provided insight into how individuals with NVLD are likely to present over the course of their development. As early as infancy, children with NVLD tend to show a lack of exploratory play. In general, they show poor motor coordination and develop self-care skills later than most children [16]. For example, learning to tie shoelaces or read an analog clock can be monumental tasks for a child with NVLD. As the child develops, their problems with motor coordination may become evident in daily life. They are generally less athletic than their peers. Many report that learning how to ride a bike took years rather than months. Children with NVLD may be physically clumsy as well, and hence more likely to injure themselves. While their performance on psychomotor tasks does improve with practice, these coordination problems frequently persist into adulthood, particularly for novel or complex tasks. In contrast, the verbal skills of young children with NVLD often exceed their developmental level, and they may be seen as clever and engaging by adults. They may ask a seemingly endless string of questions as they attempt to make sense of what their deficits prevent them from understanding implicitly or nonverbally.

Although they often struggle with sensorimotor skills such as cutting and coloring, students with NVLD often demonstrate average or above average academic achievement in early elementary school [18]. While spatial deficits may impact the mastery of letter shapes for some children with NVLD [13], any early reading struggles tend to improve dramatically once their recognition of letters becomes more automatic. The impact of their visual-motor deficits on handwriting often persists into adolescence and even adulthood.

Even with relatively strong performance throughout elementary school, most students with NVLD begin to struggle by middle school. The strong rote memorization skills that initially helped to mask their learning challenges become less effective, particularly as demands on executive functioning and abstract problem solving increase. A student who was quick to master math facts in third grade may begin to struggle with quantitative concepts such as fractions, place value, and geometry. Several characteristics of NVLD are likely to impact learning in mathematics, including difficulty with whole/part relationships, poor spacing/alignment for calculations, inaccurate measurement skills, poor concepts of time, difficulty with direction, problems with mental imagery, and difficulty interpreting visually complex information in tables, graphs, or geometric designs. As overall demands on executive functioning increase, problems with organization often extend beyond the visual domain. Students with NVLD may have trouble keeping their belongings and physical space in order and may struggle with organizing their approach to complex tasks. They often have difficulty estimating and managing time as well. While fundamental spatial and motor deficits may become less impactful over time, these deficits in nonverbal problem solving and executive functioning tend to continue or even worsen in adolescence and adulthood.

In contrast to math skills, verbal skills are often intact or even above average in students with NVLD [16]. They are often excellent spellers, may have exceptional vocabularies, and frequently read aloud quite well. While their reading might be fluent, however, comprehension and interpretive skills are lacking. Particularly during the middle and high school years, comprehension requires the individual to integrate details from the text in a holistic manner. This process relies heavily on right-hemisphere functions and is crucial for high-level comprehension skills such as predicting, summarizing, inferring, and generalizing. In some cases, oral comprehension may suffer, as even students with exceptionally strong language skills may struggle to infer information that is not explicitly stated. This disparity between content and applied meaning continues in their writing, where students with NVLD often show superior vocabulary and grammar, but poor logic and progression of ideas. Parents and teachers may note that their stories or essays seem to ramble on without saying much [15].

Individuals with NVLD may ramble on in casual conversation as well. Some may be hyperverbal, relying disproportionately upon speech when interacting with others. Difficulties with reading subtle cues such as body language, facial expression, or other "unspoken" aspects of social interaction may further impact their effectiveness in social settings [16]. Some may seem absent-minded, lacking in common sense, or dismissive of social norms. With a tendency to focus on individual details rather than gestalt impressions, individuals with NVLD may take things too literally or miss the big picture of what is happening around them. Sadly, these social deficits often lead to rejection by peers. Many individuals with NVLD seem to crave social interaction, making their social isolation an especially heavy burden.

As with all learning disabilities, the challenges of NVLD do not end with a student's graduation from high school. In fact, the academic impact of NVLD may become even more apparent in college or university, where demands on executive functioning and social competency often intensify. At institutions less familiar with NVLD, students may find themselves in need of supports that are not readily available. Unfortunately, their social challenges can interfere with their effectiveness in self-advocating for such supports. Similarly, individuals entering the work force may find employers unaware or dismissive of the nonverbal deficits that impact their job performance. Day-to-day tasks such as driving or getting around, recognizing faces, joining conversations, and keeping track of responsibilities may all be impacted by NVLD. With adulthood comes the expectation that the individual will begin to navigate their world independently. Both literally and figuratively, NVLD impacts an adult's effectiveness in doing so.

Assessment of Nonverbal Learning Disabilities

Despite their significant impact on individuals' day-to-day functioning, nonverbal learning disabilities often go undetected. The challenges of identifying NVLD stem from several key factors. Unlike language-based deficits which often stand out in social or academic settings, nonverbal deficits may be less apparent and thus more easily overlooked. Parents and teachers may point to a child's strong vocabulary and oral communication skills as evidence of their intellect, and children may initially compensate quite effectively with these verbal strengths. Even in subjects such as mathematics, early skill mastery may involve largely verbal activities such as counting and math fact memorization. As a result, students tend to perform well enough to bypass special education referrals. A child's early difficulties with letter formation, telling time, or tying shoes may be attributed to other factors, such as insufficient effort or difficulty paying attention. Indeed, students with NVLD are at particular risk of being misdiagnosed with ADHD or other disorders if their underlying nonverbal deficits are unidentified or poorly understood [16].

While the nomenclature and clinical criteria for NVLD remain a source of debate, Rourke and colleagues have proposed specific criteria for assessing and identifying NVLD [14]. In general, these focus on identifying specific impairments in spatial and sensorimotor processing, discrepancies between verbal and nonverbal measures of intellectual functioning, and academic deficiencies in the area of mathematics. More recent work has highlighted executive functioning as a core feature, with associated social impairment identified in certain subtypes of NVLD (e.g., [1, 7]. Given the variability in its presentation across individuals and the risk for misidentification, a comprehensive neuropsychological or psychoeducational evaluation is critical to the assessment of NVLD. It has utility in not only establishing the presence of a nonverbal learning disability but also in clarifying an individual's particular constellation of strengths and weaknesses. A high-quality evaluation provides a clear picture of the individual's cognitive, learning, social-emotional, and adaptive challenges. Most importantly, it provides guidance toward well-tailored interventions for addressing them.

Neuropsychological evaluations for NVLD should encompass several key cognitive and academic domains. Cognitive testing should include well-validated standardized tests of intelligence, language, spatial abilities, visual-motor processing, learning/memory, attention, and executive functioning. Careful comparison of verbal and nonverbal domains is essential for identifying the profile of NVLD. For instance, intellectual assessments typically yield a significant discrepancy or "split" between verbal and perceptual indices (e.g., verbal IQ significantly higher than nonverbal/perceptual/performance IQ). Closer examination of scores often indicates intact verbal reasoning and vocabulary but difficulty on subtests involving abstract nonverbal problem solving, spatial ability, or visual-motor skills (e.g., Wechsler tests of block design, visual puzzles, Matrix Reasoning, Figure Weights, Coding). Any areas of impairment should be confirmed across multiple measures, and an individual may be asked to perform additional tasks such as matching rotated geometric designs, judging the orientation of lines, copying increasingly complex shapes, or placing irregularly shaped pegs into a pegboard. Verbal and nonverbal measures of learning and memory should also be completed since learning of spatially or visually complex information is often significantly weaker than for verbal material such as oral narratives or word lists. As such, individuals with NVLD often show a profile of relative strengths in verbal memory coupled with deficits in their ability to learn and recall geometric designs or other abstract visual information. While the profile of NVLD presents as a pattern of nonverbal deficits, tests of verbal abilities must not be neglected since they are a crucial point of comparison and assist with identifying an individual's strengths. Lastly, neuropsychological assessments of individuals with suspected NVLD should also include structured tests of attention, as well as tests of executive functioning in areas such as planning, organization, fluent retrieval, and set shifting. A clear understanding of an individual's attentional and executive functioning capacities is crucial in identifying any co-occurring challenges, but it is equally important in ensuring that attention or executive functioning difficulties are not mistaken for deficits in the nonverbal domain. This is because attention problems may disproportionately hinder an individual's performance on nonverbal tasks since these tend to require closer attention to detail or careful differentiation of multiple-choice response options. Similarly, nonverbal tasks, such as constructing spatial designs with blocks or copying complex geometric figures, place significant demands on planning and other executive functions. While nonverbal deficits and executive functioning challenges often co-occur, skilled and nuanced interpretation of test data is often crucial in discerning the presence of true nonverbal cognitive deficits warranting a diagnosis of NVLD. Tables 6.1 and 6.2 provide a summary of neuropsychological strengths and weaknesses most relevant to the assessment of NVLD, as well as tasks and instruments commonly used for assessing each domain.

Comprehensive assessments of individuals with suspected nonverbal learning disabilities should also include academic testing.

Table 6.1 Neurocognitive strengths commonly associated with nonverbal learning disabilities

Neurocognitive domain	Sample task descriptions	Selected instruments
Vocabulary and oral language	Point to pictures matching a given word; name a series of pictures; follow oral instructions; formulate sentences using a given word or words	One-word picture vocabulary test Expressive vocabulary test Peabody picture vocabulary test Clinical evaluation of language fundamentals
Verbal reasoning	Describe similarities between two objects or concepts	Wechsler similarities subtest
General knowledge	Answer factual knowledge questions	Wechsler information subtest Woodcock-Johnson general information subtest
Verbal learning and memory	Recall details of previously heard narrative passages; learn and recall a list of words presented several times	Wide range assessment of memory and learning verbal learning and story memory subtests California verbal learning test Wechsler memory scale
Auditory attention	Repeat series of numbers or words immediately after hearing them	Wechsler digit span subtest NEPSY auditory attention and response set subtest

Table 6.2 Neurocognitive weaknesses commonly associated with nonverbal learning disabilities

Neurocognitive domain	Sample task descriptions	Selected instruments
Perceptual and spatial processing	Match pictures or designs based on their visual similarity; judge the orientation of lines by selecting those that match	Judgment of line orientation Beery test of visual perception
Visual analysis and synthesis	Identify matching rotated geometric designs; select puzzle pieces that can be fit together to form a given design; identify pictures of objects cut into pieces and rearranged on the page	Wechsler visual puzzles subtest NEPSY geometric puzzles subtest Hooper visual organization test
Fine motor and eye-hand coordination	Quickly place irregularly shaped pegs into holes; trace quickly and accurately along lines or shapes with a pencil	Grooved pegboard test NEPSY-II visuomotor precision Beery motor coordination test
Visual-motor integration	Copy a series of geometric designs of increasing complexity	Beery visual-motor integration test Developmental test of visual perception
Visual-spatial construction	Re-create pictured designs using blocks; copy/draw a highly complex geometric figure in a well-planned manner	Wechsler block design subtest NEPSY block construction Rey complex figure test Stanford-Binet visual/spatial reasoning subtests
Nonverbal reasoning	Use abstract reasoning to identify the missing design in a matrix; view scales with missing "weights" and select pattern of weights to balance the scale; recognize absurdities or impossibilities in pictures of everyday situations; deduce the rules of a card-sorting game based on implicit feedback	Wechsler matrix reasoning subtest Wechsler figure weights subtest Wechsler picture completion subtest Test of nonverbal intelligence Stanford-Binet fluid reasoning subtests Wisconsin card sorting test
Abstract visual memory	Draw previously viewed geometric designs from memory; learn and recall the locations of geometric designs within a large matrix; recognize previously viewed faces among sets of distractors	Wide-range assessment of memory and learning design memory subtest Benton visual retention test NEPSY memory for designs and memory for faces subtests
Social thinking and pragmatics	View photographs of social situations and describe how characters might be feeling; describe possible solutions to everyday social dilemmas; identify facial expressions matching a given emotion	NEPSY theory of mind subtest NEPSY affect recognition subtest Test of problems solving Test of pragmatic language

Multidimensional tests of academic achievement, such as the Wechsler Individual Achievement Test and the Woodcock-Johnson Tests of Achievement, are useful for identifying any areas of impairment across the primary domains of reading, mathematics, and written expression. Even when clear spatial or nonverbal deficits are apparent in an individual's cognitive profile, academic testing is important in determining which, if any, specific learning disorders should be formally diagnosed. Broadly speaking, learning disorders are diagnosed when significant and unexpected gaps exist between the best estimate of an individual's intellectual potential and their actual achievement in a given academic domain. DSM-5 nomenclature recognizes learning disabilities in three primary domains: reading, mathematics, and written expression. As specified by the DSM-5, a diagnosis of specific learning disorder should specify all academic domains that are impaired, as well as the specific subskills affected within each domain (e.g., "With Impairment in Mathematics, namely, accurate math calculation and accurate math reasoning").

While the academic impact and Specific Learning Disorders seen in NVLD vary by individual, areas of strength and weakness are commonly recognized in both research and clinical practice. Single-word reading, spelling, and oral reading fluency typically present as intact or well developed, while individuals with NVLD often perform poorly for tests of math computation and especially abstract mathematical reasoning. It should be noted, however, that individuals with NVLD may not struggle in all areas of mathematics. For instance, some individuals with NVLD show strong computation skills while still struggling with abstract mathematical thinking in areas such as quantitative reasoning, measurement, geometry, or part-whole relationships. For this reason, multidimensional assessments of mathematics, such as the KeyMath Diagnostic Assessment, may be especially valuable in clarifying an individual's specific math competencies. Similarly, the verbally-based strengths of individuals with NVLD may not extend to all areas of reading and writing. Difficulties with inferential thinking and organization of complex information often impact higher-level written language. For this reason, tests of reading comprehension and expository writing may be an important part of the academic test battery (e.g., Test of Reading Comprehension, Nelson-Denny Reading Test, and Test of Written Language). In addition to test scores, a skilled evaluator must rely upon their observations of an individual's approach to tasks in order to develop a nuanced understanding of their academic strengths and weaknesses.

A comprehensive evaluation should also provide information about an individual's functioning in day-to-day life. In addition to clinical interviews, norm-referenced rating scales that assess a broad range of symptoms can provide a comprehensive view of the individual's social, emotional, and behavioral functioning in settings of daily life. Commonly used measures of this type include the Behavior Assessment System for Children, the Child Behavior Checklist, and the Child Symptom Inventory. In most cases, these instruments allow information to be gathered from multiple respondents, including parents or caregivers, teachers, and the individual when appropriate. These broadband assessments of emotional and behavioral functioning are especially important in ruling out developmental or emotional disorders that may co-occur with NVLD. For instance, individuals with NVLD are at particular risk for internalizing disorders, such as depression and anxiety [11]. They may also be valuable in differentiating NVLD from other disorders that produce similar clinical presentations. Social anxiety disorder and selective mutism, for example, are conditions that may confound an individual's social presentation and require careful differential diagnosis. In such cases, domain-specific rating scales allow for more nuanced interpretations of an individual's social-emotional profile (e.g., Beck Youth Inventories of Social and Emotional Impairment, Multidimensional Anxiety Scale for Children, Revised Children's Manifest Anxiety Scale, Child Depression Inventory).

The relationship between NVLD and high-functioning autism spectrum disorders requires careful consideration by any assessing clinician or provider. The overlap between NVLD and high-functioning autism has been a particular source of debate, with some theorists even describing NVLD as a "mild" form of autism. However, recent studies suggest that the social deficits seen in NVLD may be fundamentally different than those associated with autism [4]. While higher-functioning individuals on the autism spectrum do show increased incidence of nonverbal cognitive impairment relative to those without the diagnosis, there are many individuals who present with NVLD and do not show the full range of deficits and symptoms seen in autism spectrum disorders. Nonetheless, given the recognized similarities and comorbidity of the two, clinicians involved in the assessment of NVLD should also be well versed in the signs and symptoms of autism. An in-depth assessment of the individual's social functioning, developmental history, and co-occurring behaviors is especially important. Repetitive mannerisms and intense or unusual areas of interest are features that differentiate autism spectrum disorders from NVLD. Individuals who present with these concerns should also receive specialized assessments from a clinician with expertise in autism spectrum disorders.

Diagnostic Considerations

Evaluators, psychiatrists, and other professionals face a unique set of challenges in identifying and supporting individuals with nonverbal learning disabilities. As noted previously, significant controversy remains regarding its status as a distinct diagnostic entity. It is clear that features of NVLD overlap with other established neurodevelopmental disorders, including developmental coordination disorder, social (pragmatic) communication disorder, high-functioning autism spectrum disorders, and some types of specific learning disorders. On the other hand, none of these conditions count pervasive nonverbal deficits among their clinical criteria or recognize the broad range of functional challenges that are likely to stem from such deficits. As advances in research begin to bridge the gap between cognition and psychopathology, the relationships between NVLD and recognized diagnostic entities are likely to become clearer. In the meantime, individuals with the syndrome of NVLD may be best served by a blended clinical approach that identifies existing DSM-5 diagnoses most relevant to their presentation while also recognizing and supporting their profile of NVLD. Thus, in addition to identifying the "syndrome" of NVLD, a high-quality evaluation should also provide specific DSM-5 diagnoses that best characterize the individual's resulting impairment. These formal diagnoses may be critical for obtaining necessary interventions and support, particularly since awareness and acceptance of NVLD as a stand-alone label may be limited in many educational or treatment settings.

Clinical Case Study

To further illustrate principles of assessment and diagnosis as they relate to individual with NVLD, this section reviews the case of Tanya, a 10-year-old girl brought for outpatient neuropsychological evaluation by her parents due to concerns about her school performance. Results of the evaluation, summarized below, revealed a profile of nonverbal learning disability (NVLD) resulting in DSM-5 diagnoses of specific learning disorder (with impairment in mathematics and written expression) and social (pragmatic) communication disorder. Where relevant, considerations of differential diagnosis are highlighted, particularly with regard to attention-deficit/hyperactivity disorder and autism spectrum disorder.

Background Information and History

Tanya was a 10-year-old fourth grader referred for an evaluation by her pediatrician due to her parents' concerns about her school performance. Although her greatest challenges related to mathematics, she was broadly struggling to complete work in a timely manner, keep track of assignments, and follow instructions from the teacher. Teachers reported that her handwriting was often illegible and her writing assignments were difficult to follow. Although parents described her as a typically upbeat and optimistic child without notable anxiety or moodiness, Tanya had struggled to maintain her friendships in recent years and appeared increasingly lonely. Her parents expressed concern that she often "talked nonstop," and that classmates had begun to ignore or avoid her. According to her parents, Tanya hadn't always been this way. After a healthy pregnancy and birth, she had learned to talk at an early age and seemed intelligent and happy as a toddler. She had no history of significant medical issues or serious injuries. During early elementary school, she had excelled in all subjects, and teachers often commented on how clever she was. However, handwriting had been a challenge, and she received private occupational therapy in the first grade to help with her pencil grasp. Tanya's parents described her reading skills are strong but reported they were often surprised at how little she retained when reading. They suspected that Tanya was very smart and noted that she had never received any special education services, but she seemed to have a great deal of trouble getting things done. Tanya's parents hoped that an evaluation would provide some clarity surrounding her challenges, as well as specific strategies for addressing them.

Behavioral Observations

After a comprehensive interview with her parents, Tanya was seen for testing on two separate occasions. She presented to these appointments as a friendly child with bright affect, who showed clear enjoyment in interacting with the examiner and was cooperative with all tasks. Despite her friendly demeanor, she showed difficulties with some aspects of social interaction. Her eye contact was not always well coordinated during conversations, and she had difficulty with turn-taking such that she tended to talk excessively without responding to the examiner's attempts at directing the conversation. At times, she appeared to have difficulty interpreting sarcasm or figures of speech. Her vocabulary and communication skills appeared otherwise well developed, aside from mild articulation weaknesses impacting her pronunciation or /r/ and /l/ phonemes. Tanya appeared physically uncoordinated and on one occasion knocked a small figurine from the examiner's desk as she gestured during conversation. Tanya's attention was appropriate in the one-on-one session, and she was not impulsive, but she sometimes asked for repetition of more complex instructions. At times, she appeared overly concerned that she would complete the task incorrectly and often sought reassurance from the examiner.

Test Results and Interpretation

The following tests were administered and are felt to be a valid reflection of Tanya's functioning:

- Wechsler Intelligence Scale for Children (WISC-V)
- Wechsler Individual Achievement Test (WIAT-III)
- Beery-Buktenica Developmental Test of Visual-Motor Integration (VMI-6)
- Expressive One-Word Picture Vocabulary Test (EOWPVT)
- Grooved Pegboard Test, NEPSY-II Selected Subtests, Hooper Visual Organization Test, and Wide Range Assessment of Memory and Learning (WRAML2)
- Delis-Kaplan Executive Functioning System (D-KEFS), Trail Making and Verbal Fluency Subtests
- Rey Complex Figure Test (RCFT)
- Behavior Assessment System for Children (BASC-3)
- Behavior Rating Inventory of Executive Function (BRIEF-2) and Social Responsiveness Scale (SRS-2)

Intellectual Functioning Tanya's intellectual functioning was assessed with the WISC-V. She showed significant differences between index scores, indicating that her performance was variable across domains. Her verbal abilities fell in the average range overall. However, her performance for tests involving nonverbal abilities was significantly weaker, with her nonverbal fluid reasoning and visual-spatial indices both falling in the borderline range for age. Regarding other fundamental processing abilities, Tanya's processing speed ranged from low average to average when performing visual-motor tasks under time constraints, while her performance was average overall for tests of working memory that required her to hold/manipulate information in immediate awareness. Due to significant discrepancies across domains, Tanya's Full Scale IQ was deemed an invalid summary of her intellectual potential. Because it is not impacted by her nonverbal and processing challenges, her average verbal comprehension index of 98 was determined to be the best estimate of her true intellectual potential. The gap between Tanya's verbal and nonverbal abilities was consistent with a profile of NVLD, but follow-up assessment of these suspected nonverbal weaknesses will be discussed further below.

Intellectual functioning

WISC-V composite scores	**Standard**	**Percentile**	**Description**
Verbal comprehension	109	73	Average
Visual spatial	84	14	Low average
Fluid reasoning	72	3	Borderline
Working memory	100	50	Average
Processing speed	84	14	Low average
Full scale IQ	*N/A*	*N/A*	*Invalid due to variable domains*
WISC-V subtests	**Scaled**	**Percentile**	**Description**
Similarities	11	63	Average
Vocabulary	12	75	Average
Block design	7	16	Low average
Visual puzzles	7	16	Low average
Matrix reasoning	5	5	Borderline
Figure weights	5	5	Borderline
(Picture concepts)	10	50	Average
Digit span	10	50	Average
Picture span	10	50	Average
Coding	6	9	Average
Symbol search	7	16	Average

Academic Achievement Tanya was administered selected subtests of the Wechsler Individual Achievement Test, Third Edition (WIAT-III). As shown below, her performance was average across tests of single-word reading/decoding, spelling, and oral reading fluency. However, she performed well below expectations for her age and intellect in all areas of mathematics, with impaired to borderline scores for tests of math fact fluency, math computation, and math problem solving skills. The examiner noted that Tanya had particular difficulty with test items involving three-digit subtraction, simple division, interpretation of charts or calendars, monetary value, and part-whole relationships.

Academic achievement

WIAT-III reading	**Standard**	**Percentile**	**Description**
Basic reading composite	104	61	Average
Word reading	108	70	Average
Pseudoword decoding	102	55	Average
Oral reading fluency	105	63	Average
Oral reading accuracy	105	63	Average
Oral reading rate	106	66	Average
WIAT-III mathematics	**Standard**	**Percentile**	**Description**
Mathematics composite[a]	74[a]	4	Borderline
Math problem solving[a]	75[a]	5	Borderline
Numerical operations[a]	74[a]	4	Borderline
Math fluency composite	66	1	Impaired
Math fluency – addition	75	5	Borderline
Math fluency – subtraction	57	<1	Impaired
Math fluency – multiplication	70	2	Borderline
WIAT-III written expression	**Standard**	**Percentile**	**Description**
Spelling	96	39	Average

[a] Tanya's WISC-V Verbal Comprehension Index score of 109 ($p < .05$)

Language Functioning As shown above on the WISC-V, Tanya's performance was average for Verbal Comprehension subtests that required her to describe similarities between two objects or concepts and provide oral definitions to words. On the Expressive One-Word Picture Vocabulary Test, her performance was high average when naming a series of pictured objects or actions, indicating strengths in her single-word vocabulary (Standard Score = 118, 88th percentile).

Nonverbal Reasoning Abilities Tanya scored in the borderline range for WISC-V tests of Fluid Reasoning that required her to solve abstract visual patterns (Matrix Reasoning) and deduce conceptual relationships between visual symbols (Figure Weights). Her performance was average for another nonverbal reasoning task that required her to match pictures of everyday objects based on their conceptual similarities (Picture Concepts). The latter subtest involves more concrete stimuli that can be easily verbalized, and the examiner noted that Tanya showed a tendency to verbalize her thought process aloud while solving these problems. This strategy is common among individuals with NVLD, who often seek to access to language-based processing abilities to assist with their problem solving. Through careful observation of Tanya's performance, the examiner determined that Tanya's errors on the Matrix Reasoning and Figure Weights subtest were not an artifact of inattention or impulsivity, since she often took a great deal of time considering response-options.

Spatial Abilities As shown above on Visual Spatial subtests of the WISC-V, Tanya's performance was low average for tasks requiring her to identify shapes that could be fit together to form a given design and copy designs with blocks. During the latter subtest, the examiner noted that Tanya worked slowly and carefully, but errors in the orientation of individual blocks were suggestive of spatial deficits. Additional tests were administered to provide more focal assessments of Tanya's spatial abilities without confounding executive function demands. Providing further evidence of true spatial impairment, Tanya performed below age-based expectations across tasks requiring her to identify matching or rotated geometric shapes and anticipate the targets of arrows oriented in a spatial array (NEPSY-II Scaled Scores: Geometric Puzzles = 7, 16th percentile; Arrows = 6, 9th percentile). Tanya also had difficulty with another spatially demanding task that required her to identify pictures of objects cut into pieces and rearranged on the page (Hooper = 8th percentile). Her difficulty on the latter task may also reflect difficulty integrating details to process them in a holistic manner.

Fine Motor and Visual-Motor Processing When placing irregularly shaped pegs into a pegboard, Tanya's fine motor speed/dexterity scored in the borderline range for both her right/dominant and left/nondominant hands (9th and 3rd percentiles, respectively). She scored in the impaired range on the VMI, a paper-and-pencil test that required her to copy a series of geometric designs (Standard Score = 68, 2nd percentile). Consistent with previously noted spatial deficits, Tanya's drawings of several complex designs were significantly distorted relative to the originals. Her right-handed pencil grasp was immature, and her handwriting was difficult to decipher. As noted by the examiner, Tanya's difficulties with letter formation and letter/word spacing exceeded those typically seen in children with ADHD-related deficits in attention, impulse-control, or planning.

Learning and Memory Tanya's memory for verbal information was assessed using the Verbal Learning subtest of the WRAML2, where she was asked to learn a list of words presented across four trials. Her performance was average when learning and immediately recalling the words across the four trials, as was her recall of the list 20 min later. Consistent with previously noted deficits in the nonverbal domain, Tanya had severe difficulty processing and learning visual information on the Rey Complex Figure Test. Her performance was impaired when copying the figure as she viewed it (<1st percentile), as were her scores when drawing the figure from memory 30 min later and subsequently recognizing its details in yes/no format.

Attention and Executive Functions Tanya's performance was variable for tests of executive functioning, with deficits in multiple domains. Her performance was average when rapidly sequencing information by connecting numbered dots on a page (D-KEFS Number Sequencing = 50th percentile). However, she had difficulty when asked to shift sets in order to connect numbered and lettered dots in alternating sequence (Number-Letter Sequencing: Speed = 1st percentile; Accuracy = 16th percentile). Her performance was variable for timed tests of verbal fluency, falling in the average when naming words of a given category (37th percentile) but in the impaired to borderline range for more executively demanding retrieval tasks that required her to name words of alternating categories (5th percentile) and name words starting with a given first letter (1st percentile). As noted above, Tanya had severe difficulty on a task that required her to plan and organize her approach to copying a complex geometric figure (Rey Complex Figure Test = < 1st percentile). She used a poorly planned and disorganized approach to copying the figure, and her drawing of the figure was also spatially distorted relative to the original. The latter subtest can be especially valuable in identifying underlying spatial impairment. While individuals with executive functioning challenges often have difficulty appreciating the figure's overall structure and copying it in a well-planned manner, those with NVLD show more severe distortion of the figure's spatial properties. In Tanya's case, details of the figure were copied in a piecemeal fashion and haphazardly arranged on the page, suggesting more fundamental spatial deficits in addition to her executive functioning weaknesses. Tanya's symptoms of inattention and hyperactivity/impulsivity in daily life were assessed via parent, teacher, and self-report versions of the BASC-3. Parent and self-report ratings fell within normal limits, and teacher ratings were significant for mildly elevated attention problems in the subclinical range. Tanya's executive functioning in daily life was assessed with parent and teacher report ratings on the BRIEF, which indicated significant executive functioning problems impacting her ability to initiate tasks, plan/organize her approach to problem solving, monitor her performance on tasks, and self-monitor her own behavior. While results indicated significant executive functioning challenges, which are common in both ADHD and NVLD, careful review of Tanya's test performance and day-to-day functioning did not indicate more fundamental attention deficits consistent with ADHD.

Emotional, Behavioral, and Social Functioning Tanya's mother and general education teachers also provided ratings of her emotional, behavioral, and social functioning on the BASC-3. Ratings by Tanya's mother yielded a clinically significant elevation on a scale assessing social withdrawal, as well as a subclinical or at-risk elevation for a scale assessing depressive symptoms. Tanya's mother also reported moderate weaknesses in her social skills and her independence with daily activities. On the teacher-report BASC-3, Tanya's fourth grade teacher rated her as showing significant learning problems, as well as subclinical levels of behavior/conduct problems and social withdrawal falling in the at-risk range. Tanya's teacher also reported significant deficits in her functional communication, social skills, and study skills. Tanya provided ratings of her own thoughts, feelings, and behaviors on the self-report version of the BASC-3, where she reported clinically significant for problems with her interpersonal relationships as well as subclinical symptoms of both anxiety and depressed mood.

Given the overlap of social challenges seen in both NVLD and autism spectrum disorder, detailed assessment of Tanya's social functioning was essential. In addition to comprehensive developmental interviews, Tanya's mother and teacher provided ratings of her functioning on the SRS-2, which specifically examines social and behavioral concerns associated with autism spectrum disorders. Although moderate concerns were evident in some areas of social cognition and awareness, SRS-2 results did not indicate clinically significant social and behavioral concerns consistent with an autism spectrum disorder.

Further, careful review of Tanya's history did not provide any evidence of repetitive speech or motor mannerisms, restricted interests, or intense preoccupations. These defining features of autism are useful in differentiating it from NVLD and other neurodevelopmental disorders.

Summary and Recommendations

Results of the evaluation revealed several key findings. Despite her solid verbal intelligence and well-developed language skills, Tanya showed a profile of nonverbal deficits suggestive of dysfunction in the right hemisphere of the brain often referred to as a "Nonverbal Learning Disorder" (NVLD). As seen through interviews, observations, and standardized test performance, her nonverbal deficits impacted her ability to (1) process spatially complex information, (2) perform visual-motor tasks such as writing or drawing, (3) learn information that is presented visually, (4) use abstract problem solving in subjects such as mathematics, and (5) process "unspoken" aspects of daily life such as social cues and subtle inferences. Like many children with NVLD, Tanya also presented with executive functioning deficits impacting her ability to complete tasks in an organized, well-planned, and flexible manner. However, results of cognitive testing and symptom rating scales did not reveal more fundamental attention deficits seen in ADHD. Tanya's combination of cognitive deficits was significantly impacting her academic progress, warranting formal DSM-5 diagnosis of a specific learning disorder, with impairment in mathematics and written Expression (DSM-5 Codes 315.1 and 315.2). Tanya's social and emotional adjustments were additional areas of concern. Like many individuals with NVLD, she showed difficulties with social skills. Although she did not exhibit the full constellation of social-communication deficits, repetitive behaviors, or restricted interests seen in autism spectrum disorders, her social deficits were significant enough to constitute a social (pragmatic) communication disorder (DSM-5 Code 315.39). Tanya's social challenges were contributing to feelings of anxiety and sadness, which did not meet the threshold for clinical diagnosis of an affective disorder but were flagged for close monitoring.

Evidence-Based Interventions and Support for NVLD

In the case of Tanya described above, comprehensive neuropsychological assessment provided a detailed profile of her strengths/weaknesses, assisted with differential diagnosis, and helped to identify targets for treatment and support. Recommendations were outlined in the evaluation report and, most importantly, communicated clearly to Tanya's parents and school. From an educational standpoint, it was recommended that Tanya receive special education services for her specific learning disorders and social communication disorder. Briefly, these included (1) full-time remedial instruction in mathematics geared to her current level of achievement, (2) weekly social pragmatics training, (3) weekly occupational therapy, and (4) accommodations for her nonverbal and executive functioning deficits integrated throughout her curriculum. At the request of her parents, the neuropsychologist participated in Tanya's special education eligibility meeting, which found her eligible for services under an individualized education program (IEP). In addition to school-based programming, it was recommended that Tanya participate in an after-school social skills group and receive weekly individual psychotherapy to bolster her coping. Tanya's parents were also provided with the names of executive functioning coaches and academic tutors who could be sources of additional support if needed in the years ahead. Finally, a follow-up assessment in 18–24 months was recommended to track Tanya's progress and provide updated recommendations based on changing developmental and academic demands.

Like Tanya, many children with NVLD require interventions and support from multiple providers across several domains of life. While research on the effectiveness of treatments for NVLD is only just emerging, those highlighted below reflect current best practices (for a more detailed review, see [1]).

For children and adolescents with NVLD, school-based programming is often the cornerstone of an effective support plan. School is the primary setting for learning and social interactions with peers, both of which can be challenging for a child or adolescent with NVLD. For students who qualify, a formal special education plan (known as an individualized education program or IEP) is recommended. This plan should include specific goals and benchmarks addressing key areas of difficulty, including any specific academic delays, perceptual or sensorimotor deficits, social-communication challenges, executive functioning problems, and co-occurring emotional vulnerabilities. Although they vary based on individual needs, commonly recommended services for students with NVLD include (1) remedial instruction in mathematics and sometimes in aspects of reading or written expression; (2) additional paraprofessional or aide support when needed to ensure access to the general curriculum; (3) occupational therapy to address perceptual, motor, or sensory problems; (4) social skills training or speech/language therapy focused on pragmatics; and (5) additional instruction in executive functioning strategies such as organization, time management, and planning. The IEP also specifies any modifications or accommodations to be implemented across the student's curriculum, such as access to extended time, reduced workload, course substitutions, modification of visually intensive material, assistance with note-taking, access to typing or assistive technology, and support for organization or other executive functions.

Broadly speaking, students with NVLD learn by hearing, not by seeing. Those working with them may do well to imagine themselves as sportscasters providing a running narrative, as if to listeners who are unable to see the action for themselves. Lengthy or step-by-step verbal narratives that may be tiring or redundant to most students can be especially helpful to those with NVLD. Engaging the student in these narratives is also important, so that they may eventually develop their own internal "self-talk" to compensate in challenging situations (e.g., when approaching novel tasks, confronting complex visual information, or integrating details to draw inferences about the big picture). Particularly in subjects such as mathematics, educators must be keenly aware of a student's spatial or perceptual limitations. For instance, typical multisensory approaches to math emphasize visual material and thus are not best practice for students with NVLD. By contrast, effective math instruction involves reducing, eliminating, or narrating visual elements. It depends heavily upon concrete physical manipulatives, as well as the student's development of an explicit math vocabulary to be used in accessing the material [10]. Modifications and support for nonverbal deficits must also extend beyond mathematics to include subjects such as physics, chemistry, or geography. Despite strong language fundamentals, students with NVLD often require additional instruction to develop higher-level reading or writing skills such as summarization, note-taking, story structuring, and prewriting strategies [9]. Effectiveness in remediating these concerns also depends upon an understanding of the student's nonverbal limitations, since commonly used techniques such as graphic organizers may be inappropriate.

Given the broad impact of NVLD on the individual's functioning in day-to-day life, effective treatment programs often extend beyond the educational realm. Occupational therapy may be helpful in providing more targeted interventions for perceptual, motor, or sensory difficulties, as well as strategies for addressing their impact in day-to-day life. Training in social skills may be especially beneficial and can be access via participation in a social skills group treatment, individual therapy, or speech/language therapy focused on social pragmatics. In some cases, family-based approaches may be important to assist parents with understanding and supporting a child or adolescent at home. The lack of awareness and support for NVLD-related challenges creates disproportionate demand for parental involvement, as well as the possibility for stifled progress toward adult independence. There is growing recognition that intervention and support must extend beyond adolescence and into early adulthood [2]. Particularly during the transition to adulthood, the support of a therapist or coach may be critical in facilitating independence across educational, career, social, and community settings [2]. Whether a distinct diagnostic entity or a cognitive profile in need of support, nonverbal learning disability presents significant difficulties that span multiple domains of day-to-day life. Comprehensive assessments are crucial in identifying those impacted by it, as well as implementing treatments and support strategies that will help them reach their full potential.

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Intellectual Disabilities

Brian L. B. Willoughby

Per the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disabilities are "characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills" [1]. An intellectual disability is defined as an intelligence quotient (IQ) of approximately 70 or below based on one or more standardized intelligence tests. However, intellectual functioning alone is not sufficient to classify an individual as having an intellectual disability. Significant deficits in adaptive functioning (i.e., the skills necessary for daily living, such as self-care) must also be present. Further, the disability must originate before 18 years of age. This definition of an intellectual disability is generally consistent across different diagnostic classification systems, including the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) and *International Classification of Diseases* (ICD). These classification systems also specify severity levels with regard to the intellectual disability. Mild severity is characterized with an IQ between 50 and 70, moderate is between 35 and 49, severe is between 20 and 34, and profound is less than 20. In reviewing intellectual disabilities, this chapter focuses on the following: (1) a brief review of current research; (2) clinical symptoms of an intellectual disability; (3) a description of common evaluation procedures used to assess for the disability; (4) special considerations when assessing for intellectual disability; (5) two case illustrations to highlight differences in assessment procedures, diagnosis, and recommendations based on a child's age; and (6) a review of school-based and outpatient treatments available.

Brief Review of Current Research

Numerous research studies have focused on the classification, epidemiology, and causes of intellectual disabilities. First, there has been substantial debate about the label or "term" to describe individuals with intellectual impairment. Terminology for what is currently referred to as an intellectual disability has varied historically. Over the last two centuries, terms have included idiocy, feeblemindedness, mental deficiency, mental disability, mental subnormality, mental handicap, and, more recently, mental retardation [11]. The term intellectual disability has become increasingly popular over the past decade and has replaced the now outdated term mental retardation. Intellectual disability covers the same population of individuals diagnosed previously with

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mental retardation and has the same incidence, prevalence, severity, and duration. This recent shift from mental retardation to intellectual disability is thought to be less offensive and stigmatizing to persons with disabilities, is more aligned with international terminology, and reflects language currently used in DSM-5 [11].

Epidemiological studies have emerged to elucidate the prevalence of intellectual disabilities. Using a criterion of an IQ below 70 and impaired adaptive behavior, the overall prevalence of intellectual disability is between 1% and 3% globally [3, 5]. Of those individuals with intellectual disabilities, mild, moderate, severe, and profound intellectual deficits affect about 85%, 10%, 4%, and 2% of the population, respectively [6]. A recent meta-analysis examining the prevalence of intellectual disabilities collated data from studies published between 1980 and 2009. The average prevalence of intellectual disability across all 52 studies included in the meta-analysis was 1.37%. The estimates varied by income group of the country of origin, the age group of the study population, and study design. The highest rates were seen in low- and middle-income countries. Prevalence was higher among studies based on children/adolescents, compared to those based on adults [8]. Multiple causes of intellectual disabilities have been identified and can be loosely organized into five general categories: (1) chromosomal abnormalities (e.g., Down syndrome, fragile X), (2) metabolic disorders (e.g., phenylketonuria), (3) embryonic teratogen exposure (e.g., maternal substance abuse), (4) complications during delivery (e.g., preterm birth), and (5) childhood illness or injury (e.g., encephalitis).

Clinical Symptoms of Intellectual Disabilities

As noted above, intellectual disabilities are characterized by substantial limitations in intellectual functioning and adaptive behavior, namely, communication, social, and practical skills. For the purposes of this chapter, we will focus on the clinical symptoms of intellectual disability as defined by DSM-5 [2].

First, the individual must demonstrate deficits in intellectual functioning. This includes impairment in various mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience (i.e., the ability to learn through practice, trial and error, and observation). Both clinical assessment and standardized intelligence testing must confirm these deficits. An IQ score approximately two standard deviations below average represents a significant cognitive deficit. This is typically an IQ score of 70 or below. In DSM-5, there was a shift from previous editions in that an absolute cutoff of 70 was no longer required to meet criteria. That is, due to accounting for measurement error, an IQ score in the range of 65–75 could indicate an intellectual disability.

Second, the individual must show deficits in adaptive functioning, which result in failure to live independently and responsibly [2]. More specifically, the individual must have a skills deficit in one or more activities of daily life. One activity of daily life that is commonly impaired in individuals with intellectual disabilities is communication. Communication refers to the ability to both convey information to others and comprehend information that is presented in day-to-day life. Additionally, social skills are frequently impaired. Social skills are critical to interact effectively with others and include the ability to understand and comply with social rules, customs, and standards of public behavior. A final adaptive area that is impaired in individuals with intellectual disabilities is practical skills. Practical skills include self-care, such as bathing, dressing, and feeding. It also includes being able to safely complete daily tasks (e.g., cleaning, cooking) and routine activities performed in the community (e.g., grocery shopping, utilizing public transit). These communication, social, and/or practical skills deficits must be seen across multiple environments, such as at home, school, and community settings [2].

To meet criteria for an intellectual disability, the clinical symptoms must be developmental in nature. That is, the symptoms must onset within a particular period of development, namely, in childhood or adolescence. If these problems began after this developmental period, other diagnostic labels would be more appropriate, such as a neurocognitive disorder. For example, a traumatic brain injury from a car accident in adulthood could cause similar symptoms but would be classified elsewhere in DSM-5.

The clinical symptoms of an intellectual disability may differ with regard to severity, ranging from mild to profound. Mild severity is characterized with an IQ between 50 and 70. Mild intellectual disabilities are less obvious and may not be identified until children begin school. Individuals with mild intellectual impairment are capable of attaining academic skills up to a sixth-grade level, and many learn self-care and practical skills, such as cooking for oneself or using the bus or subway. Further, as individuals with mild intellectual disability reach adulthood, many can live fairly independently and maintain employment. Moderate severity is indicated in individuals with IQ scores between 35 and 49. Moderate intellectual impairment is nearly always notable within the 1st years of life, and individuals with this level of severity need considerable supports in school, at home, and in the community to participate fully. Although academic potential may be limited, many can learn simple health and safety skills and to participate in simple activities. As adults, individuals with moderate intellectual disabilities are unable to live independently and need significant supports to help manage daily demands (e.g., shopping, banking). Individuals with severe (IQ scores between 20 and 34) or profound (IQ less than 20) intellectual disabilities require more intensive support and supervision across all domains of day-to-day living. Those with severe or profound intellectual deficits require full-time care by an attendant or caregiver throughout the lifespan.

Assessment of Intellectual Disabilities

Assessing for intellectual disabilities involves several critical components. These components include obtaining a comprehensive developmental history, documenting behavioral observations made during the evaluation, and using standardized assessment tools and questionnaires. More specifically, assessing for intellectual disabilities, including measures of *intelligence* (verbal and nonverbal) and *adaptive functioning*, is essential. In addition, it is often important to assess for some of the common difficulties that co-occur with intellectual disabilities, such as social-emotional concerns. The age of the individual will also guide assessment procedures. The components of an intellectual disabilities assessment are detailed below.

Comprehensive Clinical History

A comprehensive history is a critical part of the assessment for an intellectual disability. It is typical to rely on caregiver report (e.g., parents, guardian) to obtain information regarding the details of conception, pregnancy, delivery, perinatal health, lead exposure, developmental milestones, medical history, and family history. Further, the evaluator should obtain additional details regarding family composition, parental education and employment, family dynamics and discipline practices, exposure to traumatic events, and current living situation. Attention should be given to current symptoms, functional level, and previous/current interventions. Evaluators should also inquire about the involvement of other providers/disciplines, such as neurology, genetics, or endocrinology.

Behavioral Observations

Behavioral observations are also essential components of the evaluation process. These observations should include informal assessment of an individual's behavior throughout the testing and in different contexts (e.g., in the waiting room, when interviewing parent). These observations can serve to provide invaluable information about an individual's developmental trajectory, social abilities, temperament, motor functioning, communication, attachment, and play skills and overall functional level. Evaluators should take note of affect, ability to separate from parents/caregivers, eye contact, gross and fine motor skills, receptive and expressive language, social reciprocity (e.g., social smiling), attention, activity level, and behavioral regulation. Particular attention should be given to the presence of dysmorphic features, such as hypertelorism. Further, based on observations and parent/caregiver feedback during the evaluation, evaluators should be able to determine whether the assessment was a valid representation of an individual's abilities. For instance, if behavior dysregulation and noncompliance interfered with testing procedures, the evaluator might note that testing scores may underestimate an individual's true/underlying abilities.

Standardized Assessment

Standardized assessment of *intelligence* and *adaptive functioning* is critical when evaluating for intellectual disabilities. In North America, the most commonly used intelligence tests include the Wechsler Scales of Intelligence (i.e., WPPSI-IV, WISC-V, WAIS-IV). The specific version of the test differs depending on the age of the individual. Other common intelligence tests include the Stanford-Binet Intelligence Scales, Fifth Edition (SB-5), Woodcock-Johnson Tests of Cognitive Abilities, Fourth Edition (WJ-IV), and Differential Ability Scales, Second Edition (DAS-II). These intelligence tests measure similar constructs, including verbal abilities (i.e., vocabulary and general factual knowledge) and nonverbal abilities (i.e., pattern recognition, spatial abilities, and problem solving). Further, measures of cognitive efficiency are often included in intelligence tests, such as working memory (i.e., ability to mentally manipulate information) and processing speed (i.e., rate of information processing). Performance on these measures yields an intelligent quotient (IQ), which is a composite or "total score" representing an individual's intellect (mean intellect is a standard score of 100 and standard deviation of 15). As noted above, an intellectual disability is defined as an intelligence quotient (IQ) of approximately 70 or below based on one or more standardized intelligence tests. See Table 7.1 for a detailed list of the most commonly used intelligence scales.

An IQ below 70 by itself is not enough to classify an individual as having an intellectual disability. Substantial impairments in adaptive functioning must also be present. Again, adaptive skills refer to those abilities necessary for day-to-day living. These include conceptual skills (e.g., communication), practical skills (e.g., dressing, toileting), and socialization (e.g., responding to others). Adaptive skills of children and adults are typically evaluated via parent or caregiver report on standardized questionnaires. Two commonly used measures include the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3; interview or caregiver report versions) and the Adaptive Behavior Assessment System, Third Edition (ABAS-3; caregiver report and teacher report versions). Examples of questions include items such as: "Is he/she able to get dressed without assistance?" "Can he/she make correct change?" "Is he/she able to recite his/her telephone number when asked?" Ratings are provided using Likert-type scales, ranging from "never/not able" to "always." These questionnaires yield standard scores and percentiles to help determine the adaptive skills of an individual in the conceptual, social, and practical domains.

Recently, there has also been a move toward using more ecologically valid and performance-based assessments of adaptive functioning. That is, rather than rely on caregiver ratings of adaptive skills, evaluators may choose to directly observe and rate during the assessment. For example, the Texas Functional Living Scale (TFLS) allows evaluators to directly observe and measure an individual's abilities by assigning them tasks to complete in a contrived setting. These tasks provide information in the following adaptive domains: time (e.g., ability to use clocks/calendars), money and calculation (e.g., ability to count money and balance a budget), communication (e.g., ability to make a snack), and memory (e.g., ability to remember to take medications).

Table 7.1 Commonly used intelligence tests

	Publication date	Age range (years)	Composite score	Core domains assessed
Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition (WPPSI-IV)	2012	2:6–7:7	Full Scale IQ (FSIQ)	Verbal comprehension Fluid reasoning Visual spatial Working memory Processing speed
Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V)	2014	6–16	Full Scale IQ (FSIQ)	Verbal comprehension Fluid reasoning Visual spatial Working memory Processing speed
Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV)	2008	16–90+	Full Scale IQ (FSIQ)	Verbal comprehension Perceptual reasoning Working memory Processing speed
Kaufman Assessment Battery for Children, Second Edition (KABC-II)	2004	3–18	Fluid-Crystalized Index Mental Processing Index	Planning Knowledge Simultaneous Learning Sequential
Stanford-Binet Intelligence Scales, Fifth Edition (SB-5)	2003	2–85+	Full Scale IQ (FSIQ)	Quantitative reasoning Knowledge Visual-spatial processing Fluid reasoning Working memory
Differential Ability Scales, Second Edition (DAS-II)	2007	2–17	General Conceptual Ability (GCA)	Verbal ability Nonverbal ability Spatial ability Working memory Processing speed
Woodcock-Johnson Tests of Cognitive Ability, Fourth Edition (WJ-IV)	2014	2–90+	General Intellectual Ability (GAI)	Comprehension-knowledge Fluid reasoning Short-term memory Long-term retrieval Visual processing Auditory processing Processing speed
Cognitive Assessment System, Second Edition (CAS2)	2014	5–18	Full Scale (FS)	Simultaneous Planning Attention Successive

Developmental Considerations in the Assessment of Intellectual Disabilities

An individual's age is a critical factor to consider in the assessment and diagnosis of an intellectual disability. As noted above, an individual's age guides test selection. Some standardized intelligence tests can only be used for a specific age range, such as the WISC-V, which can be administered to children 6–16 years old. Other tests, such as the Stanford-Binet Intelligence Scales, Fifth Edition (SB-5), can be administered to individuals ages 2–90 and above. It is difficult to obtain a stable and reliable intelligence quotient for infants and toddlers. There are some tests that can be administered to very young children. Two most common examples are the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III; ages 1–42 months), and the Mullen

Scales of Early Learning (ages birth to 68 months). However, these instruments are considered measures of a child's cognitive, language, motor, and social development rather than intelligence per se. Therefore, for children below the age of 5, the diagnosis of Global Developmental Delay (GDD) may be used (versus intellectual disability) until a child is old enough for a reliable and valid assessment of "intelligence" [13].

GDD was formally included in the most recent edition of the *Diagnostic and Statistical Manual* (DSM), though it has long been included in the research literature and other classification systems (e.g., ICD). It is characterized by significant delays in two or more of the following domains: (1) speech/language skills, (2) fine/gross motor skills, (3) social/personal skills, and (4) daily living skills. It is estimated that between 1% and 3% of infants and toddlers have GDD [12]. However, it is not completely clear how many children with GDD will eventually meet criteria for intellectual disability later in development. Many clinicians and researchers view GDD as a "placeholder" diagnosis for children too young for an intellectual disability diagnosis [12]. However, longitudinal and retrospective studies indicate that perhaps only a minority of children with GDD go on to have an intelligence score below 70. For instance, in a retrospective study of children with significant early language and motor delays (i.e., children meeting criteria for GDD), only 27% had an IQ below 70 on standardized testing at age 3 [10]. The severity of the early delays, age of the child, and number of developmental domains impacted have some predictive power in terms of a later diagnosis of intellectual disability. For instance, a 16-month-old child with a mild language delay would be less of a concern compared to a 26-month-old child with significant delays across language, motor, and social development.

Assessment of Intellect in Nonverbal Individuals

Evaluators of children with developmental disabilities often face the challenge of assessing intellect in nonverbal or minimally verbal individuals. A primary symptom of many neurodevelopmental conditions is a delay in communication skills. A significant delay in language may confound the results of standardized testing because many tests rely on language abilities, such as understanding the directions of a test or verbally expressing answers. Therefore, in nonverbal or minimally verbal individuals, the assessment of intelligence must often use both *standardized procedures* and *nonstandardized procedures* [9]. Standardized procedures include the use of norm-referenced tests specifically assessing nonverbal intelligence (i.e., the ability to analyze information, solve visual problems, and recognize visual patterns without relying on language skills). Many intelligence tests include measures of verbal and nonverbal intelligence (e.g., the Wechsler Intelligence Scales), and, therefore, the nonverbal elements of these instruments can be administered. As examples, nonverbal intelligence subtests may require an individual to identify (by pointing) the next picture in a sequence (e.g., Matrix Reasoning on the WISC-V and WAIS-IV) or put blocks together to reflect specific designs (e.g., Block Design/Pattern Construction on the WISC-V and DAS-II, respectively). It is of note, however, that many "nonverbal" tests of intelligence still rely on a language component since instructions are often presented verbally (e.g., "Which of these five pictures should go next in this pattern?"). To address this issue, several tests have been designed to eliminate the need for verbal instructions and are presented entirely without language, such as pointing or using facial expressions to instruct examinees. Examples of these purely nonverbal intelligence tests include the Leiter International Performance Scale, Second Edition (Leiter), Test of Nonverbal Intelligence, Fourth Edition (TONI-4), and Comprehensive Test of Nonverbal Intelligence, Second Edition (CTONI-2).

In addition to standardized procedures, nonstandardized assessment procedures may also be especially helpful in assessing the skills of nonverbal individuals. Nonstandardized procedures go beyond the explicit guidelines of the test to qualitatively observe what an individual can do with support, such as prompting, modeling, or repetition. This nonstandardized method of assessment can provide invaluable information regarding the supports necessary for an individual to “show” their true intelligence. For example, a minimally verbal child with an autism spectrum disorder (ASD) may be initially confused by verbal or nonverbal instruction, less motivated to please the evaluator, internally distracted, or overwhelmed and anxious about the testing situation. These difficulties may necessitate nonstandardized assessment procedures, such as using hand-over-hand demonstration of pointing to response options, providing external reinforcements (e.g., edible reward following correct response), or repeating a test item. While evaluators must then be cautious about comparing facilitated performance to the (non-facilitated) norm-reference group, nonstandardized assessment can yield critical information regarding an individual’s true potential with specific supports in place.

Comorbidity

Intellectual disabilities have several clinical comorbidities, many of which may require additional assessment and subsequent treatment. It is well established that individuals with intellectual disabilities have a greater risk of psychiatric disorders compared to those with intelligence in the normal range (e.g., [4]). Some studies have indicated the prevalence of a co-occurring psychiatric disorder is as high as 41% [7]. The most common comorbid psychiatric disorders include problem behavior, mood disorders, attention problems, autism spectrum disorders, psychotic disorders, and anxiety disorders. These common comorbidities should be the focus of clinical assessment using interview and standardized assessment tools when available. Norm-referenced parent and teacher questionnaires, such as the Behavior Assessment System for Children, Third Edition (BASC-3), may be particularly helpful. Further, standardized measures of attention (e.g., Test of Everyday Attention for Children, TEA-Ch) may be useful, as well as assessment tools to rule out the presence of an autism spectrum disorder (e.g., Autism Diagnostic Observation Schedule, Second Edition, ADOS-2). Given that intellectual disabilities are prevalent in many known developmental and genetic conditions, further medical assessment may be necessary. For instance, if an underlying medical cause is suspected (e.g., based on dysmorphic features or congenital defects), referral to a geneticist is paramount.

Clinical Case Examples

Two clinical case examples (Jessica, age 2, and Carlos, age 14) are presented to (1) demonstrate the utility of a formal assessment to support diagnostic decisions and treatment recommendations in children with intellectual disabilities and (2) highlight the differences in assessment procedures, diagnosis, and recommendations based on a child’s age. See Table 7.2, which summarizes the differences in assessment procedures for these two case examples.

Jessica (Age 2)

Background Information and History Jessica was a 2-year and 3-month-old (27 month) girl referred for a neuropsychological evaluation by her pediatrician due to multiple developmental concerns, including a speech/language delay and motor delay in the context of prematurity. Jessica was born at 28 weeks and required a 3-month hospital stay secondary to marked prematurity and respiratory problems. Jessica’s development was quite delayed, as per parent report. Language was reportedly slow to progress. Her mother indicated she was saying approximately 20 words, though these were not used consistently. Motor development also lagged behind age-based expectations. Jessica was reportedly “wobbly” on her feet and showed low muscle tone. Socially, she was reportedly developing pretend play skills, engaged in reciprocal social smiling, pointed at objects of interest, and referenced the faces of others to gauge reactions. There was no report of any significant medical issues.

Table 7.2 Summary of differences in assessment procedures based on age: the cases of Jessica (2) and Carlos (14)

	Suspected cause of intellectual disability	Measure of intellectual functioning	Composite score reflecting overall intellect	Core domains assessed by intelligence test	Measure of adaptive functioning	Final diagnostic impression	Primary recommendations
Jessica (age 2)	Prematurity (28 weeks gestation)	Mullen Scales of Early Learning	Early Learning Composite	Gross motor Fine motor Visual reception Receptive language Expressive language	Developmental Profile 3 (DP-3)	Global Developmental Delay (GDD)	Continued early intervention services, transition to public preschool with services (e.g., speech)
Carlos (age 14)	Genetic anomaly (11q deletion)	Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V)	Full Scale IQ (FSIQ)	Verbal comprehension Fluid reasoning Visual spatial Working memory Processing speed	Adaptive Behavior Assessment System, Third Edition (ABAS-3)	Intellectual Disability (Mild)	Continued placement in a substantially separate program for students with developmental concerns

Family history was notable for anxiety, depression, and learning disabilities. Jessica lived with her mother and older brother (age 11). She did not have contact with her biological father. Her mother completed college. She was receiving development support from Early Intervention (EI) once per week (60 min).

Key Clinical Observations Jessica arrived to the evaluation with her mother. She was a cute girl, who looked approximately her stated age and did not present with any clear dysmorphic features. Speech and language skills were markedly delayed. This examiner was only able to decipher one or two words during the testing session. Behaviorally, she was well controlled. She played independently while the examiner interviewed her mother. Motor skills were observed to fall behind age-based expectations. She was unsteady on her feet when asked to move about the room and showed an immature pincer grasp. During an informal play session, she showed many intact basic social skills. She showed evidence of pretend play (e.g., calling the examiner using a plastic phone), showed her mother objects of interest, and shared enjoyment in the interaction. Further, she showed adequate response to joint attention and commonly referenced the examiner's face to gauge facial expressions. Results were thought to be an adequate representation of Jessica's skills.

Key Neuropsychological Test Findings

Cognitive Functioning To assess cognitive functioning, Jessica was administered the Mullen Scales of Early Learning. This measure yields five domain scores (gross motor, fine motor, visual reception, receptive language, and expressive language) and a composite score (Early Learning Composite). Jessica's cognitive functioning was variable. She showed weaker verbal abilities (i.e., receptive and expressive language = <0.1st percentile) versus nonverbal reasoning skills (i.e., visual reception = 7th percentile). Motor skills were also markedly delayed (gross motor, <0.1st percentile, and fine motor, <0.1st percentile). Her Early Learning Composite fell in the very low range overall (standard score = 52, <1st percentile). Across all areas (i.e., verbal, nonverbal, and motor), Jessica's performance was well below age-based expectations.

Language Functioning As a measure of single-word receptive language, Jessica was administered the Receptive One-Word Picture Vocabulary Test (ROWPVT), a test in which a child is read a series of single words aloud and for each one is asked to determine which of the four pictures portrays its meaning. Jessica's score fell in the very low range for her age and below the level of a 1-year-old. Regarding expressive language, Jessica also performed in the very low range on a test of single-word expressive vocabulary, the Expressive One-Word Picture Vocabulary Test. Expressive vocabulary, therefore, fell below the level of a 1-year-old. These results are generally consistent with verbal subtests of the Muller (discussed above), which indicated very low receptive and expressive language skills.

Visual-Motor Skills Jessica was administered the Beery-Buktenica Developmental Test of Visual-Motor Integration (VMI), which assesses a child's visual-motor development, perceptual discrimination ability, and skill at integrating the perceptual and motor processes. This test consists of geometrical forms that are copied in a developmental sequence, from simple to more complex. Jessica was required to copy the figures from examples using a pencil and paper. On the VMI, Jessica's visual-motor skills fell in the very low range (2nd percentile).

Parent Rating Scales To assess the key aspects of development (i.e., physical, adaptive, social, cognitive, and language development), Jessica's mother was asked to complete the Developmental Profile 3 (DP-3). Broadly, results of the DP-3 revealed delayed general development. Relative strengths were noted in the social (e.g., eye contact) domain. However, the development of physical skills (e.g., motoric functioning), cognitive functioning (e.g., identifying objects), adaptive behavior (e.g., daily living), and communication skills (e.g., expressive language) were markedly delayed.

Summary and Recommendations Jessica was a 2-year and 3-month-old (27-month) girl referred for a neuropsychological evaluation due to multiple developmental concerns, including a speech/language delay and motor delay in the context of marked prematurity (28 weeks gestation). Findings from testing indicated marked delays in the domains of language, motor, and cognitive development. Her language skills (i.e., receptive and expressive) fell at or below the level of a 1-year-old. Fine and gross motor skill weaknesses were notable and history was significant for low tone. Parent report indicated impaired communication, motor, cognitive, and adaptive living skills. Her difficulties were characterized as *Global Developmental Delay* secondary to prematurity. Her basic social skills (e.g., facial referencing, shared enjoyment) were intact, and she did not meet clinical criteria for an autism spectrum disorder. Regarding recommendations, it was critical that Jessica continue Early Intervention (EI) services, with additional speech/language therapy, occupational therapy, developmental play group, and physical therapy. At age 3, it was recommended she be placed in a specialized preschool setting with a low student-to-teacher ratio. At school, Jessica would also need intensive therapy services, including speech and language, occupational therapy, and physical therapy. Her mother was also encouraged to supplement EI and school-based services with private outpatient services. Follow-up testing in 1 year was recommended to examine developmental progress.

Carlos (Age 14)

Background Information and History Carlos, a 14-year-old young man, was referred for a neuropsychological evaluation by his geneticist. The goal for the assessment was to obtain a profile of Carlos's functioning given recent genetic findings (11q deletion) following a chromosome microarray. Previous diagnostic impressions had included "global developmental delay." Pregnancy with Carlos was uncomplicated. Delivery was at term and perinatal history was unremarkable. Speech and language milestones were delayed. That is, Carlos reportedly only knew basic words by 29 months of age. Motor development, however, progressed normally. His mother indicated that Carlos "lacked curiosity" as a young boy. Although he was described as social and interested in playing, his mother noted that Carlos often had trouble "figuring things out" and exploring new environments. Medical history was generally unremarkable. However, Carlos had a recent genetics consultation in which a deletion was noted on chromosome 11q. While the exact clinical significance of this deletion was not yet known, it was hypothesized to be the cause of his cognitive and developmental delays. Family history was notable for Prader-Willi syndrome in Carlos's brother. Spanish was spoken at home, though English was considered Carlos's primary language. He lived with his mother, mother's boyfriend, and siblings.

Carlos had a longstanding history of delays in his development, with speech and cognitive delays being the most pronounced. He had participated in special education from an early age and needed significant curriculum modifications at school. At the time of testing, Carlos was enrolled in a substantially separate 9th-grade classroom for children with developmental delays (approximately eight other children). His mother noted being concerned that Carlos's academic progress had been markedly slow. He had trouble reading single two-syllable words and had yet to learn basic math skills (single-digit subtraction). His life skills were also reportedly delayed. He had trouble independently picking out clothes to wear and could not count money; however, he could bathe himself and make snacks independently. His interests were also immature. Per parent report, Carlos played "like a little boy" (e.g., played with toy cars, watched cartoons). His mother was also concerned about Carlos's emotional functioning. He often worried and was easily upset.

Key Clinical Observations Carlos was of average height and weight. He was casually dressed and well-groomed for the appointment. No dysmorphic features were notable. Speech and language skills were markedly below age-based expectations. He rarely offered spontaneous information, though was responsive to the examiner's questions. Affect was flat. At times, he engaged in shared enjoyment of activities and reciprocal social smiling. Eye contact was appropriate. He was slow to complete tasks and performance across all measures was notably low. Attention was variable at times, often because Carlos did not seem to understand spoken instructions from the examiner. Behavior was well controlled, and Carlos was very compliant with testing procedures. Broadly, results of testing were thought to be a valid reflection of his current level of functioning.

Key Neuropsychological Test Findings

Intellectual Functioning As a measure of intellectual ability, Carlos was administered the Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V). Per the WISC-V, Carlos's intellectual skills were markedly below what would be expected based on his age. His intellectual skills fell in the very low range, including his verbal comprehension (SS = 46, <0.1st percentile), visual spatial (SS = 59, 0.3rd percentile), fluid reasoning (SS = 50, <0.1st percentile), working memory (SS = 51, <0.1st percentile), processing speed (SS = 54, 0.1st percentile), and full scale IQ (SS = 54, 0.1st percentile). Further testing of Carlos's intellectual functioning was completed using the Test of Nonverbal Intelligence, Fourth Edition (TONI-4). The TONI-4 is a test that measures nonverbal intellectual abilities, such as nonverbal problem-solving and abstract reasoning abilities. Instructions are presented through gestures and facial expressions, and a child's answers to puzzles are indicated by pointing to the correct pictures. Thus, this test does not rely on a child's verbal abilities and thus is not confounded by language skills. On the TONI-4, Carlos also performed in the very low range of intellectual functioning (nonverbal index score = 69, 2nd percentile). Thus, as per the WISC-V and TONI-4, his overall intellectual capacities were markedly below age-based expectations and consistent with intellectual impairment.

Adaptive Functioning Carlos's mother completed the Adaptive Behavior Assessment System, Third Edition (ABAS-3). Adaptive behavior is defined as mastery of personal and social demands that are expected of someone at a particular chronological age. Caregivers provide information about their child's behavior in a questionnaire format, which allows for the classification of skills per age norms in three areas of development. Questions are focused not on what a child *can* do but on what the child *does* do. As per parent report, Carlos's general adaptive behavior composite fell in the very low range. He was rated as having marked difficulties across all areas of adaptive functioning including conceptual skills (e.g., communication, SS = 40, <1st percentile), socialization (e.g., making social connections, SS = 42, <1st percentile), and practical skills (e.g., self-care and safety, SS = 40, <1st percentile).

Language Functioning As a measure of single-word comprehension, Carlos was administered several receptive and expressive language tests, such as the Peabody Picture Vocabulary Test, Fourth Edition (PPVT-4), and Expressive Vocabulary Test, Second Edition (EVT-2). His performance on these language-based tasks was commensurate with his performance on the verbal comprehension subtests of the WISC-V. Broadly, Carlos's language skills were best characterized as being at the level of a 3-year-old.

Academic Achievement Carlos was administered selected subtests of the Wechsler Individual Achievement Test, Third Edition (WIAT-III), to determine his performance in the basic areas of academic achievement: reading, mathematics, and spelling. As per academic testing, Carlos's skills fell at a first-grade level or below. That is, his reading of single words (Word Reading), computational math (Numerical Operations), ability to solve math word problems (Math Problem Solving), and spelling of single words (Spelling) all fell in the very low range (i.e., <0.1st percentile across all areas). These findings were not surprising given Carlos's intellectual impairment.

Emotional and Behavioral Functioning Carlos's emotional and behavioral functioning was assessed using various standardized parent report questionnaires (i.e., BASC-3, CSI-4). His mother noted elevations on the following scales: depression (91st percentile), conduct problems (e.g., argues; 89th percentile), and social withdrawal (89th percentile). On the adaptive skills scales of the BASC-3, difficulties were also noted, which was consistent with scores on the ABAS-3 (described above). These included troubles with social skills development (2nd percentile), suboptimal leadership (8th percentile), difficulties with activities of daily living (1st percentile), and poor functional communication (2nd percentile). On the Child Symptom Inventory-4 (CSI-4), his mother noted mild to moderate oppositional behaviors, anxiety, and depressive symptoms.

Summary and Recommendations

Carlos (age 14) was referred for a neuropsychological evaluation by his geneticist. The goal for the assessment was to obtain profile of Carlos's functioning given recent genetic findings (11q deletion) following a chromosome microarray. Previous diagnostic impressions had included "global developmental delay." Intellectual testing revealed that Carlos's overall performance fell within the very low range of intellectual functioning (WISC-V Full Scale IQ = 54, <1st percentile). Broadly, his deficits were global. Marked difficulties across domains of adaptive living, language, and academics were notable. His mother also noted some concerns about Carlos's emotional functioning. There was evidence of depressive symptoms and anxiety, as well as problems with adaptive living skills (i.e., day-to-day functioning). Carlos's difficulties needed to be understood in the context of known genetic findings, which was the suspected cause of Carlos's developmental difficulties. Diagnostically, Carlos met clinical criteria for an *intellectual disability (mild)*, with co-occurring symptoms of anxiety and depression. His previous diagnosis of "global developmental delay" was no longer appropriate.

Briefly, regarding recommendations, it was suggested that Carlos continue all the supports that were available to him in a public school setting. That is, he required continued placement in a substantially separate classroom, with a small student-teacher ratio and substantial 1:1 attention. He also required specialized accommodations, supports, and an individually tailored program for children with marked cognitive and academic delay. Further, bolstering Carlos's language skills via individualized/intensive speech and language therapy was critical in his case. Infused within his program should be a focus on adaptive living skills (i.e., day-to-day living). Outpatient supports for his emotional distress (e.g., psychologist, psychiatrist) were also recommended.

Evidence-Based Treatments for Intellectual Disabilities

School-Based Interventions for Intellectual Disabilities

For students with intellectual disabilities, schools are critical venues for intervention. There are several types of school environments suitable for student with intellectual disability. In some cases, children with intellectual disabilities are integrated into a mainstream classroom environment with significant support (e.g., one-to-one aide) and a modified curriculum. In other cases, students with intellectual disabilities may spend most the school day in a self-contained classroom for students with intellectual disabilities or other developmental delays. These are substantially separate classroom settings staffed by personnel specifically trained in educating students with disabilities. Additionally, in some states, there are entire schools specifically designed to serve students with disabilities. These private, specialized settings are typically costlier but often contain fewer students, greater one-to-one support, and specially trained staff. In some cases, these programs may involve a residential component.

No matter the placement, services for students with intellectual disabilities often focus on the following areas: communication (e.g., improving expressive language skills), socialization (e.g., greeting others appropriately), motor skills (e.g., handwriting), functional academics (e.g., counting money), daily living skills (e.g., preparing a meal), and, if necessary, behavior (e.g., reducing aggressive outbursts). These domains are often addressed by a team of specialized school personnel, which may include speech and language pathologists, occupational therapists, physical therapists, special education teachers, counselors, and/or behavior specialists.

Adaptive skills are frequently a focus in school settings. Educators may use "real-world" setting teaching methods to help students attain independent living skills. For instance, a high school student with an intellectual disability may visit a grocery store with a monetary budget. Infused within this store visit may be lessons on nutrition (e.g., buying items from the different food groups, reading nutritional labels), social skills (e.g., interacting appropriately with other customers, asking for help), and money management (e.g., budgeting and estimating total costs). For older or graduating students, vocational programming may also be significant portion of the curriculum. For instance, schools may partner with a range of supportive employment settings to hire and supervise students with intellectual disabilities. Students with intellectual disabilities may require specific transitional plans and may be eligible for special education services until age 22 (see Chap. 14, for more specific information). In sum, the overall goals of school-based service provision are to help bolster independent living skills, support effectively make relationships with others, and reduce any interfering or problem behaviors.

Outpatient Treatments for Intellectual Disabilities

In addition to school-based services, individuals with intellectual disabilities may seek further outpatient supports. Outpatient services may help individuals with intellectual disabilities and their families achieve greater independence and inclusion in the community. For children, these services may include private therapies (e.g., speech and language therapy, occupational therapy, social skills training), psychological and psychiatric care for treatment of possible co-occurring emotional or behavioral concerns, neurological consultation, and family support (e.g., respite care). For adults, services may also include case management, life skills training, vocational programming, and in-home supervision. Families may also choose to enlist the help of government and state-run programs for financial assistance and service provision. For instance, each state has department focused on services for those with intellectual disabilities (e.g., in Massachusetts: the Department of Developmental Services, DDS). These departments typically have several functions, such as providing transportation, vocational training, or housing options for individuals with disabilities. Families or caregivers of individuals with intellectual disabilities may also opt to pursue guardianship. If a child with an intellectual disability is not considered competent to make independent decisions about finances, health, or safety after age 18, an adult caregiver may assume the legal role of guardian, which grants decision-making power. While there are no medications that specifically address the intellectual deficits core to the disability, some individuals with intellectual disabilities receive medications to treat the difficulties commonly associated with the condition, such as attention problems or behavioral dysregulation. Again, the goals of treatment are to help promote independent living, support socialization, and improve the overall quality of everyday life for individuals with intellectual deficits.

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8

Attention-Deficit/Hyperactivity Disorder and Executive Dysfunction

Nathan E. Cook and Gina A. Forchelli

Background and Current Research

Attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental disorder, occurring in as many as one in ten children and adolescents [1] or more than five million children and adolescents in the United States [2]. Core symptoms include inattention, distractibility, hyperactivity, and/or impulsivity [3]. The rate of ADHD diagnosis among clinical samples appears to be increasing slightly in recent years, with some evidence of differential rate increases by age, race, and sex [4, 5]. However, evidence from non-referred populations does not suggest increased rates of ADHD diagnosis over time [6].

Considerable research across multiple disciplines, including psychiatry, psychology, genetics, and neuroscience, has focused on ADHD. Recent evidence will be briefly summarized here with citations for further reference. There appears to be consistent evidence from several countries suggesting that ADHD is highly heritable [7]. However, the most recent genome-wide association study meta-analysis did not identify statistically significant associations, suggesting that the effect sizes for ADHD risk variants must be quite small or that rare variants account for ADHD's heritability [8]. Several environmental (or nongenetic) risk factors have been identified such as prenatal exposure to lead, cigarette smoke, alcohol, and pesticides (reviewed in [7]). Nutritional factors, including both certain deficiencies (e.g., zinc) and surpluses (e.g., artificial food coloring), are considered correlates of ADHD but have not been convincingly shown to precede ADHD [9]. Additionally, meta-analytic results indicate that children from families of low socioeconomic status (SES) are more likely to have ADHD compared to children from high SES families [10].

Several recent studies have highlighted prominent differences between children with and without ADHD on neuroimaging. Structural findings have implicated the basal ganglia and limbic areas in ADHD [11]. Recent evidence has identified smaller cortical volume, cortical surface area, and average cortical thickness in youth with ADHD compared to controls without ADHD [12]. In terms of differential brain functioning, fMRI studies have identified abnormalities in

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neural networks related to attention and executive functioning [13]. More specifically, fMRI studies indicate underactivity in several regions that tend to mirror the structural findings, namely, frontal regions (such as the anterior cingulate and dorsolateral prefrontal cortex), parts of the basal ganglia, thalamus, and parietal cortices (reviewed in [14]). Additionally, functional connectivity abnormalities have been reported in youth with ADHD [15]. A recent review summarizes evidence regarding the neural mechanism of ADHD [16].

Regarding the assessment of learning needs among youth with ADHD, many researchers have documented considerable neurocognitive vulnerabilities associated with pediatric ADHD. Meta-analytic evidence suggests that ADHD is most strongly and consistently associated with weaknesses in response inhibition, vigilance, working memory, and planning [17]. Multiple studies have also established that processing speed, including reaction time, is negatively impacted in children and adolescents with ADHD [18, 19]. Of note, reaction time variability appears to be an important consideration when examining neurocognitive test performance in youth with ADHD. Specifically, a recent meta-analysis suggests that youth with ADHD may be more variable in their response speed rather than slower overall compared to typically developing peers [20]. (More information regarding the assessment of these domains of cognitive functioning is provided below.)

Many of these neurocognitive vulnerabilities are generally subsumed under the overarching concept of executive dysfunction. Executive functioning (EF) refers to a variety of higher-order cognitive processes involved in directing and managing one's learning and behavior and can be broadly defined as the regulation and maintenance of behavior to achieve optimal performance toward a future goal. It is considered the manager of cognitive processes necessary to make decisions and adapt in complex situations and has been described as the "maestro" or "boss" of the brain [21]. Although there is general agreement regarding the overarching concept of EF, there are some differences in conceptualization regarding which specific component processes and sub-skills fall under the EF umbrella [22]. Factor analyses have identified several subdomains that encompass EF. Most studies have identified the following as core EF skills: inhibition, working memory, and cognitive flexibility [23–26], though some refer to working memory as "monitoring" or "updating." Further, these three superordinate factors encompass many activities and sub-skills such as controlling attention, planning, organizing, evaluating, and modifying behavior [23, 24, 27]. More recently, researchers have begun to differentiate between "hot" and "cool" EFs [28]. More specifically, "cool" EFs encompass non-emotionally laden functions (e.g., planning an essay, remembering multi-step directions), while "hot" EFs involve emotionally or motivationally salient decision-making and goal-directed behavior (e.g., gambling, risk-taking, delayed gratification).

Ultimately, ADHD is defined and diagnosed behaviorally. That is, the diagnostic symptoms include behavioral manifestation of problems with attentional and behavioral control. For example, inattention might be characterized phenotypically by failing to give close attention to detail, making careless errors, difficulty remaining focused during conversations, being seemingly distracted even in the absence of obvious distractors, starting tasks but failing to complete them, difficulty remaining organized, poor time management, losing things, forgetting to complete tasks, etc. [3]. Problems with hyperactivity and impulsivity might be characterized phenotypically by frequent fidgeting and motor restlessness, difficulty engaging in activities quietly, being unable or uncomfortable sitting still or not moving for an extended time, talking excessively, difficulty waiting for one's turn during conversation, difficulty waiting in lines, interrupting into conversations, starting to use other people's things without asking permission, etc. [3]. Difficulties and problems in these areas are expected to be present before age 12, occur in multiple settings (e.g., home, school, work, socially, etc.), persist for 6 months or more, and are inconsistent with developmental level and directly impact daily functioning [3].

Assessing ADHD and Executive Dysfunction

Many of the symptoms and problems associated with ADHD are evident without comprehensive neuropsychological evaluations, but youth with ADHD frequently receive such clinical services. For example, a recent survey of pediatric neuropsychologists indicates that ADHD is the most common condition leading to neuropsychological evaluations [29]. Although symptoms of attention and hyperactivity/impulsivity are diagnosed behaviorally through rating scales and observations rather than via specific neuropsychological test findings (i.e., behavioral manifestations of inattention rather than difficulty with sustained attention on a neurocognitive test), an evaluation may provide useful information that informs clinical care and treatment/management. For example, repeat neurocognitive testing could be undertaken prior to and following a psychostimulant trial. Further, pediatric ADHD commonly co-occurs with several and, in some cases, quite prominent neurocognitive challenges and vulnerabilities. These challenges along with any relevant social, emotional, academic, or other functional difficulties can be identified via neuropsychological evaluation in an effort to provide comprehensive, individualized clinical care for patients [30].

This section will summarize various measures used to assess pediatric ADHD and identify relevant learning needs as well as test results that are common among youth with ADHD. First, there are a few important caveats to address. Maintaining a developmental perspective is critical because perhaps as many as 85% of youth diagnosed with ADHD will no longer meet full diagnostic criteria and around 40–60% will demonstrate partial remission by adulthood [31]. That is, a sizeable proportion of pediatric patients who are diagnosed with ADHD will no longer demonstrate clinically significant symptoms into adulthood. Additionally, regarding neuropsychological test results, many of the neurocognitive and executive functioning weaknesses described below are not unique to ADHD but, in fact, are seen across a wide variety of clinical disorders. Thus, no test result or “pattern” of results can be considered pathognomonic or diagnostic of ADHD. Furthermore, mounting research evidence highlights that healthy children and adolescents will present with some “low” neuropsychological test scores or those considered to fall below age expectations and might suggest “impairment” or “deficit” [32, 33]. This relatively common finding is important to bear in mind when reviewing test findings. Lastly, an additional consideration to be aware of when reviewing assessment results is whether the youth took psychostimulant medication (if prescribed) on the day of testing, as some evidence suggests this can influence neurocognitive test performance [34].

With these caveats in mind, when reviewing neuropsychological test results, as noted above, there does not seem to be a characteristic “profile” in overall intellectual performance (e.g., IQ) in children or adolescents with ADHD. However, verbal comprehension and perceptual reasoning skills tend to be well-preserved with vulnerabilities generally noted in working memory and processing speed (see, e.g., [35]). For example, on the *Wechsler Intelligence Scale for Children, 5th Edition* (WISC-V; [36]), this constellation of findings might be reflected by a statistically significant and uncommon (i.e., low base rate) difference between the General Ability Index (GAI) and the Cognitive Processing Index (CPI). Cognitive subtests assessing mental calculation (WISC-V Arithmetic) and fine motor response and decision speed (Coding) show the largest magnitude differences between youth with ADHD and matched controls without ADHD [37]. Overall, primary differences between youth with ADHD and matched controls appear in the domains of working memory, graphomotor processing speed, and rapid, automatic naming [37].

There are a variety of published tests and measures utilized to assess attention, hyperactivity, impulse control, and other executive functions. These include behavior rating scales and performance-based tests. Behavioral rating scales address the observable phenotypes of ADHD, including attention problems and hyperactivity/impulsivity, as well as EF and are typically completed by informed adults such as parents/guardians and teachers. Depending on the age and development level of the child/adolescent, their own self-report of symptoms can be sought. Performance-based assessment of attention, hyperactivity, and EF involves the use of standardized tasks and measures. Some specific examples of both rating scales and performance-based tests are included below, along with potential results on these measures that have been reported in association with ADHD.

In general, it is important for evaluators to use both behavioral and performance-based measures to assess attention, impulsivity, and other executive weaknesses. Children may present differently in a one-on-one testing situation but show significant attentional and/or executive weaknesses in more naturalistic settings (e.g., home, school). In certain circumstances, examiners can provide support and scaffolding during the testing session that might obscure a child's executive weaknesses by, for example, telling them how and when to complete tasks and providing consistent feedback. Further, the testing situation is designed to provide minimal distraction, which is likely dissimilar, to a degree, from a more dynamic school classroom.

In terms of executive functioning, the Behavior Rating Inventory of Executive Functioning (BRIEF2; [42]) is a checklist that assesses for behavioral evidence of various EF abilities. Raters assess the frequency of certain behaviors, allowing for age-corrected standard scores from the following scales: Emotional Control, Initiate, Inhibit, Organization of Materials, Plan/Organize, Self-Monitor, Shift, and Working Memory. Elevated scores ($T \geq 65$) will likely be highlighted in an evaluation report. In particular, elevations on the Working Memory and Inhibit subscales will be of interest for youth with ADHD, although weaknesses across all EF subdomains are not uncommon. Several other standardized questionnaires measure EF including the Comprehensive Executive Function Inventory (CEFI), a 100-item questionnaire assessing EF strengths and weaknesses from ages 5 to 18 [43]. Moreover, a commonly used broadband measure of emotional and behavioral functioning, the aforementioned BASC-3, includes several EF subscales including a Problem-Solving Index, an Attentional Control Index, a Behavioral Control Index, an Emotional Control Index, and an Overall Executive Functioning Index [40].

Behavioral Rating Scales

Several behavioral rating scales to assess for symptoms of ADHD are in common use. Many available scales specifically target and assess for symptoms of ADHD, including attention problems as well as hyperactivity/impulsivity. Examples include the Vanderbilt Assessment Scales [38] and the Conners 3 [39]. Other general, omnibus behavioral rating scales that assess a broad range of psychopathology typically include scales relevant to the assessment of ADHD. For example, the *Behavior Assessment System for Children, 3rd Edition* (BASC-3; [40]), includes primary scales assessing attention problems and hyperactivity and also provides an ADHD Probability Index. Similarly, the Child Behavior Checklist (CBCL; [41]) includes an Attention Problems scale as well as an Attention-Deficit/Hyperactivity DSM-oriented scale.

Performance-Based, Psychometric Tests

Traditional performance-based or "psychometric" neuropsychological tests tend to measure the "cool" EFs. A list of measures, organized by the skill or domain assessed, can be found in Table 8.1. There are test batteries that include a subset of tests to assess attention, hyperactivity, and executive function in children, such as the NEPSY-II [44]. There are also entire batteries of tests explicitly focused on attention, such as the *Test of Everyday Attention for Children, Second Edition* (TEA-Ch2; [45]), and executive functioning, such as the Delis-Kaplan Executive Function System (D-KEFS; [46]). Additionally, specific tasks have been developed for more focused assessment or certain skills or functions. For example, the Wisconsin Card Sorting Task (WCST; [47]) assesses, among other skills, cognitive flexibility and set-shifting. There

Table 8.1 Commonly used performance-based measures of attention and executive functions: some examples

Sustained attention/vigilance	Working memory	Inhibition	Flexibility/shifting
CPT 3 IVA-2 TEA-Ch Sky Search TEA-Ch Score NEPSY-2 Auditory Attention	WISC-V/WAIS-IV Digit Span WISC-V Picture Span WAIS-IV Arithmetic DAS-II Recall of Digits-Backwards DAS-II Recall of Sequential Order WRAML-2 Number-Letter WRAML-2 Finger Windows	NEPSY-2 Response Inhibition D-KEFS Color-Word Interference Test: Inhibition Stroop Color and Word Test CPT 3	WCST D-KEFS Color-Word Interference Test: Inhibition/Shifting D-KEFS Verbal Fluency Test: Category Switching D-KEFS Trail Making Test: Number-Letter Switching

are several computerized continuous performance tasks available, such as the Conners CPT 3 [48], which assess sustained attention and inhibitory control. Individuals with ADHD tend to demonstrate difficulties with cognitive flexibility and switching (e.g., D-KEFS Trail Making : Number-Letter Switching condition, WCST), planning (e.g., D-KEFS Tower Test), controlled/divided attention (e.g., D-KEFS Color-Word Interference: Inhibition and Inhibition/Switching conditions, Conners CPT 3), and verbal fluency (e.g., D-KEFS Verbal Fluency: Letter Fluency condition).

Inhibitory control can be assessed by analyzing errors across many tasks (e.g., was the individual able to monitor themselves and respond appropriately). More traditional measures of inhibitory control include the so-called "stroop" tasks such as the Stroop Color and Word Test [49] and the Color-Word Interference Test from the D-KEFS [46] or "go-no go" tasks such as the Conners CPT 3, described above [48]. In stroop-like tasks, individuals are required to pay attention to stimuli and respond to a novel element. Children with ADHD commit significantly more errors on such tasks; however, their overall performance can be well within the Average range for their age [50].

As noted above, there is little consensus regarding an identifiable pattern of performance on EF measures among children with ADHD; however, deficits tend to be reported on the following tasks:

- Working memory (WM) skills are typically assessed through "span tasks," requiring the individual to recall and transform an increasing number of sequenced items. Generally, children with ADHD perform more poorly than children without ADHD on all aspects of WM (e.g., verbal short-term memory, visuospatial short-term memory, verbal working memory, visuospatial working memory; [50]).
- Continuous performance or "go-no go" tasks require an individual to respond (e.g., press a button) to certain stimuli and stop themselves or inhibit responding to a certain target. Specifically, on tasks like the Conners CPT 3, children with ADHD have a significantly harder time consistently distinguishing between the target and nontarget stimuli. This is called the "Detectability" or "d'" score on the CPT 3. Further, children with ADHD will generally have more errors (e.g., omissions, commissions, perseverations) and show more variability as time goes on in the task (e.g., hit reaction time SD, variability).
- Cognitive flexibility and set-shifting refer to the ability to switch back and forth between tasks and mental sets. A traditional measure of cognitive flexibility, the WCST, requires an individual to correctly organize a deck of cards according to a set of rules and "learn from experience" or update/shift their response according to vague corrective feedback. This task is generally harder for younger children (up to around 8 years old), but differences according to ADHD diagnosis were reported among older children (10- to 11-year-olds [51]). Children with ADHD commit more perseverative errors on the WCST (e.g., they demonstrate poorer ability to switch to a new rule when needed). Similarly, the D-KEFS Trail Making Test (TMT) assesses an

individual's ability to shift attention between mental sets. As with tasks assessing inhibitory control, children with ADHD make significantly more errors when required to sequence numbers, letters, or switch between the two on the TMT [50].

Common Comorbidities

Several clinical conditions and disorders tend to co-occur with pediatric ADHD that can complicate and compound functional difficulties. For example, children and adolescents with ADHD are at markedly greater risk for comorbid emotional or other neurodevelopmental disorders including anxiety, depression, autism spectrum disorder, and Tourette's disorder [52]. Youth with ADHD commonly meet diagnostic criteria for a specific learning disorder (SLD), with some estimates suggesting up to 60% of youth with ADHD also meet criteria for an SLD [52, 53]. Regarding physical health, youth with ADHD appear at increased risk for physical injuries [54–56] and, more specifically, traumatic brain injury (TBI) [57], compared to youth without ADHD. These physical injuries and traumas, in turn, commonly carry neurocognitive and emotional health sequelae. For example, decrements in attention and information processing speed have been documented following severe TBI [58], and emotional as well as adaptive functioning challenges are consistently reported among school-aged children within 2 years of suffering a TBI [59]. Clearly, attention to potential comorbidities when evaluating youth with ADHD and executive dysfunction is strongly indicated.

Impact on Learning Across Development

Given the multiple and, in some cases, considerable neuropsychological adversity faced by children and adolescents with ADHD, it is not surprising that their academic achievement is often compromised [60]. In this section, we briefly describe the development of key neurocognitive skills that are commonly impaired in youth with ADHD and summarize how these neurocognitive vulnerabilities present challenges for learning and academic functioning.

Attention is the ability to deploy cognitive and mental resources to optimize performance toward a goal and can include, for example, the ability to analyze and identify the most important and relevant stimuli or information [61]. Attention can be considered a foundational skill underlying many other cognitive abilities [62]. Researchers generally describe three component processes including selective attention (the ability to filter incoming information and select which information will be processed), sustained attention (also referred to vigilance, refers to maintaining attention and focus over time), and attentional control (which refers to executive functions such as switching or shifting and inhibiting responses) [61, 62]. These processes map to specific neural networks with unique and differential structural development over time; however, some degree of dynamic interaction between these three is assumed [61]. Initial attention skills develop during infancy (e.g., shifting attention from one target to another) [61]. Moreover, the underlying physiological maturation for brain areas associated with attention develops early in life and continues into early adulthood [63]. Generally, parent and teacher ratings of attention and task-based measures of vigilance remain relatively stable between ages 5 and 10 years, although there does appear to be a subgroup of children whose vigilance starts out low and improves steadily over that timespan [64].

The critical importance of attention for learning and academic success has been emphasized. Compelling links between selective attention and early foundational academic skills, such as language processing, literacy, and mathematics skills, have been described [65]. During the elementary years, ADHD symptoms appear associated with lower overall levels and less improvement over time in reading skills, namely, decoding speed and text comprehension [66]. Further, inattentive behaviors measured in the first grade are associated with poorer academic achievement during middle school and also appear to decrease the likelihood of eventual high school graduation and educational achievement into young adulthood [67].

Working memory is defined as the ability to temporarily store and manipulate or transform presented stimuli [68]. This ability is central to information processing and requires multiple systems (i.e., auditory systems, visual systems, attention; [22]). It is required for individuals to adequately perform complex tasks, such as following multistep directions. While some researchers utilize the term "working memory" explicitly [23–25, 69], others label this domain "monitoring" [70] or "updating" [26]. However, all domain labels are generally defined as the ability to work with and manipulate information. Studies suggest that working memory gradually develops over time. Unlike the developmental "spurts" suggested in inhibition research (discussed below), cross-sectional studies demonstrate a slower increase in working memory performance in children between 6 and 14 years of age [25, 69, 71]. Additionally, a recent study suggested a significant difference between the development of visual and verbal working memory in children between the ages of 6 and 17 years [72]. However, larger samples with longitudinal data report comparable developmental change across various subcomponents of working memory [71]. Children with working memory weaknesses tend to perform more poorly on academic tasks that require the child to follow multiple-step directions [73]. Poor working memory performance has been positively correlated with higher-level cognitive tasks, such as reading comprehension, language comprehension, and mathematics [74], and this relationship has been demonstrated in elementary school children through adolescence [75].

Cognitive flexibility, or set-shifting, is the ability to engage and disengage from different aspects within a task [26]. This is essential for adapting to changing conditions in the environment [76]. Similar to working memory, studies appear to show a gradual improvement and progression in flexible thinking through development [25, 69]. Children begin to flexibly shift between stimuli with minimal error around ages 6 and 7 years [25, 77]. Improvements in shifting ability also appear dependent on the development of verbal strategies; that is, the ability to shift between visual stimuli develops earlier than the ability to shift between verbal materials [78].

Inhibition, or impulse control, mediates an individual's response selection during planning and problem-solving [76]. Beginning with earlier research on children with ADHD, Barkley [23] hypothesized that inhibition was the cornerstone ability and was embedded in many other EFs, including working memory, self-regulation, and flexible thinking. However, an updated model suggests that inhibition is more of an "equal partner" with other EF domain abilities, namely, working memory and attention. More recent models developed among healthy adult and child populations suggest that inhibition is a crucial factor in the development of EF. Research suggests that the ability to effectively inhibit a response without error begins to mature around the age of 8 years and plateaus around age 14. For example, a cross-sectional study found that children were able to successfully inhibit a response based on a set of learned rules around 7–8 years of age and their performance sharply increased and then plateaued around 12 years of age [69]. Other cross-sectional studies have shown that inhibition performance appears to continually mature between 14 years [25, 79] and 17 years of age [80]. In a classroom, behavioral indicators of difficulties with inhibitory control can include calling out in class, making tangential comments, touching objects without thinking/permission, or abruptly leaving their seat. These behaviors may impact a student's ability to manage demands in the classroom. A large-scale longitudinal study indicated that poor inhibitory control early in life is associated with a multitude of negative learning, physical health (e.g., cardiovascular, respiratory, and dental health), and financial outcomes as well as substance dependence and criminal offending later in life [81].

There are additional, related processes that appear more difficult to measure. One example is self-regulation and emotional arousal. Regulation of mood and emotion has been linked to EF [76]. Some researchers have attempted to examine how regulation influences EF in early childhood. For example, one study reported that a child's ability to restrain themselves from reaching for an attractive toy when instructed to do so predicted later development of EF [27]. That is, children with better self-restraint in toddlerhood performed better on some inhibition and working memory tasks later during adolescence. However, self-restraint also predicted poorer shifting, indicating that it does not account for all factors involved in EF development. This suggests that self-regulation may be involved in early EF development but more research is needed within this domain.

Overall, difficulties managing attention and executive functions have a significant impact on how one can manage their behavior within their environment. As such, children with ADHD typically demonstrate academic underachievement and impaired social skills [82], as they struggle to continually attend and update information, manage behavior or responses across settings/situations/people, organize and prioritize time and work, and quickly/efficiently process information. These difficulties can contribute to more negative academic outcomes. For example, children and adolescents with ADHD are at higher risk for placement in special education programming, grade retention, school dropout, and lower lifetime educational attainment [82].

Case Studies

Johnny Patient

Johnny was a 9-year-old boy who presented for an evaluation with an existing diagnosis of a reading disorder, more specifically dyslexia. His early developmental and physical health histories were unremarkable. His family history was notable for anxiety, depression, and learning difficulties. In addition to difficulties in reading acquisition, from an early age, Johnny demonstrated vulnerabilities in his attention and executive functioning. For example, his mother reported that Johnny has difficulty following multi-step instructions, needs reminders to complete daily tasks and routines, is chronically disorganized, and has notable difficulty initiating tasks. He can also tend to be cognitively rigid and stubborn. There was no report of excessive activity or impulsivity. Johnny was reportedly functioning well socially. Prior testing through his school district indicated intact overall cognitive skills, age-appropriate math skills, and significant weaknesses in reading. A previous neuropsychological evaluation documented similar weaknesses in reading, and Johnny was diagnosed with a specific learning disorder with impairment in reading (i.e., dyslexia), but symptoms of ADHD were not noted.

During the current testing session, behavioral observations were notable for excessive activity. Johnny was frequently out of his chair and moving around the testing room and, when seated, would often spin in his chair during tasks. Attention and concentration to tasks appeared adequate; however, Johnny appeared to have difficulty with tasks requiring sustained mental effort. He frequently complained of tasks being “boring” and required copious encouragement from the examiner to persist with tasks.

Consistent with his school testing, evaluation results revealed marked weaknesses in foundational reading skills, including scores on tests of sight word reading, phonological processing and decoding, as well as reading fluency that fell considerably below age-based expectations. These findings were consistent with his existing diagnosis. Regarding attention and executive functioning, test results revealed intact, age-appropriate working memory. Per the WISC-V, Johnny demonstrated average auditory (Digit Span) and visual (Picture Span) attention and working memory spans. On the CPT 3, Johnny committed many more perseverations than is typical for his age, seemingly responding impulsively. Also on the CPT 3, he missed many of the target responses, and his reaction time was slower than is typical for his age, suggesting inattention. However, his results were confounded by difficulties with sustained effort and motivation during this task. Still, it was notable that Johnny had marked difficulty sitting attentively at the computer to complete this lengthy, boring task. Johnny performed exceptionally well on the WCST, demonstrating strong abstract concept formation, mental flexibility, and novel problem-solving abilities. His performance was all-the-more impressive because Johnny left the room a few times during this task, complaining the task was too boring. Still, even with these interruptions, he could remember the sorting principles and pick up right where he left off upon returning to the testing room.

In terms of behavioral rating scales, Johnny's mother and teacher completed the BRIEF. Mrs. Patient did not indicate any executive function weaknesses as all scales fell within normal limits. In contrast, Johnny's teacher indicated clinically significant concerns regarding Johnny's ability to begin a task or activity and independently generate ideas or problem-solving strategies (Initiate scale), hold information in mind in order to complete a task (Working Memory scale), anticipate future events and develop appropriate sequential steps to carry out a task as well as appreciate main ideas and key concepts (Plan/Organize scale), and organize his environment and materials (Organization of Materials scale). Johnny's mother and teacher also completed the BASC-2 (the predecessor to the BASC 3 described above), a broadband questionnaire assessing a child's behavioral and emotional functioning. Mrs. Patient reported borderline elevations (At-Risk range) regarding Johnny's short attention span and tendency to be easily distracted (Attention Problems scale) as well as mild difficulty organizing daily chores and needing reminders to brush his teeth (Activities of Daily Living scale). In the school setting, borderline concerns (At-Risk range) were raised regarding Johnny's frequent worry and nervousness (Anxiety scale) and poor handwriting as well as reading and spelling problems (Learning Problems scale). Neither his mother nor his teacher endorsed any concerns regarding hyperactivity or impulsivity, which were noted as prominent behavioral observations during testing. Further, Johnny's mother also completed an ADHD symptom checklist and did not endorse clinically significant inattentive symptoms (endorsed three of nine symptoms, clinical cutoff is six) or hyperactive/impulsive symptoms (endorsed zero of nine symptoms).

In this case, behavioral observations and certain test results suggested vulnerabilities in attention and hyperactivity. However, neither parent nor teacher report indicated clinically significant difficulties or symptomatology. Therefore, a formal diagnosis of attention-deficit/hyperactivity disorder was not supported. Still, Johnny appeared at risk for difficulties in attention/concentration as well as excessive activity, and supports focused on these vulnerabilities for both the home and school settings were recommended in the neuropsychological evaluation report.

Jane Student

Jane was an 8-year-old girl who was referred for a neuropsychological evaluation due to concerns of anxiety and difficulty in processing language. She did not carry any formal psychiatric diagnoses but had been placed on an Individualized Education Program (IEP) with an educational diagnosis of ADHD. In terms of case history, labor was induced due to Mrs. Student experiencing preeclampsia. No birth complications were noted. Perinatal history was significant for jaundice which resolved after 4 days. Jane met her developmental milestones within normal limits and her medical history was unremarkable. She was reported to have difficulty initiating sleep and also sleepwalk. Family medical history was significant for Hashimoto's disease, heart disease, and hypertension. Regarding mental health history, Jane presented with some current symptoms of anxiety and perfectionism and reportedly demonstrated separation anxiety early in life. Jane was reportedly very shy and did not like being the center of attention but was functioning well socially overall. Further, Mrs. Student noted that Jane was fairly negative and self-critical at times. Family psychiatric history was significant for anxiety, depression, bipolar disorder, and learning problems. Academically, when Jane began first grade, she had difficulty keeping up in class. She received special education services since that time and was currently a third grader. Per parent report, Jane had no reading concerns but was having difficulty understanding math concepts. Per school report, Jane's math difficulties appeared closely associated with and potentially secondary to her difficulty in sustaining attention. Jane's Individualized Education Program (IEP) included several accommodations to address her attention weakness, mathematics support from a special educator or paraprofessional in the general education classroom, and weekly pullout occupational therapy (to promote her ability to attend).

During the neuropsychological evaluation, Jane exhibited long response latencies and appeared hesitant to guess or provide an answer that she was not confident was correct. Overall, she appeared attentive and remained on task. Test results revealed that Jane had mild difficulty with her immediate auditory attention and memory span (WRAML2 Sentence Memory). On the WISC-V, Jane demonstrated Average overall working memory. However, her performances within the working memory index were variable. Her auditory attention and memory span (Digit Span) fell toward the bottom of the Average range, and her visual working memory skills (Picture Span) were much stronger and in the High Average range. Jane's processing speed was also assessed on the WISC-V and fell in the Low Average range overall, although once again her performances within this domain were variable. Jane scored in the Average range on a test requiring rapid visual scanning and decision speed (Symbol Search). She had more difficulty on a test that required her to integrate visual scanning, learning, and fine motor response speed (Coding), earning a score in the Low Average range. On the CPT-II (the predecessor to the CPT 3 described above), Jane's performance did not indicate clinically significant problems with attention or impulsivity, suggesting that on a highly structured, individual task with minimal distraction, Jane can demonstrate strong sustained attention and focus. On the WCST, Jane performed well overall, demonstrating intact abstract concept formation and problem-solving. She committed slightly more non-perseverative errors on this task than was typical for her age (Low Average range). These were seen after Jane solved the first "category" rather quickly (i.e., identified and matched the cards to the first organizing principle) but was unable to identify the second organizing principle right away. However, once Jane solved the second principle, she proceeded through the task effectively, and, again, her overall performance was within normal limits for her age. On the D-KEFS Trail Making Test, Jane had considerable difficulty switching between sequencing letters and numbers (number-letter switching), scoring below age expectations. On the TEA-Ch, both Jane's visual attention (Sky Search) and auditory attention (Score!) were intact for her age.

In terms of behavior rating scales, Jane's mother completed the BRIEF and endorsed clinically significant executive function weakness with regard to Jane's ability to begin a task or activity and independently generate ideas or problem-solving strategies (Initiate scale), hold information in mind in order to complete a task (Working Memory scale), and anticipate future events and develop appropriate sequential steps to carry out a task as well as appreciate main ideas and key concepts (Plan/Organize scale). Further, on the BASC-2, Mrs. Patient's responses suggested that Jane exhibited clinically significant inattention (Attention Problems scale, e.g., has a short attention span, is easily distracted) as well as social anxiety (Withdrawal scale, e.g., shows fear of strangers, is shy around others). Results also indicated borderline elevations (At-Risk range) with regard to impulsivity/hyperactivity (Hyperactivity scale) and socially aloof behavior (Atypicality scale, e.g., often stares blankly, acts confused, sometimes seems unaware of others). Additionally, mild adaptive functioning weaknesses were reported with regard to Jane's adaptability (e.g., never recovers quickly after a setback), leadership skills (e.g., never joins clubs or social groups, has some difficulty making decisions), and activities of daily living (e.g., difficulty following regular routines, never organizes tasks or chores well). Lastly, Mrs. Patient completed an ADHD Behavior Checklist and endorsed six out of nine symptoms of inattention but did not endorse symptoms of hyperactivity or impulsivity.

Taken together, Jane exhibited notable executive functioning weaknesses, with particular vulnerability on less structured tasks and tasks requiring multiple steps. Also, parent report and her educational record were both significant for difficulty sustaining attention. Given Jane's history, presenting complaints, and test results from the current evaluation, a diagnosis of ADHD (predominantly inattentive presentation, mild current severity) was made. However, it was important to highlight for her parents and her educational team that under conditions of increased structure and when she was not fatigued, Jane could summon extraordinary focus. Unfortunately, she had difficulty consistently applying those skills, particularly during tasks requiring multi-step procedures, planning, and organization. A concern for Jane was that her vulnerabilities might become more pronounced over time as academic demands increase. Additionally, Jane's executive functioning weaknesses and attention problems appeared to be exacerbated by her anxiety. Parent report indicated notable anxiety, particularly regarding social situations. Further, during the interview, Mrs. Patient reported that Jane appears quite shy. Moreover, behavioral observations during testing included several instances when Jane appeared anxious about her performance and seemingly quite concerned about getting the answer "right." Although not rising to the level of clinical significance at the time of evaluation, her anxious symptoms required close monitoring, and Jane was judged to likely benefit from intervention and support to manage her anxiety.

Summary and Discussion

A few key features of these two cases bear mentioning. First, it is noteworthy that in the first case (i.e., Johnny), behavioral observations and certain test results appeared to strongly suggest problems with inattention and hyperactivity, but neither parent nor teacher report indicated clinically significant difficulties or symptomatology. In contrast, in the second case, tests of attention and executive functioning were "normal," and, behaviorally, she was attentive and on task and demonstrated good behavioral control during testing. Thus, it is important to appreciate the potential inconsistencies between behavioral observations during testing, performance-based test scores, and parent as well as teacher report of behavioral symptoms in daily life. Test findings described in neuropsychological reports may or may not align closely with ratings of a child or adolescent's behavior at home and/or at school. It is also noteworthy that weak performance on a performance-based test of attention does not necessarily lead to a diagnosis of ADHD. For example, in the cases presented, the patient who was diagnosed with ADHD performed quite well on a computerized test of sustained attention, while the other patient performed poorly on the same test but did not meet diagnostic criteria for ADHD. Lastly, these cases highlight the potential for co-occurring neurodevelopmental problems (such as learning disorder) and/or emotional health problems (such as anxiety) to mimic or magnify ADHD-like symptoms.

Best Practices for Supporting ADHD and Executive Dysfunction

Supporting ADHD

Pharmacological treatment has well-established efficacy for ADHD. For example, meta-analytic findings indicate that stimulant medication can reduce the behavioral symptoms of ADHD, and the improvement appears to be roughly comparable in inattentive symptoms and hyperactivity/impulsivity [83]. Moreover, recent meta-analytic evidence has suggested that stimulant medication can also improve cognitive functioning in children and adolescents with ADHD, including memory, reaction time, reaction time variability, and response inhibition [34]. While pharmacological treatment is associated with significant reduction of inattention and hyperactivity/impulsivity, certain psychosocial and executive function difficulties often remain [84, 85]. Research has demonstrated that children with ADHD benefit from an approach that combines both pharmacological and behavioral interventions. Some empirically based interventions and potentially beneficial strategies are discussed below.

Three broad types of school-based interventions for children with ADHD have been described: behavioral interventions, academic interventions, and self-regulatory interventions [86]. Research shows the strongest evidence for behavioral interventions. These should "set up" the expectations and consequences for certain behaviors and include "proactive strategies," such as reminding students of classroom rules throughout the day and using nonverbal cues to redirect behavior (e.g., hand on their shoulder or tap on their desk). These strategies can bring less attention to the negative behavior. Teacher attention is another strategy, where positive praise is provided to children who are engaging in socially desirable behavior (e.g., "I love how you are quietly completing your worksheet!"). Token reinforcement/response-cost plans and daily report cards can also be used, where reinforcers (e.g., sticker, smiley face) are provided for achieving a specific behavioral expectation (e.g., sitting quietly for 5 min).

Targeted academic interventions also are beneficial for many of these students, as children with ADHD are at a higher risk for academic decline. These can include explicit instruction, where the teacher reviews what is to be learned at the beginning of the lesson, presents skills in small incremental steps, and continuously assesses for understanding during instruction. Computer-assisted instruction (CAI) is another method that can be more engaging for students with attention difficulties. Further, peer tutoring, where students work in pairs and help each other practice academic skills, can be beneficial.

Self-regulatory interventions are a third strategy aimed to promote a child's ability to control their behavior across environments. In this approach, a target behavior is identified (e.g., recognize when they are attending to a task) and asked to record/monitor their performance on this behavior. Further, children with ADHD can exhibit difficulties with appropriate social interactions with peers, such as higher rates of noisy, disruptive, and rule-violating behavior that makes them more susceptible to social rejection and isolation [87]. There does not appear to be a "well-established" intervention for the social problems among children with ADHD; however, there are positive results for use of social skills training programs [88].

At home, similar interventions can be implemented to manage expectations. Parents can use behavioral interventions noted above to increase a child's ability to complete homework or assist with chores. Praise and positive attention are beneficial to increase adaptive and desirable behaviors.

While ADHD symptoms tend to decrease with age, adolescents with ADHD still exhibit significant difficulties managing themselves in their environment. Adolescents with ADHD have significantly lower grades, higher dropout rates, and increased delinquency and substance use and are less likely to pursue postsecondary education [89]. School-based supports aim to help students independently manage the increased academic demands. For example, many schools provide accommodations for students with ADHD, such as providing extended time to complete an assignment or test. These accommodations can often be clinically indicated based on specific test findings, such as a deficit in processing speed. Unfortunately, the scientific evidence base regarding the direct benefit for many of these supports is limited [90].

Supporting Executive Dysfunction

Comparatively, more research has explored executive function interventions. A meta-analysis reviewed cognitive and executive function training programs intended to improve cognitive, academic, and behavioral skills in children with ADHD [91]. Two types of non-pharmacological treatment options for EF-related deficits in children with ADHD were identified. The first approach involves "facilitative" training, where children engage in activities (usually computer-based) to strengthen areas of EF weakness. Meta-analytic results from 17 studies involving facilitative EF training in children with ADHD indicated small to negligible change. The authors postulate that findings might be due to incongruence between the intervention and the area of greatest impairment in children with ADHD (e.g., focusing on improvement of phonological short-term memory and not more complex use of working memory).

A second approach to EF intervention is to aid the child in developing compensatory strategies, which are practiced by the child in individual coaching/therapy sessions or are a result of environmental/curricular restructuring (e.g., breakdown multi-step directions). Two school-based programs to increase EF skills (e.g., planning, organization) are the Challenging Horizons Program (CHP) and the Home Organization and Planning Skills (HOPS) intervention (reviewed in [92]). The CHP can be implemented as an after-school program or mentor/coach model to improve organization and homework tracking. The HOPS program requires weekly sessions during the student's school day and two family meetings to promote generalization of skills to the home environment. Meaningful gains have been noted across studies in social, academic, and family functioning.

Clinicians and researchers have also suggested individual EF coaching/tutoring as a helpful intervention for children with ADHD. However, there are few empirical studies supporting the effectiveness of such programs [93]. A model with good face validity is the practitioners' guide *Executive Skills in Children and Adolescents: A Practical Guide to Assessment and Intervention* [94].

Conclusion

In summary, considerable research and clinical efforts have focused on developing an evidence base regarding best practices in assessing and supporting the learning and developmental needs of youth with ADHD. To support child psychiatrists in their work with these children and young adults, we close this chapter by listing some potential learning accommodations and supports that we commonly recommend for patients with ADHD and/or executive dysfunction (see Table 8.2).

Table 8.2 Potential learning accommodations/supports for patients with ADHD and/or executive dysfunction

Inattention
Preferential seating at the front of class as a means of reducing sources of distraction in the classroom
Separate, quiet room to take tests
Extended time (at least time-and-a-half) for all assignments, classroom tasks, and standardized tests
Brief, concise directions
Call *patient* by name and establish eye contact before providing directions or, when giving directions to the whole class, use cues such as "Eyes and ears on me!"
Have *patient* repeat and rephrase important information, especially instructions for tasks, to ensure she was attending
Draw *patient's* attention to the main idea and check in with her at the beginning of the task to assure she is on track and understands what is expected of her
Hyperactivity/impulsivity
Permission to stand or fidget with objects to stay stimulated or be provided with movement breaks
If there are behavioral control challenges in classroom, a Board Certified Behavior Analyst (BCBA) should be made available to consult with classroom teachers to help with developing behavioral programs to build *patient's* regulation skills in the classroom. The BCBA should also be available to consult with *patient's* parents to provide guidance regarding how to keep behavioral interventions consistent across home and school settings
Implementation of a "Daily Behavioral Report Card" may be beneficial to assist with the monitoring undesired behaviors (website: http://ccf.buffalo.edu/resources_downloads.php)
Executive dysfunction
To support weaknesses in self-monitoring, prompting and reminders to work slowly and carefully as well as to double-check work for accuracy might be helpful
To support organizational difficulties, teachers might assist the student in breaking down large tasks into smaller steps
To support shifting difficulties, teachers might make clear to the student that instruction on one topic has ended and allow extra time before moving on to another topic
To support difficulties in cognitive flexibility and shifting, teachers might provide advanced warnings of upcoming transitions
It might be helpful to provide prompting and reminders to organize belongings, prioritize assignments, break tasks into steps, and plan out the most efficient approach to completing a task

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9

Autism Spectrum Disorders

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Introduction

Children and adolescents with autism spectrum disorder (ASD) display an array of individual differences in their social-emotional, communicative, and behavioral symptom profiles, as well as variability in their developmental trajectories and treatment outcomes. Accordingly, within the specific field of clinical assessment of ASD, there is a quote which is frequently stated: “If you’ve met one person with autism, you’ve met one person with autism (often credited to Dr. Stephen Shore).” Mundy et al. [33] provided one theoretical model and framework for this heterogeneity that suggests that in addition to the multiple syndrome-specific etiological pathways that are involved in ASD (i.e., multiple genetic, epigenetic, and neurodevelopmental factors; [12]), there are likely a myriad of non-syndrome-specific modifier processes (e.g., individual differences in self-monitoring, social attribution, motivation, behavioral activation/inhibition systems, and environmental factors) that alter the expression and contribute to the array of phenotypic differences of the disorder. In other words, as with most psychopathology and neurodevelopmental disorders, ASD is best understood within a biopsychosocial framework. Given the complexity of this syndrome, one of the overarching goals for psychiatrists and related professionals working with individuals with ASD is to continue to develop and utilize reliable and valid assessments and, importantly, accurately interpret evaluation results (e.g., neurodevelopmental, neuropsychological, or psychoeducational testing) to inform treatment and educational programming for their patients and families. To assist with this ever-evolving process, provided here is an overview of the current state of the research on ASD, a discussion of early signs and symptoms of ASD and their associated impacts on learning, and a review of best practice assessments tools. Additionally, this chapter will discuss common comorbid conditions and their effects on test results, will provide a case study, and will review best practices for both school- and home-based interventions.

Current State of the Research

ASD is a pervasive neurodevelopmental condition, or a group of symptom-sharing disorders given the multiple etiologies and heterogeneity (perhaps more appropriately termed ASD<u>s</u>), which involves persisting deficits in social communication (e.g., poorly modulated eye contact, impaired social-emotional reciprocity) and social interaction (e.g., difficulties with developing, maintaining, and understanding social

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relationships) across settings and throughout an individual's life span [1]. Additionally, what often sets ASD apart from other conditions (e.g., social anxiety disorder [social phobia], attention-deficit/hyperactivity disorder [ADHD]) is the presence of restricted, repetitive patterns of behaviors, interests, and/or activities (e.g., narrow, atypical or fixated interests, atypical motor mannerisms, and sensory processing issues [1]). It is a condition that affects all racial, ethnic, and socioeconomic groups. Efforts are also being made to identify specific gender differences within this population as sex may serve as another moderator resulting in further heterogeneity within this disorder (see [26]).

The Centers for Disease Control and Prevention [5] currently estimates that 1 in 68 children (1 in 42 boys, 1 in 189 girls, i.e., approximately 5 times more common in males than females) in the United States is diagnosed with ASD. Notably, different research methodologies have resulted in even higher estimates as of late. While many of the specific factors (e.g., environmentally based) that may have contributed to the frequently and alarmingly referenced "rise in prevalence rates" have yet to be identified, the more recent broadening of the definition of ASD; the increased level of understanding of the syndrome across research, clinical, and nonclinical settings (e.g., schools); and the development and improved access to sophisticated assessment tools all likely play an integral role in the increase in prevalence. Generally, this discussion requires that the differences between the terms "incidence" and "prevalence" are strongly considered. Incidence is the number of individuals in a population in whom the condition begins within a specified *time period* (e.g., tracking rates of increase of identified children with ASD across a 1-year timeframe), versus prevalence, which refers to the number of individuals in a population at a particular *time point* (i.e., a snapshot of how many individuals have a diagnosis on a particular day [18]). Thus, while the prevalence of ASD has certainly increased, it is not entirely clear at this time whether the incidence has followed suit.

In terms of etiology and risk factors for ASD, by and large the extant literature suggests that there is likely a myriad of causes, although specific pathways remain somewhat elusive. However, various research camps have supported that genes play an integral role. Heritability estimates for ASD have historically ranged from 37% to higher than 90% based on twin concordance studies [3, 14, 48], and more recent work continues to suggest a range of estimates from moderate (e.g., 38%; [20]) to high levels of genetic heritability (e.g., 64–94%; [51]). Children who have a sibling with autism are at higher risk (2–18%) for this condition as well [39]. Importantly, Yuen et al. [53] recently illustrated the substantial genetic heterogeneity that exists in ASD, demonstrating the notion that affected siblings do not necessarily inherit the same autism-risk genes from their parents. This work highlights not only the polygenic nature that is involved in this complex syndrome but it also suggests that the culpable genes that were passed from the parents to affected "child A" will not necessarily be the same autism-causing genes that will increase the risk that child A's sibling *may* have in developing the condition. Additionally, there have been certain genetic or chromosomal conditions, such as Fragile X syndrome, in which ASD is more common [19]. There is also some evidence for higher risk with certain prescription drug intake during pregnancy (e.g., valproic acid and thalidomide), and research has suggested that the age of parents and low birth weight may be contributing factors as well [6, 13, 50]. Moreover, there are several neural and brain anatomical abnormalities that have been associated with ASD, including aberrant brain activity or neural markers [41] and early brain overgrowth and dysfunction evidenced within the prefrontal and temporal cortex [49]. There is one factor that we know that does *not* cause ASD: vaccines (see [37]). Currently, ongoing and comprehensive efforts are being made to further elucidate and/or identify the genetic, environmental, epigenetic (i.e., gene-environmental interactions), pre-/perinatal, brain anatomical, and other neurodevelopmental factors that are at the etiology of this complex condition.

Early Signs, Symptoms, and the Impacts on Learning and Development

ASD can be identified as early as 18 months or younger, and it is most reliably diagnosed at 2 years of age [30]. However, while these symptoms can be overtly observed and formally evaluated via clinical assessment during this critical time in development, we know that the architecture of the brain begins to develop much earlier in the prenatal period (i.e., around week 5 of pregnancy). In addition to genetics, a child's interaction with "the world" and, if you will, "the world's" interaction with that child during the pre- and perinatal periods and beyond begin to alter neural connections, pruning, and neural functional connectivity (e.g., [41]) and ultimately lay the blueprint for later brain architecture and function. More than 700 synapses are made every second in the first years of life. Thus, if a child is biologically engineered to develop autism via one or more of the multiple etiological pathways, it is then plausible that the early signs and symptoms of this disorder start to significantly impact that child's learning much earlier than when symptoms are identifiable. For example, relative to "neurotypical" infants, if an affected ("pre-diagnosed") newborn's brain responds differently to speech sounds as research supports or the child has a decreased proclivity to engage in fundamental social interactions (e.g., face-to-face interchanges with his/her caregivers) or cannot tolerate being held too long due to an early onset of sensory sensitivities, then that child is missing out on vital nurturing and early "learning" opportunities that are important for healthy brain development. These early neurodevelopmental disturbances, for instance, impaired joint attention (i.e., following others' eyes and facial expressions when being directed to look at an object; see [33]), have been shown to hinder that child's foundational skill sets that are important for early learning and development (e.g., self-regulation/self-monitoring, attention, language acquisition, motor development, etc.). This is precisely why early identification is imperative in order to establish treatments as early as possible that will decrease the duration and level of adverse impact that ASD symptoms have on a child's learning and maturation.

Even when a child reaches the age range of 18 months to 2 years and the early signs and symptoms of ASD are manifested behaviorally and thus can be overtly observed and formally evaluated, the process of early identification is still not an easy task for clinicians. In fact, on average, children identified with ASD are not diagnosed until after age 4 [5]. This is largely due to the heterogeneity, the vast variability in development in all children, and the fact that there are several other developmental challenges (e.g., speech and language weaknesses) and atypical behaviors (e.g., motor delays or stereotypies) that can still fall on the cusp of "normal" developmental expectations or be associated with other conditions (e.g., language disorder, stereotypic movement disorder, or global developmental delay). Delays in development can occur in isolation and naturally resolve simply through further biological maturation or with early intervention with no long-standing or future impacts (e.g., single-word acquisition at 14–15 months (versus 12 months) with language acquisition progressing as expected from that time point). Nonetheless, there are hallmark symptoms related to ASD that prominently emerge between the ages of 18 months and 5 years in an affected child's life and greatly impede on their learning experiences and development. Sometimes these concerns are noted earlier as studies have shown parents often notice developmental differences prior to age 1 [25].

A child's ability to learn from their social experiences, their acquisition of language, and their fine and gross motor development (see [4]) can all be impaired due to ASD, and as a result, these vulnerabilities can greatly hinder a child's successes within early childhood educational settings (e.g., preschool and kindergarten). Children with ASD can not only experience challenges with learning letters and numbers and how to appropriately draw and/or trace, but they also have difficulty with social relationship development, learning how to navigate peers and early social conflicts (e.g., sharing), learning how to adaptively process or tolerate certain sensory inputs, and meeting fine and gross motor expectations, and they experience challenges with an array of other important school readiness abilities (e.g., self-regulate in circle time, follow daily rules and expectations). Some of the most common symptoms from the ages of 2–5 years that significantly impact a child's early learning experiences and development, which are also considered core symptoms of this condition, are indicated in Table 9.1. It is important to note that any one, or even several, of these characteristics do not warrant a diagnosis of ASD as a formal clinical evaluation is necessary. These are simply early signs and symptoms that may warrant follow-up.

The presentation of symptoms of ASD evolves across development into the school-aged years on into adolescence (i.e., ages 6–17 years) as academic and learning expectations simultaneously increase. Through biological maturation as well as the impacts of environmentally based factors (e.g., interventions, family supports, educational services, or psychosocial stressors), the symptoms associated with ASD for a particular youth will change. For example, some symptoms may remit, some may become more prominent/severe, or others may progress into a nuanced behavioral manifestation. These changes may occur due to the implementation of interventions, or lack thereof, in addition to the exponential increase in expectations that are set forth in an adolescent's environment. Even for the highest-functioning children and adolescents with ASD, the core symptoms of this syndrome can frequently result in academic challenges across most areas, including reading, math, and written expression. Generally speaking, children and adolescents with ASD tend to perform more poorly on standardized academic testing that involves comprehension (e.g., reading) and written expression relative to controls but do better (i.e., commensurate with estimates of intellectual functioning) on mechanical reading, spelling, and math tests [18, 32]. Some of the commonly observed symptoms associated with ASD within the school-aged years and into adolescence that can impede a youth's successes within an educational setting include the following:

- Persisting challenges with poor or inconsistent eye contact that adversely affects social functioning.
- Difficulties with the use, and interpretation, of nonverbal communicative behaviors such as gestures for describing objects or events, which impact social successes and can also lead to missing elements of curriculum presented within the classroom setting.
- Challenges with reciprocal or to-and-fro conversation, providing an account of an event and cultivating social relationships with agemates. Moreover, these difficulties can compromise a student from fully accessing concepts presented in the classroom by precluding richer conversations or engagement in more dynamic learning moments with school personnel or peers.
- Excessive or repetitive interests in topics to a degree that impairs social functioning and relationship development as well as engagement in non-preferred academic tasks.
- Vulnerabilities with executive functioning (e.g., organization, self-monitoring, time management, forgetfulness, and planning) that negatively impact academic functioning, such as engagement in curriculum or learning activities. In addition, weaknesses in sustained attention, concentration, or restlessness can compromise engagement in learning activities and the efficacy of teaching.
- Cognitive rigidity and/or inflexibility in routines and poor adaptability to transitions or change, which impact a students' ability to fluently navigate the school setting and expectations.
- Challenges with more abstract thinking or a tendency to think about concepts more concretely, which creates barriers to accessing school curriculum.
- A more prominent onset of emotional dysregulation, particularly internalizing challenges (e.g., anxiety, depression, or poor self-esteem), due to the resulting day-to-day obstacles presented within a school setting.

Table 9.1 Symptoms and areas affected in early childhood educational settings

Symptoms	Social functioning	Language acquisition	Access to school curriculum	Mobility in classroom	Self-regulation	Following classroom rules and expectations
Poorly modulated eye contact when interacting with both unfamiliar and familiar adults and age-mates	X	X	X		X	X
Speech and language challenges and/or atypical use of language that is peculiar, including significant speech delays, echolalia or delayed echolalia, pronoun reversals, unusual volume, speech prosody, or intonation	X	X	X		X	X
Limited social initiation or response with both unfamiliar and familiar adults and age-mates, such as poor or inconsistent response to name, and peculiar attempts to engage others—either verbally or nonverbally (e.g., hand-over-hand attempts to use another's body part as a tool)	X	X	X		X	X
Difficulties fluidly interacting with peers	X		X		X	X
Limited use of nonverbal communication means, such as gesturing, pointing, or providing descriptions of events or objects with their hands	X	X				
Limited display of facial expressions to direct affect and/or emotional expressions that are incongruent with circumstances	X		X		X	
Challenges with responding to joint attention and/or following others' eyes and facial expressions when being directed to look at a remote object	X	X	X			X
Limited initiation of joint attention, such as attempts to direct another's attention to objects of that particular child's interest	X	X	X		X	X
Minimal displays of showing objects to others in efforts to demonstrate their own interest and/or engage the interests of others	X	X	X			
Limited displays of shared enjoyment or interest in social games	X	X			X	X
Poor imaginative play or "play" that is nonfunctional in nature and comprises categorizing, lining up objects, peering at parts of toys in a peculiar way, and/or other uses of toys that appears atypical	X	X	X			X

Table 9.1 (continued)

Symptoms	Social functioning	Language acquisition	Access to school curriculum	Mobility in classroom	Self-regulation	Following classroom rules and expectations
Sensory-seeking behaviors or atypical and repetitive motor mannerisms, such as hand flapping, spinning, walking on toes, looking at objects through the corner of their eye	X		X	X	X	X
Hyper- or hyposensitivity to sensory stimuli	X	X	X	X	X	X
Intense and/or repetitive interests in objects or topics	X		X		X	X
A strict adherence to routines, a need for predictability, and difficulties with adapting to change or transitions	X		X	X	X	X
Markedly impaired impulse control or overactivity	X	X	X	X	X	X
Impaired fine and/or gross motor control (e.g., using scissors, joining routine, group-based, social games within the classroom)	X		X	X		X

"X" denotes area likely to be affected

As indicated here, the symptoms associated with ASD begin to impact a child's learning and development early in life. A patient's profile of strengths and weaknesses will evolve into the school-aged years, adolescence, and beyond as academic and learning expectations simultaneously increase. These symptoms can continue to hinder an affected patient's social, emotional, behavioral, speech and language, sensory processing, academic, and adaptive development across their life span. As such, early identification is vital in establishing tailored interventions, which serve to mitigate the adverse impacts symptoms of ASD have on affected patient's learning and development.

Assessment Process and Tools

If you've evaluated one person with autism, you've evaluated one person with autism. The complexity and heterogeneity of this syndrome accordingly require a comprehensive, multi-method, and at times multi-informant as well as multidisciplinary evaluation process. The procedure should comprise clinical interview, clinical observation, standardized assessments, and report measures. The general methodology behind the assessment process, such as test battery selection, will depend on several factors similar to many other clinical evaluations, including but not limited to chronological or mental age, informal or formal estimates of intellectual functioning, language abilities (e.g., nonverbal versus verbal), behavioral functioning, motor development, sensory tolerance, and multicultural considerations (e.g., bilingualism or English as a second language). A clinician's overarching goal during the assessment of ASD is to determine whether the reported symptoms of concern fall within the realm of "neurotypical/normal" age-appropriate developmental expectations and/or to differentiate these symptoms from other psychopathology or neurodevelopmental conditions.

Generally, an evaluation should answer the following questions: (1) Is there currently the presence of persisting symptoms, observed across multiple settings, which are associated with ASD as delineated in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; [1])? (2) Were these symptoms present in early development given ASD is a pervasive developmental disorder? (3) Are there enough symptoms, which have a duration and severity level, which result in functional impairment? (4) Are these symptoms better accounted for by another psychiatric or neurodevelopmental condition, such as global developmental delay, intellectual disability, ADHD, "nonverbal learning disability (NVLD)" neurocognitive profile, language-based disorders (i.e., language disorder, social [pragmatic] communication disorder), motor/movement conditions (e.g., stereotypic movement disorder), anxiety, or any other conditions? Figure 9.2 illustrates this clinical procedure in a simplified fashion for the purposes here, but readers should keep in mind that a similar graph could likely be made for each of the domains, or the "spectrum," of functioning in patients with ASD (i.e., one graph for social functioning; communication; restricted, repetitive behaviors and interests; flexibility in thinking or adherence to routines; and sensory processing). Overall, this is not an easy task, and questions 3 and 4 noted above can be particularly challenging to answer for an evaluator.

The assessment of ASD can be a highly involved process due to the variability in presentations. This is not always the case with some patients, as symptoms associated with the disorder can be prominent across settings and a patient's life span. However, ASD can often be clinically perplexing due the substantial overlap between other conditions (see section below discussing comorbidity) and even non-pathological symptom profiles. For example, children with subclinical social or behavioral vulnerabilities that do not meet criteria for any diagnosis can evidence a smattering of autism-related symptoms (e.g., strong interests in Minecraft™ or sensory sensitivities to clothing or food textures) as can those youth with ADHD, specific neurocognitive profiles associated with NVLD, or language-based conditions as noted above. These symptoms are also frequently at the forefront of referral questions and can, at times, serve as a "red herring" and misguide the clinical formulation process. Some of these particular clinical profiles can fall within the gray area depicted in Fig. 9.1. These patients conceptually present with what is termed as a "broader autism phenotype (BAP)," which has been defined as a condition involving subclinical characteristics associated with ASD (see [38]). Notably, patients with this BAP presentation may not meet the "diagnostic threshold" as per an evaluator's clinical opinion at one particular assessment time point (e.g., 5 years), but as expectations exponentially increase within the home and school settings, a child's symptoms might become more prominent and lead to increased functional impairment at a later age (e.g., 9 years) falling at or on the right side of that threshold. Similarly, a child may present differently across environments. For example, a child may function well socially with some presence of ASD-related behaviors with neighborhood friends that have similar socio-communicative and behavioral profiles or while at a particular summer camp. However, that same child may evidence increased social challenges within a highly populated school setting with significantly more nuanced and/or abstract social situations. This may in turn lead to more distress, perhaps sensory overloads, an increased need for routine, and social withdrawal resulting in a retreat into their more comfortable world of "gaming" (e.g.) that further impacts their social successes. Therefore, children and adolescents may fall to the left or right side of that diagnostic threshold in Fig. 9.1 depending on age and expectations, the way their environment(s) exploits their particular weaknesses or supports their vulnerabilities, and various other factors. An evaluator's responsibility is to both consider and disentangle all of these variables in efforts to make sound clinical diagnostic decisions in their patients' best interest. This will ultimately provide access to and inform treatment and educational planning. Below is an overview of some of the best practices in achieving these goals.

The clinical interview is one of the most vital tools in the assessment of ASD. It should comprise a comprehensive developmental history for a patient in addition to a review of the more

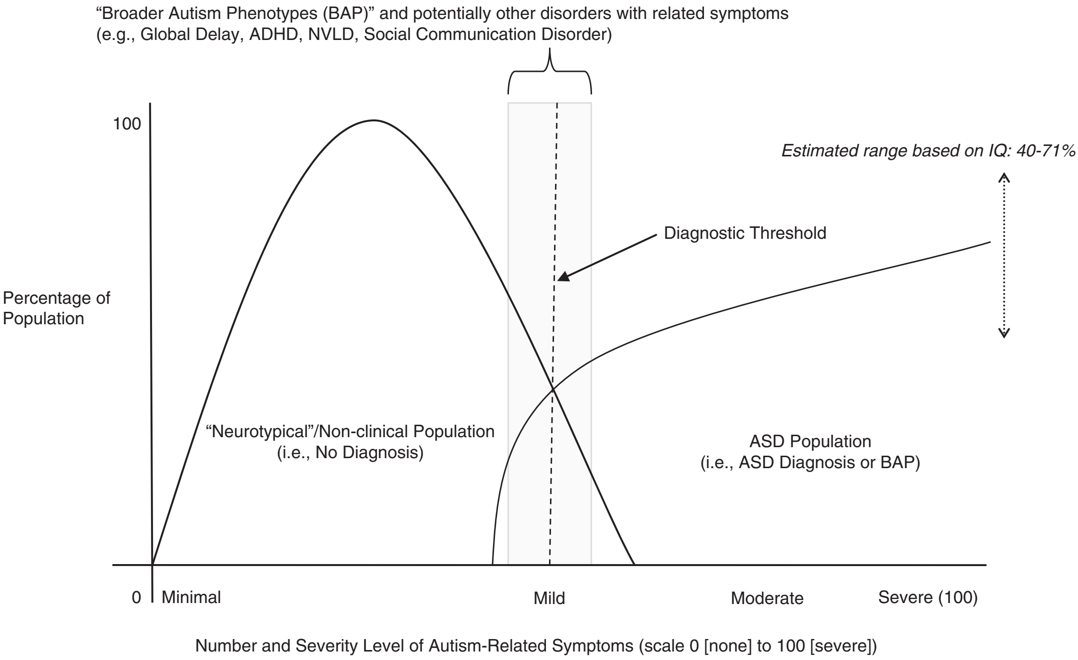

Fig. 9.1 Differentiating ASD from neurotypical and other psychiatric

recent concerns. In order to make a formal diagnosis, symptoms must be present in early development, although they may not manifest fully until developmental and societal expectations begin to exceed a patient's capacities. Whether a clinician is evaluating young children (i.e., ages 18 months to 5 years), those that are of school age (i.e., ages 5–12) or adolescents (i.e., ages 13–17), there are key symptoms that are essential to identify both from a historical perspective and current level of functioning while determining the presence of the disorder. Many of these symptoms are listed in the section above. Specifically, clinical inquiry should involve questions surrounding the following: eye contact, initiation of and response to joint attention in early childhood, response to name, overall social reciprocity, use of nonverbal means to communicate (e.g., gesturing), language development or display of stereotyped speech patterns (e.g., delays and/or peculiarities, such as echolalia or pronoun reversals), motor development (e.g., poor fine motor control or gross coordination), play (i.e., imaginative versus nonfunctional and/or atypical play), stereotyped or sensory-seeking behaviors (e.g., hand flapping, toe walking, spinning, or inappropriately smelling objects), sensory processing issues (e.g., sensitivity to stimuli, such as certain touch or certain noises), atypical and/or excessive interests in themes or objects, rigidity or strict adherences to routines, and any regression in any of these skill sets (research estimates that around 41–46% of children experience a loss of skills by age 3 [21, 40]). The higher the frequency of all of these symptoms, the severity of impairment, and their consistency across development, the more confident a clinician is in determining a diagnosis of ASD.

In addition to the clinical interview, it is very beneficial for an evaluator to profile a patient's neuropsychological strengths and weaknesses through an array of standardized assessments. Some of this testing will not necessarily assess specific symptoms related to ASD; however, importantly these measures can be vital in identifying potentially confounding factors (e.g., cognitive potential and language ability) that may be contributing to a patient's socio-emotional or behavioral vulnerabilities . The DSM-5 also currently requires clinicians to specify social and behavioral severity levels (Level 1 "requiring support," Level 2 "requiring substantial support," and Level 3 "requiring very substantial support" [1]) and determine whether the ASD diagnosis coexists with intellectual or language impairment. Comprehensive testing procedures clearly help inform how a diagnosis is specified and/or qualified in this manner. Therefore, the assessment of ASD often entails many of the evaluation practices described throughout other chapters in this book and should involve (and is not limited to) measurements of the following: cognitive/intellectual potential or developmental level; language functions; nonverbal, visual-spatial, and visual-motor processes; fine and gross motor development; sensory functioning; attention and other executive functions; memory and information processing; academic functioning; socio-emotional and behavioral functioning; personality assessment; and adaptive functioning. The reader is referred to the accompanying chapters in this book to review assessment procedures for each of these areas.

Once a comprehensive neuropsychological profile is obtained, a clinician is able to rule in or out other confounding variables (which may be leading to symptoms associated with ASD that can be better explained by another condition), or that clinician is able to qualify a diagnosis of ASD if indeed it is clinically indicated. To confirm the latter circumstance, there are several standardized assessments and report measures that are considered the "gold standard" in ASD diagnostic confirmation. Goldstein et al. [18] provides a comprehensive account of many of these measures. Some of the most commonly utilized assessment tools come in the form of semi-structured clinical observation, structured clinical interview, observation, and rating forms. Probably the most widely utilized and evidenced-based assessment tool is the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; [28]), which is a semi-structured clinical observation tool used to assess social and communicative behaviors using a series of "presses" (i.e., opportunities for individuals to demonstrate social competence) and other activities (e.g., free play) that may elicit atypical behaviors associated with ASD. Patients are assessed using one of the five modules, which are selected based on that individual's age/developmental level as well as language functioning. Another observation (as well as rating) tool utilized, yet arguably less sophisticated and objective than the ADOS-2, is the Childhood Autism Rating Scale (CARS; [46]), which is a 15-item behavior rating scale that can either be completed via clinical observation or parent report. Additionally, the Autism Diagnostic Interview-Revised (ADI-R; [44]) is a lengthy structured interview comprising 93 questions surrounding the hallmark symptoms of ASD from both a historical and current level of functioning perspective. Moreover, there is an array of helpful rating scales that can be completed by caregivers and school personnel, or both, which assess the three hallmark areas of social, communicative, and behavioral functioning in youth suspected of ASD. These include, but are not limited to, the following: CARS (as indicated above); Social Responsiveness Scale, Second Edition (SRS-2; [9]); Social Communication Questionnaire—Lifetime and Current Behavior (SCQ; [43]); Gilliam Autism Rating Scale, Second Edition (GARS-2; [16]); Gilliam Asperger's Disorder Scale (GADS; [17]); and PDD Behavior Inventory (PDDBI; [7]). Table 9.2 provides a list of all of these measures along with information pertaining to appropriate age range use, format of the assessment tool, psychometrics (see manuals for more details), type of score utilized in interpretation, what score(s) ultimately would suggest an ASD diagnosis, and some additional comments.

Comorbidity and the Effects on Testing Results

ASD shares a substantial number of symptoms and accordingly some genetic risk factors, with several other psychiatric (e.g., anxiety, OCD, and mood disorders), neurodevelopmental (e.g., ADHD, NVLD learning profiles), and medical conditions (Fragile X syndrome; [11]). The percentage of comorbidity with one or more non-ASD developmental diagnosis is 83% and one or more

Table 9.2 Common ASD assessment tools and utility

Measure	Age range	Form	Psychometrics	Type of scores	What scores support ASD diagnosis?	Other considerations
ADOS-2	12 months to adults	Semi-structured observation	Good reliability (e.g., intraclass correlations, 0.79–0.98; test-retest, 0.68–0.92) and validity (e.g., sensitivity, 87–98%; specificity, 19–94%)	"Raw scores" (however, ordinal data) placed into specific algorithms	Toddler module: 8 (older with some words) to 10 (if young and few words) and higher	Extensive training for administration and scoring
					Module 1: 8 (if some words) to 11 (if few to no words)	
					Module 2: 7 (if < age 5) to 8 (if > age 5)	
					Module 3: ≥7	
					Module 4: communication score ≥2; social interaction score ≥4; and combined ≥7	
ADI-R	Mental age of 2 years – adults	Structured clinical interview	Good reliability (e.g., intraclass correlations, 0.93–0.97) and validity (sensitivity, 82–91%; specificity, 75–78%)	"Raw scores" (however, ordinal data) placed into specific algorithms	Cutoff scores on age-specified algorithms: social ≥10; verbal ≥8; nonverbal ≥7; stereotyped behaviors ≥3; and abnormal development ≥1	Lengthy interview process
SRS-2	2.5–18 years	Rating scale	Good reliability (e.g., test retest, 0.88–0.95) and validity (e.g., sensitivity and specificity, 92%)	T-scores	Total T-score ≥60 ("mild")	Provides gender norms; while good specificity reports, our clinical practice finds measure is frequently elevated in other conditions (e.g., ADHD)
					T-score 66–75 ("moderate")	
					T-score ≥76 ("severe")	
SCQ	Mental age of 2 years – adults	Rating scale	Good reliability (e.g., internal consistency, 0.81–0.92) and validity (e.g., area under curve (AUC) analyses, 0.74–0.92)	Raw scores	Cutoff score ≥15	Two forms: lifetime (for diagnosing) and current behavior (for profiling and treatment planning)
CARS	2 years – adults	Observation and rating scale	Good reliability (e.g., internal consistency, 0.81–0.92) and validity (e.g., sensitivity, 82–89%; specificity, 82–80%)	"Raw scores" (however, ordinal data)	Cutoff score ≥30 ("mild to moderate"); 37–60 ("severe")	Can be completed via observation or parent report. No standardized setting
GARS-2	3 years – 22	Rating scale	Good reliability (e.g., test-retest, 0.64–0.84) and adequate validity (e.g., concurrent correlations with autism behavior checklist −0.64)	Standard scores	Scaled scores ≥70 ("possible")	Includes caregiver interview section
GADS	3 years – 22	Rating scale	Adequate reliability (e.g., internal consistency, 0.70–0.94) and validity (e.g., sensitivity, 84%; specificity, 84%)	Standard scores	Scaled scores ≥70 ("borderline" probability)	Includes caregiver interview section
PDD-BI	1.5–12 years, 5 months	Rating scale	Good reliability (e.g., internal consistency, 0.80–0.98) and validity (e.g., sensitivity, 92%; specificity, 69%)	T-score	The average child with autism will have scores between T-scores of 40–60	Normative data available across ages in specified range

The reader is referred to Goldstein et al. [18] for a more detailed description of many these measures

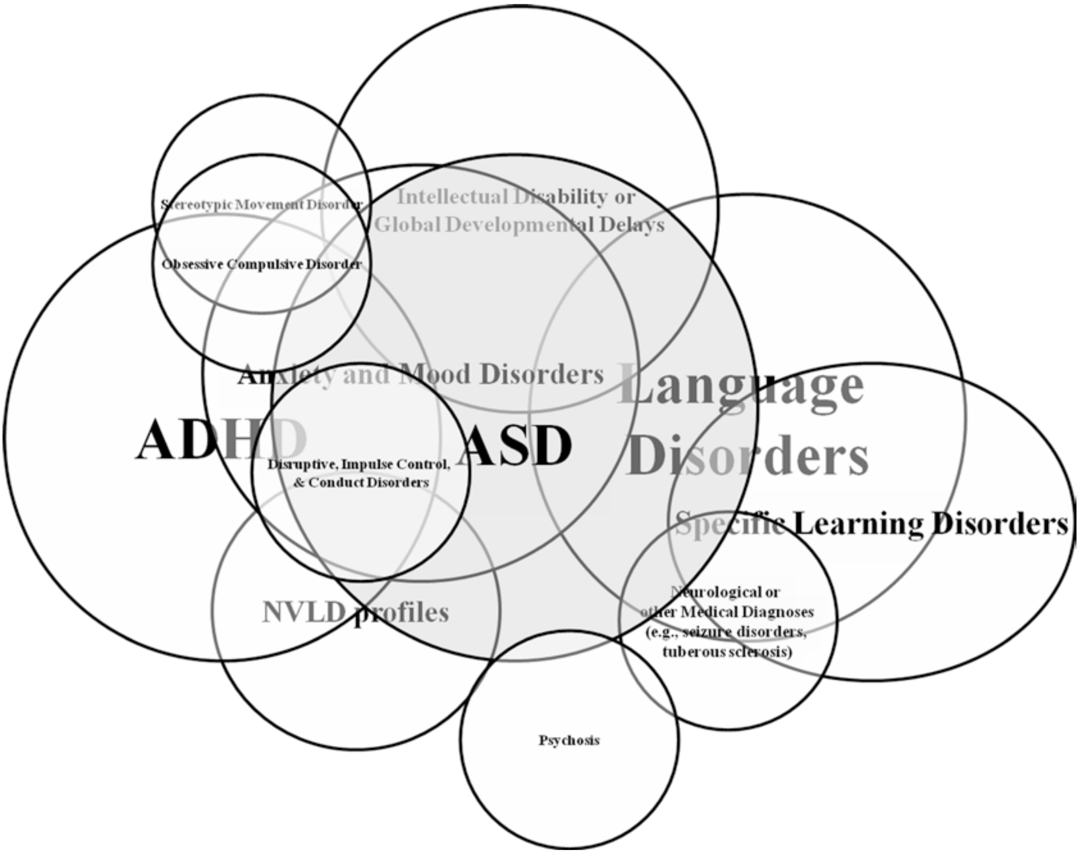

Fig. 9.2 Comorbidity across ASD and other major psychiatric, neurodevelopmental, and medical conditions

psychiatric diagnosis is 10% [5]. While by no means all-inclusive, one illustrative example of the extent of the overlapping symptomatology across ASD and several other conditions is depicted in Fig. 9.2. This also further highlights factors leading to the significant heterogeneity within this condition. Moreover, the extant research suggests that approximately 54% of youth with ASD have intelligence scores falling below average [5], with some estimates suggesting the median rate of intellectual disabilities to be around 70.4% for those that would have previously been diagnosed with “autistic disorder” [15]. One more recent study suggested that approximately 18.3% of individuals (aged 8) with ASD were found to have an intellectual disability [27]. In addition to the co-occurrence of intellectual disabilities, some estimates of rates of comorbidity within the ASD population (age range, 4.5–9.8 years) include the following (see [27, 45] for an extensive review): any DSM disorder (90.5%); any DSM emotional disorder (80.0%); anxiety disorders (3.4–78.9%; generalized anxiety disorder is the highest at 66.5%); ADHD (21.3–59.1%); major depression (1.1–14.6%); disruptive, impulse-control, and conduct disorders (30.7%); epilepsy (15.5%); enuresis (13.5%); encopresis (1.9%); intellectual disability (18.3%); learning disorder (6.3%); language disorder (63.4%); and sleep problems (44–83%; [24]).

These relatively high rates of comorbidity in patients with ASD present several challenges for evaluators as they can often significantly confound results of standardized testing. A primary role of the evaluator is to obtain a reliable and valid estimate of their patient’s functioning across several domains (e.g., intelligence, language, attentional capacity, academic skill sets);

however, the core symptoms of ASD along with these co-occurring conditions can frequently compromise these efforts. Specifically, as with most clinical evaluations, patients with ASD presenting with comorbid language or cognitive impairment, attentional challenges, hyperactivity, impulsivity, other executive dysfunctions, anxiety, mood-based disturbances, as well as any other condition and/or symptom(s) that can confound performances can at times achieve below their potential on standardized testing. This can at times bring into question the validity and reliability of test results. For example, a patient with ASD presenting with significant language deficits who is administered an intelligence test (e.g., Wechsler Intelligence Scale for Children) may perform markedly below expected levels, resulting in an overall estimate of their intellectual potential falling substantially below expectations. However, language deficits can significantly affect a patient's performances on standardized testing as many of these instruments of intelligence are confounded by one's ability to utilize and understand language. A test of nonverbal intelligence, which is not confounded by language, can at times be a more appropriate measure as it provides a better estimate of cognitive potential in the context of marked language deficits. Similarly, a patient with ASD who is highly inattentive, hyperactive, and/or impulsive, and perhaps anxious, may have difficulties attending to instructions, scanning all options for correct responses, or generally engaging in a one-to-one testing environment with the evaluator. Thus, that particular patient's performances on standardized testing will be highly confounded by these symptoms, and the results may have to be interpreted with some caution. Overall, when interpreting results of testing strong consideration is needed as to how a patient's particular clinical profile, including those symptoms outside of the core traits of ASD (e.g., anxiety, inattention, self-regulation), may affect their performances on standardized testing. Psychiatrists and related professionals reviewing evaluation reports should always seek out additional information in that evaluator's narrative of the report, as well as within the behavioral observations section, to ensure the validity of test findings; in particular, a statement about validity of findings is almost always provided in the behavioral observations section of assessment reports.

Case Study

Provided here is a case example that highlights important features of the evaluation process along with the testing results that were utilized in making a diagnostic determination of ASD for a young boy presenting with several concerns. Information was obtained through a neuropsychological evaluation comprising a clinical interview and observation, collateral with a referring pediatrician, standardized testing, and parent and teacher reports on standardized measures.

Reason for Referral *James was a 5-year, 11-month-old, right-handed, monolingual (English) boy of Hispanic descent referred for a neuropsychological evaluation by his pediatrician and his biological parents (Mr. and Mrs. Smith). In the context of a prior diagnosis of attention-deficit/hyperactivity, combined presentation (ADHD-C), James's parents and pediatrician were seeking further diagnostic clarification due to a history of concerns regarding socio-communicative weaknesses, sensory processing difficulties, as well as emotional (e.g., anxiety) and behavioral (e.g., outbursts) dysregulation patterns.*

Early Development *James was only utilizing approximately 3 words at 18 months; however, his phrase speech and use of simple sentences developed as expected. He reportedly received an evaluation around that time, which was noted to be unremarkable. James's early motor milestones were remarkable for fine motor weaknesses (e.g., learning to hold and use a writing utensil) in the context of receiving occupational therapy at school.*

Medical History *Medical history was reported to be largely unremarkable, with the exception of ear infections, sleep disruption, and nighttime* *enuresis. He took melatonin to assist with sleep. Notably, James had been followed by a developmental pediatrician for over 2 years due to persisting ADHD-C concerns, sensory-seeking behaviors, and social difficulties despite treatment efforts.*

Psychosocial/Psychiatric History *James's early developmental history was remarkable for eye contact that was better modulated in more comfortable settings, inconsistent response to name, sensory sensitivities, and some atypical play behaviors (e.g., more organizational play patterns rather than imaginative play). Some subtle patterns of excessive interests were noted at a young age as well, where he was reported to be able to provide some level of finite information on certain topics. Socially, James was reported to have preferred to play alone on occasion and to struggle at times to relate consistently well with age-mates, although he engaged successfully at times with his peers.*

At the time of the evaluation, Mrs. Smith reported that James exhibited challenges with hyperactivity, sensory processing (e.g., wears earmuffs on occasion), and fine motor control. Socially, despite having some friends at school, he was noted to be somewhat "awkward" and to experience challenges with self-monitoring. Mrs. Smith also noted challenges with understanding social boundaries and personal space. Some excessive and atypical interests in content (e.g., Greek mythology) were indicated. Daily tantrums/outbursts triggered by adult requests were evident. He was also reported to experience challenges with running away at school and to have evidenced some very brief and subtle stereotypies at times (e.g., hand flapping). Further, Mrs. Smith reported some symptoms of anxiety qualified by perfectionistic tendencies.

Educational History *James's academic tenure is notable for tantrums/outbursts as well as inconsistent social successes. Academically, Mrs. Smith reported that he performs well when he is able to sustain his engagement in tasks. James was at the time enrolled in Kindergarten in a substantially separate classroom under the auspices of an Individualized Education Program (IEP).*

Key Clinical Observations *While James exhibited some appropriately developed social behaviors (e.g., direction of affect/facial expressions, nonverbal gesturing, social referencing, and sharing information), the modulation of his eye contact and overall social reciprocity was limited for his age and language abilities. Speech and language was notable for pragmatic difficulties. In addition, James exhibited some stereotyped speech patterns such as sporadic peculiar vocalizations with odd intonation, a loud volume, and/or a stressed tone. He also evidenced very brief hand mannerisms when excited and some atypical use of fingers for pointing and referencing remote objects. His interests in specific topics were observed. James also experienced significant challenges with restlessness, distractibility, and sustained attention. However, the impact of these vulnerabilities on his test performances was mitigated by positive behavioral supports and redirection. Thus, the results of testing were considered a valid representation of his abilities in the context of a one-to-one testing setting.*

Key Neuropsychological Test Results *James was administered the Differential Ability Scales, Second Edition, an assessment battery that includes tests of cognitive abilities. A General Conceptual Ability, an estimate of James's overall cognitive potential, fell within the high-average range (standard score [SS] = 116; 86th percentile). His verbal abilities were superior (SS = 120; 91st percentile), his nonverbal abilities were high average (SS = 117; 87th percentile), his spatial abilities were average (SS = 109; 73rd percentile), his working memory was average (SS = 101; 53rd percentile), and his processing speed was high average (SS = 117; 87th percentile). Separate tests of his language functioning indicated that his abilities fell at or above expected levels. Separate measures of his nonverbal/perceptual reasoning and visual-spatial processing fell at/or above expected levels; however, James evidenced markedly impaired visual-motor integration skills on the Beery-Buktenica Developmental Test of Visual-Motor Integration, Sixth Edition (SS = 81; 10th percentile). Tests of verbal and visual memory revealed intact abilities that were hindered by attentional* *weaknesses. Academically, James performed at expected levels on tests of achievement, with the exception writing fluency. Parent and teacher reports on rating scales suggested marked executive dysfunction along with several other concerns regarding hyperactivity, aggression, anxiety, depression, somatization, social skills, withdraw, sustained attention, adaptability, and adaptive functioning (6th percentile) in both the home and school settings.*

Key ASD-Specific Test Results *In addition to the clinical interview and observations, the SRS-2 was completed by Mrs. Smith and James's teacher, Ms. Johnson, and reflected "mild to moderate" social challenges as well as "moderate to severe" restrictive-repetitive interests/behaviors within the home and school settings. Teacher reports were more highly elevated than parent reports on the SRS-2. James's social functioning and communication and restricted/stereotyped interests were also examined using ADOS-2—Module 3. Findings from the ADOS-2 indicated that James demonstrated weaknesses in his socialization and communication skills, as well as evidence for some stereotyped behaviors and restricted interests. Overall, James's performance on the ADOS-2 indicated that he did meet clinical cut-off (total raw cutoff score = 7) for an autism spectrum disorder (ASD; total raw score obtained = 8). His level of autism spectrum-related symptoms, which is separated from the overall criteria total score, fell within the "moderate" range (ADOS-2 comparison score = 5 out of 10 [1 = minimal-to-no evidence; 10 = high evidence for ASD).*

Overview of Summary and Clinical Impression *Overall clinical impressions and results of testing were consistent with a young boy who was presenting with a social, communicative, and behavioral profile that met the DSM-5 criteria for autism spectrum disorder (ASD), without accompanying intellectual or language impairment. Collectively, results indicated Level 2 severity: "requiring substantial supports with social communication and restrictive, repetitive behaviors."*

More specifically, testing was notable for an early developmental history comprising inconsistent eye contact and response to name, sensory sensitivities, patterns of excessive interests, and somewhat poor imaginative play. James also had a long-standing history of social vulnerabilities. His social and sensory processing challenges as well as smattering of excessive interests, repetitive behaviors, and behavioral regulation difficulties persisted for him across his development. The results of standardized testing (e.g., ADOS-2) and report measures (e.g., SRS-2 and BASC-2) corroborate these as current symptoms. Lastly, close monitoring of a specific learning disorder was indicated given the writing fluency challenges noted above and indications of weak visual-motor integration skills.

DSM-5 Diagnostic Impressions *299.00 Autism spectrum disorder (ASD)*

- *Without accompanying language and intellectual impairment.*
- *Level 2 severity: "requiring substantial support with both social communication and restricted, repetitive behaviors."*

R/O (i.e., at risk) specific learning disorder with impairments in written expression

by history: ADHD-C

"Best Practices" for Educational Programming

For many families affected by ASD, the primary source of intervention is provided through public school-based educational services [31] that are mandated through the Individuals with Disabilities Education Act (IDEA). The IDEA ensures that children with all disabilities have available to them free and appropriate public education (FAPE [35]). Whether a child is enrolled into a public or private school setting, the vast array of individual differences in ASD requires highly individualized and systematic educational programming with targeted goals and measurable outcomes. However, the heterogeneity within this disorder often convolutes the educational planning processes, as there is not a universal recipe for educating or treating students affected by ASD. In fact, every student's unique profile (e.g., age, cognitive and learning strengths and weaknesses, and behavioral functioning) should dictate the specific ingredients that comprise their programming within an educational setting. This is by no means an easy task for school districts or caregivers, but it is essential, and it is one that psychiatrists and related professionals are often required to assist families with across their patient's treatment. Many families also greatly benefit from hiring professionals, such as educational advocates, to help assist them with this process. Provided below are some of the "best practices" in educational programming for students with ASD.

First and foremost, a comprehensive assessment that utilizes the practices indicated throughout this chapter is vital to school-based service delivery. Most students with ASD will require an Individualized Education Program (IEP) which is a document that delineates educational goals and objectives along with *how* these will be measured and attained within the school setting (see Chap. 14 for further review). The IDEA requires that school districts create an IEP for students identified with ASD and an evaluation can be integral in the development of this document. Whether conducted at school, in a clinic, or in both settings, a good assessment will elucidate a student's distinctive profile of strengths and weaknesses across their functioning and will greatly assist in determining the appropriate school and/or classroom placement (e.g., full inclusion, partial inclusion, substantially separate classroom [i.e., ASD-specific classroom] or a residential program) as well as the specific accommodations (e.g., extra time), direct services (e.g., speech and language therapy), and ancillary supports (e.g., ongoing consultation with a speech and language pathologist) that will fulfill that student's educational needs. For example, a comprehensive assessment can be key in ensuring a high-functioning adolescent with ASD is not placed into a classroom setting with peers that require a significantly higher level of support (i.e., helps protect the "least restrictive environment" right as specified in IDEA), and just as important, it can assist in ensuring that inclusion practices into mainstream settings are appropriate.

While there is no universal recipe for school programming for students with ASD, there are several overarching principles that can help effectively guide all parties through this process in addition to specific components that should be included in their education. The National Research Council [29] set forth some of these "best practice" parameters for educating students with ASD, which include the following: (1) interventions should begin as early as possible; (2) interventions should be intensive; (3) families should be active partners in education and treatment; (4) school-based treatment programs should be directed and implemented by a team of professionals with extensive training and specialized ASD experience; (5) systematic instruction and ongoing objective assessment of progress is essential; (6) structured learning environments should be provided with varied instructional formats; (7) teaching procedures should be highly individualized and evidenced-based and allow for generalization and maintenance of skills; (8) all transitions (e.g., graduation or transition to college or workforce) should be carefully planned and well supported; and (9) all core and related deficits in ASD should be targeted. In other words, learners with ASD should receive educational programming that addresses all aspects of their functioning, including, but not limited to, curriculum and services targeting cognition, socio-communication, emotional and behavioral controls, speech and language, motor, sensory processing, executive controls, and adaptive functioning. The promotion or treatment of these areas should also be provided across all aspects of a student's school day and curriculum. Consistent communication between the family, school administration, teachers, special education support staff, and both school- and community-based treatment providers is key as well.

There are multifaceted treatment models that are provided within some school settings that integrate many if not all of these guiding principles for learners with ASD. The literature refers to these as comprehensive treatment models (CTMs) . CTMs comprise a set of practices that are organized around a conceptual framework/theory/philosophy, and they are designed to achieve a broad learning or developmental impact on the core deficits of ASD [52]. These programs integrate multiple modalities of intense treatment (e.g., child-focused interventions and family-focused supports), their procedures are manualized, they have a broad scope (i.e., offered in multiple settings, such as a classroom, clinic, and home), they address an array of ASD-related symptoms, and they have longevity (i.e., occurring over months or even years; [36, 8]. Odom et al. [36] provided an extensive review of many of these CTMs and indicated that several well-established models are available and demonstrate some evidence for efficacy (e.g., The Lovaas Model/Early Intensive Behavioral Intervention, The Early Start Denver Model, Learning Experiences: An Alternative Program for Preschoolers and Parents [LEAP], May Institute, Princeton Child Development Institute, DIR/Floortime, Pivotal Response Treatment, and Division TEACCH). Notably, however, CTMs vary widely on the age group served as well as location of delivery (e.g., public school settings versus a clinic). That is, some of these programs are not applicable to all age groups, and they may not be available in certain geographical regions nor are they provided across all school districts.

There are also a myriad of more focused intervention practices as well as classroom-based accommodations that can be integrated into a student's educational programming. Wong et al. [52] provided a comprehensive review of the more focused intervention practices, which are defined as an intervention designed to address a single skill or goal of a student with ASD [36], and they indicated several evidenced-based interventions (e.g., discrete trial training, pivotal response training, functional behavior assessment [FBA], prompting, modeling, peer-mediated strategies, social narratives, visual supports, picture exchange communication system [PECS], and cognitive behavioral therapy/intervention). These focused intervention practices are often implemented within schools and/or classrooms that are designated for children and youth with ASD or related conditions. Several of these approaches are grounded in the techniques of applied behavior analysis (ABA), which involves the application of empirically derived learning principles (i.e., antecedent, behavior, and consequence contingencies) across a variety of treatment modalities to produce meaningful changes in behavior [2, 10]. In other words, it encourages positive behaviors (e.g., functional language) and discourages negative behaviors (e.g., self-injury) in order to develop various skill sets. Interventions grounded in ABA are considered the "gold standard" in ASD treatment (and have been endorsed by the US Surgeon General). While quality over quantity should be at the forefront of ABA service delivery, the collective literature suggests that young children with ASD require intense treatment, where "intense" is defined as 25–40 h per week.

In addition to the array of interventions grounded in ABA, many learners with ASD will benefit from other direct services, accommodations, and additional supports which are listed in Table 9.3. It is important to note that a diagnosis of ASD also does not preclude the necessity to address specific learning disorders (comorbidity estimates = 6.3%) and other vulnerabilities such as executive dysfunction. Therefore, some students with ASD will require 1:1 or small group tutorials across certain academic areas (e.g., multisensory and phonics-based approaches to address comorbid dyslexia) and executive functioning tutoring. As students' progress through the high school years, it is also essential that there is ongoing transition planning to prepare them and their family for the next steps into a college setting, work force, and/or a delineation of avenues to continue to promote independence and overall quality of life. Lastly, and as noted above, a learners' unique profile will dictate the specific ingredients that comprise their programming within an educational setting; thus, only some of these services listed in Table 9.3 may be indicated.

Table 9.3 Beneficial direct services and accommodations in the classroom

Direct services	Accommodations and additional supports	
Services grounded in ABA (e.g., discrete trial training) Speech and language therapy Augmentative and alternative communication supports Assistive technology (e.g., speech generative devices) Occupational therapy Sensory integration therapy Physical therapy Social skills training Regular access to a counselor/school psychologist Extended school year services (to prevent a regression) 1:1 aide and/or small group instruction Self-help/life-skills building Vocational training Transition planning into college or workforce 1:1 or small group academic tutoring 1:1 or small group executive functioning tutoring In-home behavioral consultations	Ongoing consultations with a speech and language pathologist, occupational therapist, certified behavioral analyst (i.e., BCBA), or other providers Extra time on all tasks, tests, and standardized testing Modified workloads, testing formats, and flexible deadlines Systematic instruction with clearly defined learning objectives and systematic teaching methods Targeted learning objectives tailored to student's functioning level A clear schedule and routine, one that concretely delineates expectations throughout the day Transitions and/or major changes are supported by providing advanced warnings Structure and support, consistent feedback, and frequent monitoring (i.e., 1:1 attention in the classroom) Breaking assignments into smaller "chunks" The presentation of materials in a multisensory format, including the use of visual aids Use visual aids to assist student in identifying where materials go Using concrete examples before teaching abstract examples Learning activities that increase motivation or arousal to facilitate sustained engagement (i.e., interactive, hands-on, or laboratory learning activities, rather than desk work) A visual schedule placed in the classroom and/or on a desk in order to help student consistently understand/follow the daily routine and classroom expectations Preferential seating and area that minimizes distractions Structure work areas with physical boundaries to assist in classroom navigation	Visual reminders for appropriate behavior placed on desk (e.g., raise hand for help) Encouraged to associate new material with previously learned material and to elaborate new concepts The rate of presentation of materials and concepts can be altered Provide a written checklist of steps required to complete a task (also a completed work example is beneficial) Complete written work on a computer with spell-checking functions. The use of laptops/keyboard for all writing assignments Graphic organizers Books (and textbooks) on tape to facilitate learning Use graph paper to help keep numbers lined up and an extra piece of paper to cover up most of what's on a test so student can focus on one problem at a time Have student repeat and restate instructions to confirm understanding of tasks presented Provide outlets for energy and physical activity on a needed basis Use headphones in classroom to mitigate effects of sensory input Use fidget toys, sensory objects, and/or chew gum to assist with restlessness The use of a "standing" desk/chair/seat Breaks and/or sensory breaks as needed Having lessons repeated on different days and engaging in the rehearsal concepts, perhaps in condensed form, in order to ensure that this information is well encoded into memory Assign a peer role model to assist getting started with classroom activities and assignments, as well as to assist with social development

"Best Practices" for Interventions at Home

Patients and their families can access many of the same interventions that are provided within the school setting within the home- and/or a community-based clinic. However, accessing treatment can often be a cumbersome process for families. After a patient receives a formal diagnosis, families are required to navigate a sea of available interventions and conduct their own research on what is and what is not evidenced-based or what may or may not be helpful for their child's particular profile. They also have to decide on what is logistically and perhaps financially feasible, and in that same vein, it is not uncommon for families to encounter a convoluted insurance process fraught with "red tape" and confusing parameters. Not surprisingly, the extant literature suggests caregivers' of individuals with ASD experience higher levels of psychological distress relative to parents of neurotypical children or those with other disorders [22, 23]. There is even a biological toll on families affected by ASD as noted in Nelson et al.'s [34] fascinating work on shortened telomeres (end regions of chromosomes associated with human immune function and aging) and the potentially resulting impacts on physical and mental health. The difficulties faced in accessing appropriate treatment for these families likely contribute to these phenomena. Thus, as a psychiatric provider or related professional, it is imperative to be knowledgeable about not only what is available but what is "best practice" and how you can help and guide your patient and their family in accessing the necessary care.

At the helm of this process is once again a comprehensive evaluation. Early detection and early intervention are essential. Once a diagnosis is confirmed, the selection of treatment(s) will depend on the child's age and particular profile of strengths and weaknesses. For children under the age of 3 with ASD (or related concerns), families should contact their particular state's agency that delivers early intervention (EI) services as mandated by IDEA (Autism Speaks® provides a user-friendly database: www.autismspeaks.org). EI services typically connect families with a care coordinator and other specialty providers (e.g., developmental specialist) and will initiate what is called an Individual Family Service Plan (IFSP). An IFSP essentially mimics an IEP, although it is geared toward younger children who aren't yet enrolled into a school setting. EI services frequently involve initial evaluations, progress assessments, and various interventions that include but are not limited to speech and language therapy, occupational therapy, physical therapy, interventions grounded in ABA (e.g., discrete trial training), and play/social groups. Children can receive EI services up until the age of 3. At that point, families should begin to access services within their local school district.

In addition to EI services, each state has their own existing programs (e.g., care coordination, treatments, parent trainings, etc.) that are available to youth (and adults) with ASD along with related policies. In 2014, the Centers for Medicare and Medicaid Services (CMS; www.cms.gov) released a helpful report that summarizes all of the services available for all 50 states and the District of Columbia. Several of these state provided programs not only enable families to receive particular interventions, but they also offer access to wrap-around services, including intensive care coordination, in-home and outpatient therapies, family partners, therapeutic mentorship programs, vocational skills training, independent living assistance, and respite care.

The array of interventions and services available can be overwhelming for families. As such, it is helpful to guide families to taking a three-pronged approach with regard to treatment: (1) treatment should be evidenced-based; (2) treatment should be individualized; and (3) treatment should be intense. That is, interventions should be scientifically supported in their efficacy, they should be tailored toward the child's profile and the family's needs, and families should receive quality treatments that are delivered with a duration and frequency conducive to promoting positive therapeutic effects. Caregivers should be encouraged to seek information around validated, research-based, empirically supported treatments and interventions for ASD, which has been conveniently provided by the National

Standards Project (website: www.nationalautismcenter.org). Furthermore, in addition to Wong et al.'s [52] review of comprehensive treatments for ASD, providers of families are encouraged to access Rogers and Vismara's [42] seminal review of the empirical evidence evaluating comprehensive treatments for young children with autism. As noted above, this literature supports several focused intervention practices as evidenced-based interventions (e.g., discrete trial training, pivotal response training, etc.) most of which are grounded in the techniques of ABA: the "gold standard" in ASD treatment. To reiterate, 25–40 h a week is considered an "intense" level of ABA grounded services. Youth with ASD will also greatly benefit from other treatments (many listed in Table 9.3 under "direct services") that include, but are not limited to, the following home- and/or clinic-based services: speech and language therapy, occupational therapy, sensory integration therapy, physical therapy, social skills training, assistive technology and/or augmentative communication supports, academic or executive functioning tutoring, vocational skills training, psychotherapy (e.g., cognitive behavioral therapy), and behavioral parent training. Obtaining educational advocacy assistance as indicated above can be very beneficial to families as well when navigating the IEP process.

Finally, access to specialized medical professionals (e.g., psychiatrists, neurologists, gastroenterologists, etc.) can be imperative for monitoring and treatment of a patient's symptoms (see [2, 47] for reviews on psychopharmacological treatments) as well as for management of other comorbid medical conditions (e.g., sleep disruption, seizures, feeding problems, gastrointestinal issues, etc.). Clinics that comprise multidisciplinary teams are highly beneficial, as they facilitate the coordination of care and communication among treatment professionals and can often lead to the most positive treatment outcomes. There are various avenues for finding all of these different types of treatment. In addition to consulting with their mental health or medical providers, caregivers can contact any one or all of these national organizations for getting assistance in accessing local agencies and treatment facilities: Autism Speaks (www.autismspeaks.org); Autism Society of America (www.autism-society.org); National Autism Association (www.nationalautismassociation.org) ; or the US Autism and Asperger Association (www.usautism.org).

Conclusion

If you've met one person with autism, you've met one person with autism. If you've assessed one person with autism, you've assessed one person with autism. If you've treated one person with autism, you've treated one person with autism. Hopefully, this point has been made clear: ASD is a complex, highly heterogenic, neurodevelopmental, and pervasive disorder with multiple etiological pathways to its onset and variability in treatment outcomes. Understanding these facts alone enables mental health professionals to truly hone in on a child's unique spectrum of neuropsychological and developmental strengths, weaknesses, and perhaps just differences. That is often half the battle in being able to effectively and comprehensively assess, interpret evaluation results, and guide patients and their families to the appropriate and necessary educational programming and access to evidenced-based treatments.

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Part III

Common Psychiatric Disorders in Childhood

10

Mood Disorders

Julie A. Grieco and Mary K. Colvin

Abbreviations

ADHD	Attention-deficit/hyperactivity disorder
APA	American Psychiatric Association
CBT	Cognitive behavioral therapy
DMDD	Disruptive mood dysregulation disorder
DSM-5	*Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition
FBA	Functional behavior analysis
IEP	Individual education program
IPT	Interpersonal therapy

Introduction

Mood disorders, and associated comorbidities, may adversely impact youth across all aspects of their functioning, including the school environment where the student's ability to consistently engage in learning may be disrupted. Current estimates indicate a relatively high prevalence of depression (approximately 14%) and bipolar disorder (1–2%) in pediatric and adolescent populations [31, 33, 122, 134]. Although adjustment disorders may arise secondary to changes within the individual's life, in some youth, primary mood disorders may emerge in childhood and adolescence and mark the beginning of a lifelong chronic illness, characterized by periods of exacerbation and remission.

Youth who are eventually diagnosed with primary mood disorders are at increased risk of having pre-existing weaknesses in certain cognitive and academic skills that become exacerbated when mood symptoms become more severe [48, 52, 99, 122]. Underlying vulnerabilities in the neurological networks mediating executive functions place youth at higher risk for emotional and behavioral dysregulation. Executive functions are key skills supporting the self-regulation of cognition, emotions, and behavior. Disruption of executive function skills is a core feature of mood disorders, particularly in the developing brain, and requires special attention in the conceptualization of such cases. Of importance, predisposition to mood dysregulation and neurocognitive vulnerabilities may persist even during periods of euthymic mood. Awareness of these inherent vulnerabilities is essential for families, educators, and care providers in order to provide effective

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interventions. In fact, educators may be among the first to notice a change in students' emotional, behavioral, or academic functioning and can be important informants as to a child's response to treatment. An interdisciplinary approach can be most effective in monitoring a child's symptoms, providing intervention, monitoring response to intervention, and providing preemptive strategies to prevent relapse.

The classification of dysregulated mood symptoms as mood disorders captures extended or severe changes in mood that are atypical in quality or duration. The spectrum of mood disorders includes sadness to depressive episodes and hypomania to a manic episode and may even include psychosis. The experience of these symptoms may be mild in nature or may be severe and debilitating, requiring inpatient hospitalization. Mood episodes may last for brief periods (few hours) or may persist for long durations of time (months to years). The duration, quality, and severity are what classify an individual's mood dysregulation into a more specific diagnostic category, guiding clinicians in their conceptualization in the neurobiology and physiology of the individual's illness, further guiding their selection of tools to assist with providing optimal intervention.

Categorization of mood dysregulation in the developing brain poses a unique challenge to providers. Children and adolescents inherently experience immature emotional regulation secondary to the ongoing development of their frontal lobes and executive functions. Therefore, classification of mood disorders in youth requires careful attention and monitoring to ensure accurate classification, using a framework that compares other typically developing children to the identified patient to determine if the presenting difficulties extend beyond that expected for an individual with the same developmental level.

Classification of Mood Disorders

The *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (DSM-5) characterizes the presence of primary symptoms of dysregulated mood under two main categories: depressive disorders and bipolar and related disorders [4]. Attention to the differences among the presentation of mood symptoms in youth is important as the quality and duration of symptoms in youth may differ from adults.

It is also important to understand whether mood symptoms are primary in nature or secondary to another etiological process. There are multiple factors that may contribute to the development of a mood disorder. There may also be youth who have specific learning disorders and go on to develop symptoms of depression secondary to their learning difficulties [17, 98, 125]. Additionally, some youth experience medical conditions, which predispose them to develop mood symptoms (e.g., epilepsy, endocrine disorders, etc.). Careful delineation of the symptoms is important in accurately conceptualizing etiology in order to guide optimal treatment. These distinctions are also required per the DSM-5 to aid in accurate differential diagnosis and must be considered in terms of the individual's developmental level [4].

Depressive Disorders

The depressive disorders include major depressive disorder, persistent depressive disorder, and disruptive mood dysregulation disorder. In addition, premenstrual dysphoric disorder and depressive disorder due to substances, another medical condition, or unspecified etiology fall under this category.

Major depressive disorder is diagnosed when there is a depressive episode that lasts for at least 2 weeks in duration. Depressive episodes are characterized by marked changes in one's emotional experience and may include physiological and cognitive changes. In children, depressed mood often presents with anger, irritability, and excess motor energy; whereas, adults with depression often present with sadness and anhedonia. Episodes often occur more than once in an individual's lifetime; however, periods of remission often exist in between. In contrast, persistent depressive disorder (previously referred to as dysthymia) is recognized as a chronic type of depression persisting for over 1 year. Low mood in children often involves loss of interest in activities the child usually enjoys, social withdrawal and isolation, and an indifferent disposition.

Disruptive mood dysregulation disorder (DMDD) is a more recent addition to the DSM-5. The main features include a persistent irritability and temper outbursts that occur multiple times per week and are inconsistent with the situation and developmental level [4]. These children are often fussy, quick to tantrum, and difficult to soothe. Their reactions are intense and immature for their developmental level, and these symptoms are often disruptive across settings. This disorder is characterized as unique to the pediatric population in that symptoms must be present before age 10. The symptoms must not be episodic, and the child must not meet criteria for mania or hypomania for more than 1 day. The child must not be without symptoms for more than 3 months within the 1-year period required for diagnosis. The defining feature of DMDD is a persistent irritability that is not cyclical as in other primary mood disorders, such as depressive and bipolar disorders. Careful evaluation of symptom quality, duration, and frequency can help delineate DMDD from primary mood disorders.

Depression can be diagnosed secondary to other factors. Depressive disorder can also be induced from substances introduced to the body and may be either prescribed or consumed electively. Examples of substances that may induce depression include alcohol, marijuana, or antiepileptic medication. Depressive disorders can also be associated with medical conditions such as hypothyroidism, multiple sclerosis, and cardiac conditions. Premenstrual dysphoric disorder is a unique type of depression that emerges and remits in sync with an individual's menstrual cycle and significantly disrupts one's functioning. Youth often are unaware of the associations between their physical state and their emotional functioning; careful assessment of psychological functioning in the context of overall health is essential.

Adjustment disorders, characterized by disruption in mood or behavior secondary to an environmental factor such as significant loss or an abrupt change, may also emerge. These children often have typical developmental trajectories, but there is an abrupt change in mood following a specific event, such as the loss of a grandparent, moving, or following an injury. For some individuals, these symptoms may persist and become progressively more severe and complex, thus eventually warranting a formal depressive disorder diagnosis.

Bipolar Disorders

Bipolar disorders are characterized by alternating cycles of elevated mood (mania or hypomania) followed by periods of euthymia or depression. Mania is defined as a distinct period of elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity that lasts for at least 1 week for most of the day, almost every day that results in impairment in the individual's functioning [4]. At least three of the following symptoms must be present: inflated self-esteem/grandiosity, decreased need for sleep, more talkative/pressured speech, flight of ideas/racing thoughts, distractibility, psychomotor agitation or increased goal-directed activity, and excessive involvement in high-risk behaviors [4]. Hypomania requires at least three or four (irritable mood only) of these symptoms during a sustained period of elevated, expansive, or irritable mood that lasts a shorter duration than a full manic episode (4 days) [4]. Children who experience mania often present with difficulty sitting still, decreased need for sleep, excessive talking, and difficulty following instructions. These symptoms are a change in their baseline level of functioning, and they are often difficult to understand. Increased engagement in pleasurable activities or those of preferred interest is often observed, and it is often difficult to match their level of energy. The duration, severity, and presentation will vary depending on the individual.

The type of cyclical pattern is captured by the diagnoses, which include bipolar I, bipolar II, cyclothymic disorder, and bipolar disorder due to either substances, another medical condition, or unspecified etiology. Individuals who meet criteria for a full manic episode meet criteria for bipolar disorder I, whereas individuals who meet criteria for a hypomanic and depressive episode meet criteria for bipolar disorder II. Cyclothymic disorder is characterized by a 1-year period during which the individual experiences numerous hypomanic and depressive symptoms that don't met criteria for full episodes. They must not be without symptoms for more than 2 months, and symptoms must be present for at least 6 months of the year.

Bipolar disorder due to substances (e.g., cocaine, hallucinogens, alcohol, etc.) can include mood-induced symptoms either during intoxication or during withdrawal. Bipolar disorder due to another medical condition (e.g., hyperthyroidism, multiple sclerosis, etc.) may include manic, hypomanic, or mixed episodes. Finally, bipolar disorder other-specified and unspecified are the categorical terms used for individuals who experience symptoms of both elevated and depressed mood but are not better classified by any of the aforementioned diagnoses.

Diagnosis of bipolar disorder in youth has been controversial. The DSM-5 states that the mean age of onset of first mood episode is approximately 18 years old for bipolar I and in the mid-20s for bipolar II [4]. While the criteria recognize diagnoses in children, there are cautions embedded in the text surrounding careful attention to diagnoses given that this is not the norm. Over the past several years, the prevalence of bipolar disorder in pediatrics has grown exponentially. For example, recent estimates indicate that pediatric bipolar disorder affects approximately 2% of youth less than 18 years of age [93]. Studies indicate that clinicians need to be more observant to manic symptoms in youth, as it often takes a year before an accurate diagnosis is made from the time they initially present for treatment [135]. Given differences in both symptom presentation and on neuroimaging (structural and functional) between youth that meet criteria for bipolar disorder and youth with other common psychiatric diagnoses of childhood, the field is more widely recognizing pediatric-onset bipolar disorder as a clearly defined disorder [23, 41, 103, 122]. At this time it remains unclear if pediatric-onset bipolar disorder will manifest similarly to adult-onset bipolar disorder in adulthood. As such, longitudinal and comparison studies are needed to more carefully delineate symptoms and prognosis across the life span among these entities.

Risk Factors

Risk factors for developing a mood disorder include a genetic predisposition; a positive family history of a mood disorder places an individual at higher risk for also developing one. Individuals with predisposed neurochemistry are also at higher risk when prescribed certain medications. For example, individuals with both mood elevations and depressions are at a higher risk for developing mania if prescribed an antidepressant medication versus a mood stabilizing medication. Additional factors, such as sleep disturbance, consumption of substances (e.g., alcohol, marijuana, cocaine, etc.), traumatic stress, and chronic stress, all place individuals at higher risk for developing a mood disorder. Medical disease is often associated with higher disease burden and can contribute to mood disorder, as well.

Comorbidities

Many symptoms co-occur with mood disorders. It is important to consider the comorbidities that exist with mood dysregulation in order to more fully appreciate the experience of the individual. Common comorbidities are described here and can be referenced in Table 10.1.

Anxiety-related disorders often co-occur with mood disorders and in fact tend to precede the onset of pediatric bipolar disorder [53]. Generalized anxiety, panic attacks, specific fears, and social phobia are often co-occurring with prevalence estimated to fall around 54% [53]. Regardless of the type of comorbidity, it is imperative that symptoms are properly acknowledged and addressed in order to provide optimal interventions.

Table 10.1 Common comorbidities among youth with mood disorders

Psychiatric
Anxiety
Learning disorders
Attention-deficit/hyperactivity disorder
Disruptive behavior disorders (oppositional, conduct)
Communication disorders
Autism spectrum disorders
Psychosis
Medical
Epilepsy
Cancer
Endocrine disorders (thyroid disorders)
Autoimmune disorders (multiple sclerosis, lupus, etc.)
Organ transplant
Substance use/abuse
Deafness/blindness
Sleep disorders
Psychosocial
Poverty
Trauma
Homelessness
Divorce
Loss/bereavement
Parental mental illness
School failure
Gender identity/sexual orientation

Specific learning disorders are also commonly associated with mood disorders [17]. Learning disorders place youth at higher risk for internalizing mood symptoms (e.g., depression, low self-esteem, etc.) [17, 35, 73], and learning problems have been associated with disruption of the family system and mood symptoms in parents [16, 77, 125]. In addition, weaknesses in the neurological systems that mediate emotional regulation, attention and executive functioning, and learning is a unifying factor that also contributes to high rates of co-morbidity [9, 17, 72, 98, 109]. Altogether, the combination of environmental factors, in adjunct with weaknesses in the neurological networks that mediate learning and emotions, place youth with learning disorders at high risk for mood disorders.

High rates of attention-deficit/hyperactivity disorder (ADHD) are commonly comorbid with mood disorders secondary to the weaknesses among shared neurological underpinnings that mediate executive dysfunction. Similar to youth with mood disorders, youth with ADHD also have altered developmental maturation patterns of cortical and subcortical networks involving the frontal lobes, which are important in mediating higher-ordered thought processes and behavioral and emotional regulation. As such, individuals with comorbid ADHD and mood disorders experience dysregulation of behavior (e.g., hyperactivity, impulsivity), thought processes (e.g., distractibility, poor concentration), and mood (e.g., emotional lability, outbursts). Careful differentiation between symptoms is important for accurate diagnosis. For example, symptoms of hyperactivity and impulsivity can mimic symptoms of mania such as pressured speech, psychomotor agitation, reduced need for sleep, and pressured speech. It is important to delineate the presence of/exacerbation of symptoms during a mood episode, versus symptoms of hyperactivity and impulsivity that are persistent even in the absence of a significant mood episode. Careful determination of symptoms of dysphoric or dysregulated affect in adjunct with overactivity/impulsivity is needed to appropriately classify the symptoms. Recent studies reveal that 48% of youth with bipolar disorder have comorbid ADHD [53]. Estimates suggest between 12% and 50% of youth with unipolar depression have comorbid ADHD [36]. Children with this neurological profile are inherently at higher risk for experiencing dysregulation of mood, and children with primary mood disorders are at higher risk for experiencing dysregulated thought processes and behavior.

Behavioral dysregulation, impulsive actions, and risky decisions can contribute to behavioral misconduct. Co-occurring oppositional defiant disorder or conduct disorder may evolve in youth who have mood disorders, particularly with the additive diagnosis of comorbid ADHD [53]. The engagement in risk-taking behavior paired with the reduced appreciation for others' emotional and physical well-being creates an active atmosphere for conduct problems. Approximately 31% of youth with bipolar disorder have comorbid disruptive behavior disorders [53]. It is important to appreciate that an individual's actions during such a mood episode may not reflect their general character or values; many mood disorders go untreated resulting in persistent states of behavioral vulnerability [31, 47, 48, 52, 74].

In some situations, psychosis can occur in the context of a mood episode. Studies reveal that 4–8% of youth in clinical samples experience psychosis (e.g., delusions, hallucinations, etc.), and symptoms can include either mood congruent or incongruent hallucinations [24, 132, 137]. Accurate assessment for symptoms of psychosis requires specialized training of a psychologist or psychiatrist. The specialist will also provide psychoeducation about the neurobiological basis in developmentally friendly terminology and specializes in communicating these complex conditions with child and their family. Research has shown that the presence of psychotic hallucinations during a period of depression in adolescence placed youth at a much higher rate of having suicide plans or attempts compared to those with depression who did not experience psychosis [79]. As such, clinicians need to be screening for the presence of psychosis and performing safety assessments and planning accordingly. The presence of psychosis during one mood episode places the individual at higher risk for experiencing psychosis during a subsequent episode; therefore, careful monitoring and education are essential. Of importance, the presence of psychosis does not imply that there is a risk for violence, although the psychologist or psychiatrist will perform a risk assessment to ensure the safety of the child and those around them. When symptoms of psychosis occur in the absence of a mood episode, further screening for a primary thought disorder is indicated.

It is also imperative to monitor for self-injurious and suicidal behavior. Individuals with bipolar disorder are significantly more likely to commit suicide than those without mood disorders [4]. Youth are at particular high risk due to inherent neurodevelopmental factors, such as immature development of the frontal lobes, which assist with judgment and decision-making. While suicidal ideation and rates of attempts are high, rates of completed suicide are fortunately low and occur approximately one in 100,000 among youth with bipolar disorder [68]. Proper risk assessments must be conducted routinely, as hormonal and medication changes may influence youth during particularly sensitive times. Since decision-making and judgment are more vulnerable in all youth, the additional distress of mood dysregulation makes impulsive actions a normative component within these circumstances.

Substance use is common among youth with mood disorders. Estimates suggest that 26% of adolescents with unipolar depression and 31% of individuals with bipolar have comorbid substance use disorders [37, 53]. The use of external substances can further impair judgment and decision-making, as well as exacerbate neurochemical vulnerabilities. Individuals may develop dual diagnoses with mood disorder and substance dependence, greatly complicating the treatment profile. Alternately, substance use may be secondary due to attempts to stabilize mood disorders. Careful delineation of the timeline of symptoms is important in determining appropriate course of treatment and determination of etiology.

Cultural/Religious Considerations

In addition to understanding how mood disorders manifest at different developmental stages, it is important for clinicians, educators, and providers to appreciate and consider cultural conceptualizations of depression, mania, and behavioral dysregulation. Beliefs surrounding etiology, treatment, and family member involvement in interventions may vary greatly in relation to an individuals' cultural or religious framework [126]. Clinicians also need to be aware of a disparity in mental health services available for individuals of various ethnic, cultural, religious, and geographic backgrounds and those of varying socioeconomic statuses. For example, studies show disproportionate outpatient mental health services and higher unmet needs for ethnic minority youth, treatment is less adequate, and antidepressants are prescribed less frequently to non-Hispanic White individuals [22, 27, 34, 57, 70, 126, 143, 144].

In addition, providers may overlook situational factors contributing to symptoms and may neglect to include them in treatment plans. For example, chronic trauma exposure in urban settings may result in presentations that may easily be overlooked for mood disturbance [126]. Disproportionate rates of symptoms also exist among different cultural backgrounds. For example, Native Americans adolescents completed suicide 2.4 times higher than White youth and Asian-American girls had rate 1.2 times that of White girls [25]. Special attention to specific symptoms and the manifestation of symptom presentation must therefore be considered.

Neurological Basis

Structural and functional differences among individuals with specific mood disorders have been routinely examined in the adult population and are now becoming the focus of research in pediatric populations. While the quantity of the studies thus far is not as robust in the pediatric population, research has discovered that overlapping systems are involved among all mood disorders. A fundamental challenge in understanding the developmental course of mood disorders is to consider the developmental trajectory of the brain. The most consistent findings among the current literature are discussed here.

Depression The majority of research indicates alterations in networks connecting the frontal lobes, which are involved in higher-order cognitive skills such as planning and reasoning and subcortical networks involved in emotional regulation (limbic structures) as well as behavioral regulation (striatal structures). Structural studies examining depression in youth reveal reductions in the volume of the basal ganglia and the hippocampus [122]. Reduced gray matter in the prefrontal cortex, amygdala, striatum, and caudate nucleus of depressed children was also demonstrated; however, these results are less consistent [50, 56, 85, 101, 122, 123]. A limited number of studies assessing functional imaging have been conducted among youth with depression; however, the most consistent finding is alternations in the underlying structures of the frontal-subcortical networks that assist in mediating emotions, cognition, and behavior.

Bipolar Disorder Imaging studies revealed that a greater number of abnormalities in the prefrontal-limbic circuits were evident among youth with bipolar disorder than depression. Among individual comparison studies, significant differences from healthy controls included reduced amygdala volumes [15, 28, 38, 1], reduced intracranial volumes [55, 127, 140], and ventricular abnormalities [18, 127]. Volumetric changes in the anterior limbic network including the thalamus, striatum, and hippocampus have also been demonstrated [1]. Meta-analyses consistently revealed reduced prefrontal cortex and increased globus pallidus volumes in children and young adults [5].

Alterations in connectivity throughout the developing brain have also been demonstrated. Reduced corpus callosum volume and a greater number of deep white matter hyperintensities have been identified as specific to pediatric bipolar disorder [86, 110, 122]. Diffusion tensor imaging studies also implicate altered connectivity among prefrontal-limbic regions associated with affective regulation [85, 122, 107, 2].

Neuroimaging studies are helping to define differences between children with unipolar and bipolar disorder, as well as differences from children with other neurodevelopmental disorders offering support for neurological underpinnings associated with these disorders. While there are not yet enough findings to implicate neuroimaging as a tool to aid in differential diagnosis, emerging results assessing differences between mood disorders and other pathologies will hopefully prove promising.

Neurocognitive Profiles

Depression The neuropsychological correlates of depression in the pediatric population have rarely been studied independent of a comorbid diagnosis. This fact is important to consider when conceptualizing youth with depressive disorders, as many exist comorbid with ADHD, learning disorders, head injury, chronic pain, and other medical and psychiatric conditions. In adults with major depressive disorder, reduced processing speed and executive dysfunction are core components of neurocognitive symptoms [26, 46, 64, 78]. Impairments in effortful attention [66], working memory [100, 128], inhibition [60, 89], problem-solving and planning [100], and mental flexibility [3, 8, 100] among adults are demonstrated. Verbal and visual long-term memories have also been reported as impaired [81, 112, 138]; however, difficulty with initial encoding accounted for these weaknesses rather than an actual memory storage weakness. Weaknesses in verbal fluency were reported as well [114].

In childhood, studies examining those with solely a depressive disorder diagnosis revealed significantly slower processing speed and executive functioning difficulties relative to healthy controls and a subset demonstrating difficulty with cognitive flexibility and timed sequencing [48]. Many of the performances were within the average range across measures of intelligence and executive functioning when compared with healthy controls [48]. However, given the fact that depressive disorders occur so rarely in isolation among youth, studies examining depression comorbid with ADHD, learning disorder, and anxiety may more clearly depict the neuropsychological profile associated with this more commonly observed phenomenon. With this in mind, improved conceptualization of neuropsychological correlates of unipolar depression among the pediatric population is needed to better understand the sole impact of underlying neuropsychological weaknesses associated with depression in youth.

Bipolar Disorder The neurocognitive profiles among adults with bipolar disorder have revealed specific patterns of significant weaknesses in verbal learning and memory, attention, and executive functioning with smaller effect sizes observed among sustained attention, verbal fluency, visuospatial processing, reading, and overall cognitive ability [6, 10, 74, 116, 121]. Many have proposed that these weaknesses and pattern of cognitive functioning may predate the onset of individuals' mood disordered symptoms and worsen with the onset of mood symptoms. While the number of cognitive studies is much smaller in the pediatric population, the available literature demonstrates cognitive patterns largely consistent with those observed in the adult literature [74].

Meta-analyses of executive functioning in the pediatric population revealed significant weaknesses among youth with bipolar disorder than healthy controls in the domains of processing speed, working memory, and memory retrieval [45, 52, 82, 119, 130, 107]. Mixed results were also evident on tasks of sustained attention, cognitive flexibility, and response inhibition [14, 42–44, 52, 76, 92, 103]. Weaknesses in verbal fluency and reading, slower motor speed, and lower overall intelligence were also demonstrated [74].

Neurocognitive and associated symptoms of pediatric bipolar disorder adversely impact academic skill development as well [62]. Studies demonstrate that youth with bipolar disorder perform worse than healthy controls on tasks assessing mathematics and reading and writing tasks independent of the presence of specific learning disorders [14, 69].

Social cognition weaknesses have also been consistently demonstrated among youth with bipolar disorder characterized by difficulty recognizing emotional prosody in spoken language, identifying emotional facial expressions, and engaging in interpersonal problem-solving skills [21, 39, 58, 61, 80, 118]. These vulnerabilities place youth with mood disorders at higher risk for inaccurately interpreting social interactions and likely contribute to increased isolation and victimization, as well as reduced quality of interpersonal relationships. When evaluating outcomes of those whom are identified, youth with mood disorders experience greater difficulty with peer relationships. On self-report rating scales completed by adolescents, those with mood symptoms (e.g., depression, mania, hypomania) endorsed reduced quality of friendships and a sense of increased relational victimization relative to typically developing peers [124].

Most studies examining cognition have found that neurocognitive differences among youth who have mood disorders persist despite medication treatment [38, 39, 42, 105, 106]. Similarly, there do not appear to be significant differences in cognitive functioning between youth who have been acutely diagnosed and those who are assessed after a longer disease duration [38, 52, 105, 106, 118]. However, history of psychotic symptoms demonstrated more impairment on tasks of executive functioning and verbal memory [130, 131]. Also, youth who are treated with antipsychotic medication also demonstrate slower processing speed [11].

Assessment of Mood Disorders

Psychiatric Assessment

Many youth with mood disorders initially present to their primary care physician (pediatrician) for consultation. The child's pediatrician is often the one to make further referrals for more detailed analysis of the child's psychiatric care. Referral to a child psychiatrist, psychologist, or psychiatric nurse practitioner who specializes in diagnosis of mood and behavior disorders is essential in obtaining proper diagnostic clarity. Psychiatrists, psychologists, and/or their support staff may conduct a scheduled, standardized interview to assess for specific symptoms. Examples include the Young Mania Rating Scale and the Personality Assessment Inventory-Adolescent. If symptoms of significant mood dysregulation are present, the psychiatrist and/or psychologist will work carefully with the pediatrician to rule out an underlying medical etiology (e.g., epilepsy, hypothyroidism, etc.) to inform treatment.

Once a diagnosis is made, the psychiatrist and psychologist will often work closely with the patient and caregiver to discuss interventions that are best suited for the patient (interventions are described in greater detail below). Once the initial assessment is conducted, families usually return to meet with the psychiatrist or psychologist on a bi-weekly or monthly basis to monitor response to medications and interventions.

Neuropsychological Assessment

Neuropsychological assessment provides the opportunity for a comprehensive evaluation of the youth's cognitive, emotional, social, academic, and neurodevelopmental profile. The pediatric neuropsychologist specializes in understanding brain-behavior relationships in the context of the developing brain. Neuropsychological testing is important because it can rule out comorbidities and delineate the complex relationship between mood and cognitive strengths and weaknesses (e.g., executive dysfunction). Social, emotional, behavioral, cognitive, and academic functioning are understood in the context of the structural, functional, and chemical neurology that influence functioning. Neuropsychologists obtain information from multiple sources including objective testing, projective emotional testing, patient, parent, and teacher rating scales, prior medical records, neuroimaging (if applicable), and academic records. Please refer to Table 10.2 for a list of standardized measures commonly used to assess mood in children and adolescents.

Projective assessment of emotional and personality functioning can also be conducted to obtain supportive data containing themes related the individual's symptom pattern. These measures often require extensive training and supervision for accurate interpretation, and the reliability and validity of these measures are not as well established as that of standardized rating scales [84]. Examples of such measures include the Rorschach Inkblot Test, Thematic Apperception Test, sentence completion tasks, and projective drawings. Common findings that emerge on projective tasks among youth with mood disorders may include themes of sadness, anger, emotional reactivity, negative interpersonal patterns, sense of incompetence or inferiority, or negative resolution. Favorably, these projective tools can yield patient-specific insight into the patient's worldview, and the content may provide important information that can guide treatment.

Given the specialized nature of this service, referrals for this type of evaluation often come from a psychiatrist, neurologist, therapist, or primary care physician. The benefits of

Table 10.2 Common mood disorder assessment tools

Measure	Age range	Primary indices	Administration time	Who administers	Raters	Languages available	Reading level
BYI-II	7–18	Self-concept Anxiety Depression Anger Disruptive behavior	5–25 min	Qualification B	Child	–	2nd grade
BASC-3	2–25	Externalizing, internalizing, behavioral symptoms indexes, adaptive skills	10–30 min	Qualification B	Child Parent Teacher	Spanish	Parent – 4th grade Self – 2nd grade
CASI-5	5–18	Symptom count, symptom severity, impairment cutoff, clinical cutoff	15–20 min	Qualification B	Parent Teacher	–	–
CBCL	1.5–18	Internalizing Externalizing Total problems	15–20 min	Qualification B	Parent Self	90+ languages	5th grade
CDI-II	7–17	Emotional problems, functional problems	5–15 min	Qualification B	Child Parent Teacher	Spanish	2nd grade
CMRS	9–17	–	10–15 min	Qualification B	Parent Teacher	–	–
MAPI	13–18	Basic personality style Expressed concerns Behavioral correlates	20–30 min	Qualification C	Child	Spanish	6th grade
MMPI-A	14–18	Validity and clinical scales Content scales Supplemental scales PSY-5 scales	60 min	Qualification C	Child	Spanish	4.9th grade
PAI-A	12–18	Validity scales, clinical scales, treatment consideration scales, interpersonal scales	30–45 min	Qualification C	Child	–	4th grade
Piers-Harris self-concept second edition	7–18	Behavioral adjustment, freedom from anxiety, happiness and satisfaction, intellectual and school status, physical appearance and attributes, and popularity	10–15 min	Qualification B	Child	Spanish	2nd grade
RCDS-2	7–13	–	10–15 min	Qualification C	Child	Spanish	2nd grade
RADS-2	13+	Dysphoric mood, anhedonia/negative affect, negative self-evaluation, and somatic complaints	10 min	Qualification C	Child	–	3rd grade
YMRS	5–17	–	15–30 min	Qualification B	Clinician	–	–

BYI-II Beck Youth Inventory, 2nd Edition, *BASC-3* Behavior Assessment Scale for Children-3rd Edition, *CASI-5* Child and Adolescent Symptom Inventory-5th Edition, *CBCL* Achenbach's Child Behavior Checklist, *CDI-II* Children's Depression Inventory-2nd Edition, *CMRS* Childhood Mania Rating Scale, *MAPI* Millon Adolescent Personality Inventory, *MMPI-A* Minnesota Multiphasic Personality Inventory-Adolescent, *RCSD2* Reynolds Child Scale Depression-2nd Edition, *RADS-2* Reynolds Adolescent Scale Depression-2nd Edition, *YMRS* Young Mania Rating Scale. Qualification levels for test administration are set forth by the American Educational Research Association, the American Psychological Association, and the National Council on Measurement in Education to maintain professional and ethical standards of test administration and interpretation neuropsychological evaluations are the comprehensive and integrated conceptualization of brain-behavior relationships, uniquely tailored to that child and their history. This service differs from a school evaluation in that one examiner explores multiple domains of cognitive, emotional, and behavioral development by exploring functioning in the context of underlying neurological structures. The findings inform diagnosis and patterns observed on testing inform recommendations for treatment across multiple disciplines, including school, to devise an integrated treatment plan that expands across multiple disciplines.

School-Based Assessment

School evaluations can be initiated by parents or educators when there is concern about a child's academic performance. The school assessment will usually involve a review of the child's report card, academic record, and discipline records, as well as conversations with the child's parents and educators. The school may then conduct an assessment of the child to determine their eligibility for special education services and accommodations to modify the learning environment to make the classroom accessible for a child who experiences dysregulated mood. In the United States, these evaluations are often conducted once every 3 years, although yearly meetings to assess the efficacy of the interventions are conducted and monitoring through less formal means of assessment should be conducted to ensure the child is making effective educational progress. The goal of school-based evaluations is to assess if a child's cognitive or academic skills are on grade level or delayed. School-based evaluations inform recommendations within the school system to help the child reach grade-based standards. In school-based evaluations, there is less emphasis on etiology, and recommendations are generally not made outside of the school environment. School-based evaluations are of no cost to families, and the family returns to discuss proposed recommendations resulting from the evaluation with school providers. A plan is agreed upon and implemented to educate the child in the context of their learning needs. Please refer to the chapter on special education for more detailed information.

Interventions for Mood Disorders

Mood disorders impact youth pervasively across settings. As such, it is important that providers consider interventions across disciplines and settings in order to facilitate improvement. Interventions discussed here include therapeutic techniques, pharmacological methods, and school-based interventions.

Psychosocial Interventions

Depression Randomized clinical trials demonstrate that only 20% of youth with mild depression respond to routine monitoring and check-ins with their providers in the early stages of depression [29, 63]. When children present with mild initial symptoms, children are monitored for 2–4 weeks, and if symptoms persist or worsen, a higher level of intervention is attempted [63]. Alternately, many children initially present with moderate to severe symptoms of depression. In both situations require more formal therapeutic interventions.

Cognitive behavioral therapy (CBT) and interpersonal therapy (IPT) have been demonstrated as efficacious in treating depression among youth [32, 96, 97, 139]. CBT is a structured, time-limited therapy that treats depression by identifying behavioral and cognitive patterns and changes them to alter people's perceptions of themselves, their worlds, and their futures [31]. IPT is also a time-limited therapy that is based on the negative impact of depressive symptoms on interpersonal relationships and the impact relationships have on depressive symptoms and is most suitable and beneficial for youth who experience high conflictual relationships [31].

These interventions are considered an effective monotherapy for many youth with depression; however, they may not be best suited for individuals with learning disorders or intellectual disabilities. In such cases, adapted psychotherapy in adjunct with medication may be a more advantageous approach. Individuals who do not respond to CBT or IPT alone or who are experiencing suicidal thoughts often improve with the addition of antidepressant medication [19, 136] (described in greater detail below).

Bipolar Disorder At this time, there is not one universal behavioral intervention that is deemed the standard intervention of choice for children and adolescents with bipolar spectrum disorders. Of the interventions evaluated, family psychoeducation in adjunct with skill building has received the highest rating within this class – "probably efficacious" – by the Task Force on the Promotion and Dissemination of Psychological Procedures guidelines [54]. While no studies were deemed well established, a combination of family intervention, psychoeducation, and skill building was rated among the most successful, particularly when used in adjunct with medication [54, 94].

Collaborative problem-solving is an approach that facilitates adult-child problem-solving through teaching skills (e.g., flexibility, tolerance, problem-solving, etc.) to points of performance and helping resolve issues of disagreement collaboratively [65]. This approach has been demonstrated to be particularly effective for individuals with mood dysregulation and oppositional/disruptive behavior [65]. Other commonly used intervention modalities include CBT (rated as possibly efficacious), dialectical behavioral therapy (rated as experimental), and IPT and social rhythm therapy (also rated as experimental) [54].

Regardless of the specific modality provided, factors that proved efficacious included family involvement, psychoeducation, skill building, and relapse prevention [54]. Of importance, factors that influenced the individuals' response to intervention included adjunct pharmacology, greater initial impairment, high levels of stress and trauma in the child, and parents with lower levels of personality disorder symptoms [54, 87]. The implementation of social skill instruction may also prove beneficial, given the weaknesses in children's ability to detect and respond appropriately to social cues, as well as reduced quantity and quality of sustained peer relationships.

Pharmacological Interventions

Psychopharmacological intervention is commonly required to stabilize a child's mood and permit them the ability to participate in daily life activities.

Depression Studies demonstrate the utility of the addition of an antidepressant medication in adjunct to CBT among youth with depression, particularly if symptoms do not improve solely with CBT or if the symptoms are severe in nature [19, 88, 136]. The use of selective serotonin reuptake inhibitors (SSRIs) is the preferred class of medications for youth with depression [29, 30] as they have been shown to be efficacious. Fluoxetine has the most support from randomized clinical trials and is the only medication approved for young children with depression [20, 91, 96], although citalopram, escitalopram, or sertraline may also be considered [71].

Bipolar Disorder Psychopharmacological intervention is the gold standard for youth with bipolar disorder; however, randomized, double-blind, placebo-controlled studies are lacking. Young patients with bipolar disorder are commonly prescribed mood stabilizers and antipsychotics [40, 95]. Anticonvulsants and second-generation antipsychotics are also prescribed [40, 102, 129]. Lithium is approved by the Food and Drug Administration for managing bipolar in youth under age 12 [40]. Risperidone, aripiprazole, and quetiapine are approved to treat children over age 9, and olanzapine has been approved for adolescents over age 12 [40].

Treatment of comorbid ADHD and bipolar disorder with carbamazepine monotherapy or lamotrigine monotherapy was each shown to be effective in reducing manic, depressive, and ADHD symptoms [13, 75]. The addition of stimulants and atomoxetine to address symptoms of ADHD has not been shown to worsen mood symptoms [104, 117, 145]. Youth with comorbid disruptive behavior disorders and bipolar disorder have been shown to have improvement in overall psychopathology when treated with quetiapine monotherapy [90].

Treatment of disordered sleep is imperative in facilitating the child's ability to obtain restful, restorative sleep necessary to stabilize neurochemistry, as well as improve cognition and capacity for behavioral regulation. Insufficient sleep can cause or further add to problems with attention, learning, memory consolidation, slowed processing speed of information, and impulsive and careless responding. Increased irritability, mood lability, and cognitive difficulties can also result from insufficient sleep. Hypersomnolence can also contribute to psychosocial and cognitive processing and must also be addressed during periods of excessive sleepiness generally associated with depressed mood. Social isolation, cognitive and physical slowing, and attention and executive functioning problems may result from excessive sleeping and are similarly disruptive to the child's ability to attend to their daily tasks.

It is important for psychiatrists to provide ongoing pharmacological management, as children's response to medication can be unique and has often been less researched than in adult populations. Unique challenges in prescribing medication to children and adolescents include hormonal changes, neurological maturation, and an increase in physical body mass. As such, adjustments to the dose, type, and frequency of medication administration must be carefully monitored.

School-Based Interventions

Youth diagnosed with a mood disorder often require accommodations and/or services within the academic setting even during periods of euthymic mood given the presence of neurocognitive vulnerabilities, as well as interpersonal sensitivities, and behavioral and mood dysregulation.

Under the Individuals with Disabilities Education Act (IDEA) legislation, students are eligible to receive environmental accommodations and/or specialized education services tailored to their unique needs in order to provide the individual access to the curriculum. The legislation cites that students should make "effective educational progress in the domains of academic, emotional, behavioral, and social functioning" such that academic performance is not the sole qualifying reason for a student to receive special education services [133].

A 504 Accommodation Plan implements environmental modifications to the classroom and school setting to allow a child to access the information being presented. An Individual Education Program (IEP) is a tailored educational program in which direct service and environmental modifications are necessary for the individual to access the curriculum.

Many individuals with mood disorders qualify for a 504 Accommodation Plan or an IEP on the basis of an emotional disability. Examples of commonly provided accommodations and services for individuals with emotional disability are listed in Table 10.3. For youth with problematic and off-task behaviors, a functional behavior analysis (FBA) may take place to assess triggers and reinforcers of undesired behaviors. A formal behavior management plan is implemented based on the findings of the FBA, which guides interventions for inappropriate behavior so that they are implemented in a consistent manner regardless of the time of day or who the child is with. In turn, this promotes consistency and predictability, which are known to help improve behavior over time.

Given that many youth with mood disorders experience comorbid emotional, social, behavioral, and cognitive difficulties, it is expected that the child's 504 plan or IEP include accommodations that are appropriate to address their specific learning needs. For example, children with comorbid ADHD will often receive accommodations to support their learning environment such as preferential seating in the classroom, reminders to turn in assignments, separate rooms for test-taking, etc. Another example is a child with comorbid autism spectrum disorder who experiences significant difficulty with navigating peer relationships. This

Table 10.3 Possible school-based accommodations and services

Special education accommodations and services emotional disability
Scheduled meetings with school psychologist and/or counselor
Establish homeschool communication system
Schedule regular meetings with guardian and treatment specialists
Develop behavioral contracts and behavior management plan
Implement treatment plans into school environment
Excused absences for psychiatric hospitalizations and appointments
Frequent encouragement and positive feedback about performance
Post rules for classroom behaviors
Social skill instruction
Frequent breaks
Inform of upcoming changes in routine
Offer student choices within assignments
Encourage use of relaxation techniques

child may attend a social skill instruction group to support the development of social skill awareness and appropriateness.

The law is written such that children within the school system are to remain in the least restrictive environment, meaning that, when possible, the child should remain in the general education classroom and receive the most minimal disruption from a typical school day. However, some children with mood disorders are unable to remain in a general education classroom due to a variety of reasons that impact their ability to make developmental progress. As such, a variety of alternative placement arrangements can take place. A child may be placed in a smaller classroom for a portion or the duration of the day in an environment with the educator is trained in managing challenging behaviors and emotional difficulties. If the child does not make progress in this type of setting, an alternative may be a therapeutic school environment designed with a higher level of treatment. Oftentimes, therapy is embedded into the school day, and medication management may be a service offered, as well. Residential placement is another alternative during which the child resides at a facility equipped to manage psychiatrically and behaviorally complex youth.

Outcomes for Youth Diagnosed with Mood Disorders

Depression Accurate detection is the first step in providing interventions for youth with mood disorders. Research indicates that less than 50% of children and adolescents with depression ever receive treatment [47]. Of those who do receive evidence-based treatment, they rarely receive it as recommended [47]. Thus, the most important aspect of influencing outcomes is to accurately identify and provide recommended treatment for depression among youth.

Longitudinal studies of youth with depression revealed an increased risk of recurrence in adulthood, later interpersonal difficulties, unemployment, impaired school performance, early parenthood, and adult disability [7, 49, 67, 111, 122, 141].

Bipolar Disorder Youth with pediatric bipolar disorder demonstrate poorer overall quality of life and poorer relations with family and friends than youth with unipolar depression, behavior disorders, and other psychiatric diagnoses [51, 124]. Parent-report assessment of youth with bipolar disorder and quality of life revealed significantly lower quality of life than same-aged youth in the general population and youth with chronic physical conditions [51, 113]. Youth with pediatric bipolar disorder, particularly those with social cognition deficits, demonstrate greater psychosocial impairment than healthy control subjects [14, 115, 120]. Youth with bipolar disorder frequently demonstrate more impaired social skills than community controls and reported having a minimal number of friendships [58, 124]. Youth with severe mood dysregulation experience frequent hospitalizations and, in some cases, legal problems that contribute to high absence from expected activities [12].

Longitudinal studies demonstrate that 4 years after initial diagnosis with bipolar I disorder in youth, individuals continue to experience persistent psychopathology into their mid- and late adolescent years [142]. Even those with subsyndromal symptoms demonstrated higher levels of family dysfunction and psychiatric comorbidity

[142]. Early-onset bipolar disorder is associated with comorbid substance abuse, suicide attempts, hospitalization, and legal difficulties [59, 83, 122]. Persistent diagnosis is associated with high levels of morbidity and dysfunction; however, even those with subsyndromal forms were also found to be associated with morbidity and dysfunction [142]. Persistent neuropsychological deficits and school dysfunction were also demonstrated to be evident at follow-up [142].

Conclusion

Mood disorders are complex entities that alter developmentally appropriate emotional, behavioral, and cognitive regulation secondary to underlying vulnerabilities in the neurological networks that mediate these functions. Predisposition to such dysregulation exists during periods of euthymic mood and becomes exacerbated during mood episodes. Neurocognitive weaknesses, most notably executive dysfunction, adversely impact the child's capacity to attend to and learn information, consequently impacting their academic performance. Furthermore, executive functioning weaknesses related to mood disturbance place youth at higher risk for social difficulties, family discord, and behavioral problems. Comorbidities, such as anxiety, ADHD, and disruptive behavior disorders, often contribute to greater disease burden and divergence from expected developmental trajectories.

Conceptualization of mood disorders as complex neurological entities requires specialized training in child psychiatry or psychology in order to appreciate the underlying biological changes associated with these disorders. Accurate diagnosis of the mood disorder and its comorbidities is key in informing appropriate treatment recommendations. Interventions must be implemented across all settings in order to facilitate optimal developmental growth and may include pharmacological management, individual and family therapy, behavior management planning, and school services and accommodations. Response to interventions may vary in relation to the child's stage of development, the types of services implemented, the severity of the disease course, and their comorbid symptoms. Longitudinal outcome studies demonstrate heterogeneity secondary to these factors but place youth with mood disorders at higher risk for academic underachievement, unemployment, interpersonal difficulties, disease recurrence, and disability. Overall, professionals need to work together to more accurately identify and implement comprehensive interventions for youth with mood disorders, as this is the most important aspect of influencing outcomes.

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Anxiety Disorders

11

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Overview of Youth Anxiety Disorders

Anxiety disorders are common among youth across the age span [16, 31]. Epidemiological studies find median prevalence rates ranging from 2% to 24%, with overall rates higher among girls [38]. Currently, the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5; [2]) includes the following anxiety disorders: separation anxiety disorder, specific phobia, selective mutism, social anxiety disorder, panic disorder, agoraphobia, and generalized anxiety disorder (GAD). Obsessive-compulsive disorder (OCD) and posttraumatic stress disorder (PTSD), which were previously categorized as anxiety disorders in the DSM-4 [1], now fall under the categories of "obsessive-compulsive and related disorders" and "trauma- and stressor-related disorders" in the DSM-5 [2], respectively. The core feature across anxiety disorders is excessive fear and/or anxiety, resulting in behavioral disruption. Although there is some debate regarding whether fear and anxiety are truly distinct from each other [43], the DSM-5 [2] defines fear as the emotional response to a present and/or imminent threat, whereas anxiety involves the anticipation of future threat.

Anxiety disorders differ from each other based on the specific triggers that elicit such fear or anxiety. For a detailed description of each disorder, please refer to the DSM-5 [2]. In brief, a child with separation anxiety disorder exhibits excessive fear or anxiety when separated from home or caregivers. Youth with specific phobias have strong fear reactions to certain objects (e.g., dogs) or situations (e.g., being on an airplane). Children with selective mutism demonstrate typical speech when interacting with immediate family members but fail to initiate speech with others or verbally respond when others try to engage with them. Youth with social anxiety disorder have excessive fear or anxiety about social situations in which they may be negatively evaluated by others. Panic disorder consists of recurrent unexpected panic attacks and worry about having additional panic attacks. Individuals with

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agoraphobia fear or avoid situations in which they believe they will have a panic attack or might not be able to escape if a panic attack occurred (e.g., public transportation). Generalized anxiety disorder involves frequent and persistent worry about a variety of domains (e.g., school performance, the future) and is accompanied by at least one of the following symptoms: restlessness, fatigue, concentration difficulties, irritability, muscle tension, or disrupted sleep.

Youth with OCD experience obsessions (e.g., persistent unwanted thoughts, urges, or images that evoke anxiety) and/or compulsions (i.e., repetitive behaviors one feels driven to perform in order to alleviate distress). Unlike the previously mentioned disorders, which may not have a clearly identifiable initial trigger, PTSD involves exposure to a traumatic event, followed by intrusive symptoms (e.g., recurrent distressing memories), avoidance of internal or external reminders of the event, negative changes in cognitions and mood, and increased arousal and reactivity. Across all anxiety and related disorders, symptoms cause either high levels of distress, significant interference within life domains (e.g., school, home life, peer relationships), or both.

Differences are found in the rates of specific subtypes of anxiety across the age span [38, 60]. Such differences appear to be consistent with normal developmental periods [57]. For example, rates of separation anxiety and specific phobias tend to peak during early to mid-childhood, whereas social anxiety disorder peaks in middle adolescence [38]. Symptoms of selective mutism typically appear between ages 3 and 6, with a formal diagnosis given when the child enters school between ages 5 and 8 [48]. Fears and worries consistent with generalized anxiety appear to express themselves in late childhood [60], but a formal diagnosis of generalized anxiety disorder is most likely in young adulthood [38]. Panic disorder seems to peak during late adolescence [38]. OCD has a bimodal age distribution with first peak around age 11 and a second peak in adulthood [55]. In contrast to a trend of higher anxiety disorder prevalence rates among girls, boys have higher rates of OCD during childhood [55].

Comorbidity across anxiety disorders (i.e., homotypic comorbidity) and between anxiety disorders and non-anxiety disorders (heterotypic comorbidity) is considered the rule, not the exception [27]. As children age, the likelihood of having a “pure” anxiety disorder decreases [5]. With regard to non-anxiety disorders, youth with anxiety disorders, particularly those with multiple anxiety disorders, are at increased risk for developing depression [5]. Additionally, having an anxiety disorder increases vulnerability to developing a substance use disorder [62]. Despite anxiety being characterized as an internalizing disorder, many youth with anxiety disorders also present with comorbid externalizing disorders, such as oppositional defiant disorder or attention-deficit/hyperactivity disorder [27]. The burgeoning field of research on autism spectrum disorders reveals that approximately 40% of youth with a principal diagnosis of an autism spectrum disorder also meet criteria for at least one anxiety disorder [52].

Impairment Associated with Youth Anxiety

Anxiety disorders in youth can lead to impairment across multiple domains. Untreated childhood anxiety disorders, along with associated comorbid disorders (e.g., substance use disorder, depression), can be chronic, persisting into adulthood [30]. Anxious youth are also at greater risk for experiencing social stressors, academic problems, and functional difficulties. They are significantly more likely to be rated as depressed and oppositional by parents and teachers relative to non-anxious youth [20]. Socially, high anxiety is linked with interference in social skills development and peer relationships [3, 22, 36]. Anxious youth self-report higher levels of social maladjustment, increased social neglect and peer rejection, and poorer self-image [23, 53]. Social skills deficits are also observed by others, with teachers rating anxious students as lower in social acceptance [20]. Because of impairments in social development, youth with anxiety may also be less likely to seek social interactions with peers or be less skilled when interacting with peers.

Anxiety is further linked with poorer academic performance [19, 22] and difficulty taking tests; indeed, anxiety is associated with significantly lower scores on standard achievement tests of reading and math [20]. School-related anxiety can also lead to avoidance of different school situations, such as participating in class, giving oral reports, eating in the school cafeteria, working on group projects, asking the teacher for help, riding the school bus, or walking in crowded hallways. As such, anxious youth may have difficulty engaging in the overall curriculum due to a tendency to attend to situations or events that are perceived as threatening (e.g., focusing on worries that the teacher will call on the child to answer questions or fears of doing or saying the wrong thing while in class), which interferes with their ability to pay attention and remember the lessons taught in class. In turn, poor academic performance may contribute to the maintenance of anxiety in school. Continued poor performance in school can increase anxiety symptoms, thereby compounding and exacerbating academic difficulties. Indeed, while early-onset anxiety symptoms are associated with greater rates of academic failure, reductions in childhood anxiety are linked to improvements in school performance [32, 61].

Severe school-related anxiety may result in refusal to attend school altogether, where the youth has recurrent absences or partial absences (i.e., attends school, but is unable to stay for the entire day) due to anxiety symptoms. School refusal can lead to a series of negative consequences. As school attendance is usually a legal requirement, excessive absences may lead to the involvement of truancy officers (e.g., officer comes to the home to escort the child to school) and even legal action against parents. Outside of the legal consequences, school refusal is associated with a number of adverse outcomes, particularly in regard to a child's social and academic development. Short-term consequences include academic underachievement, premature dropout rates, difficulties with peer relationships, and increased family conflict (for review, see [33]). Furthermore long-term follow-up studies have found that school refusal in youth is associated with increased rates of psychiatric illness, general difficulties with mental/psychological well-being, poorer adjustment to work and social relationships, and difficulties in family relationships [8, 10, 14, 36].

Assessment of Anxiety in Schools

As described above, anxiety symptoms, as well as anxiety-related school refusal, can be detrimental to a child's functioning. To determine the appropriate intervention to target the youth's anxiety symptoms, a comprehensive evaluation, including child-, parent-, and teacher-report measures as well as in-class observations, is needed. In addition, since learning disorders are associated with higher anxiety levels in children and adolescents, a referral for neuropsychological testing should be made if a learning disorder is suspected. Additionally, when available, schools should work closely with the youth's treatment provider (e.g., counselor, outpatient therapist, psychiatrist) to garner a complete understanding of the clinical picture and collaborate to determine the intervention that will best address the youth's needs.

Schools typically use screening measures to assess for the presence and severity of anxiety along with other internalizing and externalizing symptoms in youth. The Behavior Assessment System for Children, Third Edition (BASC-3; [46]), is a questionnaire that consists of parent, child, and teacher versions and assesses multiple behavioral and emotional domains as well as overall externalizing and internalizing problems. The scale provides scaled scores and percentile ranks to easily identify domains that reach clinical significance and warrant further examination. The BASC-3 also includes a Student Observation System (SOS), which records direct observations of a youth's classroom behavior. The SOS assesses adaptive and maladaptive behaviors, including positive peer interactions and various disruptive behaviors. The Spence Children's Anxiety Scale (SCAS; [50]) is another parent- and child-report measure that assesses the presence and severity of anxiety symptoms related to obsessive-compulsive disorder, panic/agoraphobia, separation anxiety, social phobia, generalized anxiety, and physical injury fears. As anxiety disorders are often comorbid with depression, it may also be helpful to administer a depression measure, such as the Children's Depression Inventory-2 (CDI-2; [35]), which assesses cognitive, behavioral, and affective symptoms of depression and helps identify the presence of critical depressive symptoms (e.g., suicidal ideation). Youth who score within the clinical range on the aforementioned screeners should be referred for clinical evaluation and treatment (see below for information on making referrals). Clinic-based assessments of anxious youth would include an unstructured or semi-structured clinical interview (e.g., Anxiety Disorder Interview Schedule-IV, Child and Parent Versions [49]) to determine the presence/absence of an anxiety disorder.

For school-refusing youth, the most basic and traditional measure of school refusal involves calculating the number of full or partial school days that are missed. Number of school absences can also be used as a measure to track the progression of the behavior over time (i.e., increased absences suggest increased severity of school refusal behavior) or to determine the effects of a treatment on the behavior.

Aside from number of absences, there are evidence-based assessments that can be used in school and clinical settings to evaluate the function of school refusal behavior. As school refusal behavior may have multiple functions, researchers and clinicians have emphasized the importance of identifying the motivating and maintaining factors through a functional analysis. Kearney and Silverman [25] developed a four-factor functional model, which posits that school refusal occurs due to negative and/or positive reinforcement. Specifically, school refusal occurs so that the child may (1) avoid negative affect, such as feelings of anxiety or depression (negative reinforcement); (2) avoid aversive social and evaluative situations, such as peer interactions or class presentations (negative reinforcement); (3) gain attention from others, such as family members, friends, and teachers (positive reinforcement); and/or (4) gain tangible reinforcement, such as playing video games at home instead of attending school (positive reinforcement). A functional behavioral analysis based on the four-factor model can be completed in both school and clinical settings, and information regarding the factors can be gathered through a clinical interview. Observations of the youth in class can also provide further data regarding the function of the school refusal behavior.

The School Refusal Assessment Scale – Revised (SRAS-R; [24]) is a 16-item parent- and child-report measure, which maps onto the four-factor functional model. The SRAS-R assesses the relative strength of the four factors; the highest rated scale is identified to be the primary function of the school refusal behavior. The SRAS-R also takes into account that school refusal behavior may have multiple functions; scales that are within 0.5 points of one another are indicative of a mixed function profile. Another child-report measure, the Self-Efficacy Questionnaire for School Situations (SEQ-SS; [21]), examines youths' cognitions to school-related situations, such as completing homework and being separated from parents to attend school, and their perception of their ability to cope with each of these anxiety-provoking situations. Similar to the SRAS-R, the SEQ-SS can be used to determine targets for cognitive and behavioral interventions as well as a measure of progress or change over time.

Case Example Kelly is a 13-year-old female in the seventh grade who began seeing the school psychologist because of ongoing difficulties attending school. At the time of assessment, Kelly attended school sporadically, regularly missing between 1 and 3 days of school each week. As a younger child, Kelly experienced separation anxiety and reluctance to separate from her parents when it was time to go to school. While the separation anxiety symptoms remitted in third grade, Kelly's difficulties with school attendance reemerged in sixth grade following several instances of peers teasing her. Recently, Kelly's school refusal exacerbated, and she was unable to attend school for 3 straight weeks. With the help of her school psychologist, she began reintegrating back into school for an hour in the afternoons, but she continued to struggle to get to school in the morning. Specifically, her anticipatory anxiety caused her to have panic attacks while getting dressed, riding in the car to school, and leaving the car to enter the school. Social interactions were especially difficult as Kelly feared being negatively evaluated by her peers or otherwise saying the "wrong" thing or embarrassing herself. In school, Kelly attempted to avoid social interactions by spending the majority of the day in the guidance counselor's office. Due to the frequent absences from school, Kelly also started to experience pervasive worries related to school performance (e.g., taking tests, completing homework). She avoided schoolwork and fell behind in her coursework.

Kelly's school psychologist asked her and her parents to complete a battery of screening questionnaires. The SRAS-R revealed a mixed function profile where her school refusal behavior was associated with avoidance of negative affect and escape from aversive social and evaluative situations. Her parents reported that when Kelly was not in school, she made efforts to avoid talking about her school-related anxiety or engaging in any school-related activities (e.g., completing homework, discussing plans for the next academic year). In addition to making efforts to avoid social interactions in school, Kelly also avoided areas in her neighborhood where peers from school would congregate (e.g., local park, mall, restaurants in town). On the SEQ-SS, Kelly's self-reported ability to cope was lowest with regard to answering peer's questions about absences, further highlighting Kelly's anxiety regarding social interactions in school and how Kelly's school refusal created a self-maintaining cycle of anxiety and avoidance (i.e., Kelly refrained from going to school because she was anxious; she then became fearful that her peers would ask about her absences when she returned to school; therefore, she continued to avoid attending school). Kelly also endorsed a low score on her perceived ability to cope with homework completion. Kelly's BASC-3 symptom index profile was typical of an anxious adolescent with elevated scores on internalizing problems, anxiety, and somatization across reporters. Scores on the depression scale were within normal range. From the BASC-3 SOS, no disruptive behaviors were recorded; however, undesirable classroom behaviors, such as putting her head on her desk and not being on task, were observed. Child and parent reports on the SCAS were consistent with findings from the previous measures with elevated scores on the social phobia and generalized anxiety scales. Finally, Kelly's CDI-2 profile indicated slight elevations on the ineffectiveness and interpersonal subscales, suggesting that Kelly has difficulties enjoying herself while in school and problems interacting with peers. However, other scales indicative of depressed mood (e.g., negative self-esteem, negative mood/physical symptoms, emotional problems) were normal.

Based on the school assessment, Kelly was referred to a therapist specializing in anxiety disorders, who conducted a clinical interview that supported a primary diagnosis of social phobia and comorbid generalized anxiety disorder. The school assessment and clinical evaluation highlighted pervasive avoidance behaviors related to her social anxiety; her school refusal behavior was maintained through negative reinforcement, meaning that she was able to avoid negative affect and aversive social situations by refraining from attending school. These target symptoms were incorporated into her therapist's treatment plan with the goal of returning Kelly to school full time and reducing intensity of social and generalized anxiety symptoms.

Outpatient Interventions for Youth Anxiety

When to Refer for Clinical Assessment and Treatment

While many students with mild anxiety do well in school-based interventions (see below), those with moderate to severe anxiety likely require assessment and treatment from a clinician outside of school (i.e., clinical psychologist, psychiatrist, licensed social worker) with expertise in youth anxiety disorders. Signs that it is appropriate to refer a student for clinical assessment include (1) scores in the clinical range on self-, parent-, and/or teacher-report measures of youth anxiety (as described in the assessment section, above); (2) verbal reports from parents or teachers that express concern about the frequency and intensity of the child or adolescent's anxiety symptoms; (3) notable interference in the youth's ability to attend certain classes (or school altogether), engage in the curriculum, participate in class, or go to assemblies or the school cafeteria; or (4) frequent visits from the youth to the guidance counselor because of anxiety (including reports of panic attacks).

Not every mental health practitioner has specific expertise in child and adolescent anxiety disorders, so caution should be taken when making a referral to an out-of-school provider. In many larger metropolitan areas, there are anxiety disorder clinics within academic medical centers that offer comprehensive anxiety disorder assessment and treatment. However, these clinics may have long waitlists; if the referral is urgent, then it is appropriate to ask clinic staff for a list of trusted referrals. In areas where there are no specialty programs in youth anxiety, it is important to refer to therapists who have explicit supervised training (i.e., at least a year) in cognitive behavioral therapy (CBT) for youth anxiety disorders (these therapists are also likely to be members of national organizations focusing on CBT and/or anxiety disorders) or psychiatrists who are board certified in child and adolescent psychiatry with explicit training in youth anxiety disorders.

CBT for Youth Anxiety Disorders

CBT is a skills-based, well-established treatment for children and adolescents with anxiety disorders. The treatment tends to be short term (i.e., 10–20 sessions) and can be administered in individual, family, or group formats. Though CBT protocols vary, key components of CBT for youth anxiety disorders include the following:

1. *Psychoeducation:* children/adolescents and their parents learn about the interaction of anxious thoughts, physical feelings, and avoidant behaviors and how these factors contribute to the maintenance of the anxiety disorder.
2. *Thought identification and challenging:* children/adolescents learn to identify distortions (or "mistakes") in their thinking, such as overestimating the chances of something bad happening, and then practice challenging the thoughts and generating coping thoughts.
3. *Exposure therapy*: this involves creating a list of feared or avoided situations and then gradually engaging in each situation while tolerating feelings of anxiety; exposure exercises are conducted both in session and between sessions as homework.

Anxiety tends to dissipate with repeated practice, while a sense of mastery increases. Exposures are arguably the most important and effective component of CBT for youth anxiety [9, 29].

Researchers have examined the efficacy of CBT protocols for a wide range of youth anxiety disorders, including social phobia [6, 7], specific phobia [42], panic disorder [45], OCD [44, 54, 59], GAD, or separation anxiety disorder [26], with studies showing that compared to waitlist control groups or attention control groups (i.e., those receiving non-CBT intervention for the same amount of time), youth receiving CBT show significant reductions in anxiety symptoms at posttreatment. In a study of one of the most widely used cognitive behavioral interventions for children (ages 9–13 years) with GAD, social phobia, or separation anxiety, the Coping Cat [26], 50–65% of those receiving the intervention no longer met criteria for their primary anxiety disorder at posttreatment [26, 28]. Treatment gains are largely maintained at follow-ups of at least 1 year (e.g., [7, 15]), with one study finding that remission of anxiety disorder symptoms and improvements in functional impairment continue to be maintained into young adulthood [47].

Pharmacotherapy in Combination with CBT

Two large-scale studies have directly compared CBT and pharmacotherapy with placebo for youth anxiety [56] and OCD [54]. The Child/Adolescent Anxiety Multimodal Study (CAMS) randomized 488 children and adolescents (ages 7–17 years) with separation anxiety disorder, GAD, and/or social phobia to one of the four interventions: 14 sessions of individual CBT, sertraline (up to 200 mg), combination CBT plus sertraline, or placebo drug. The combination treatment was most efficacious, with 80.7% considered responders (rated independently as much or very much improved), compared to 59.7% CBT alone, 54.9% sertraline alone, and 23.7% placebo [56]. A similar pattern of results was found in the Pediatric OCD Treatment Study (POTS), which also randomized 112 youth (ages 7–17) to CBT alone, sertraline alone, CBT plus sertraline, or placebo drug over the course of 12 weeks (plus 4 additional weeks for those responding to treatment). On a gold standard measure of OCD symptoms (the Children's Yale-Brown Obsessive-Compulsive Scale [CYBOCS]), combination treatment resulted in the greatest improvement, followed by CBT alone and sertraline alone (which were not significantly different); all active treatments showed superior improvement compared to placebo drug [54]. Thus, for children and adolescents presenting with moderate to severe anxiety disorders and OCD, a combination of CBT and pharmacotherapy (specifically, a selective serotonin reuptake inhibitor, or SSRI) is recommended.

School-Based Anxiety Interventions

Within-School Supports and Accommodations

If a student is receiving psychotherapy from an outside provider, it is important for that provider to collaborate closely with the student's guidance counselor or school psychologist to discuss anxiety management strategies helpful to the student as well as ways the school can facilitate gradual exposure to feared situations. Many students with anxiety disorders meet regularly with their school counselor, with sessions focusing on (a) problem-solving ambiguous or challenging academic situations (e.g., generating a plan to complete several large assignments by their due dates), (b) social problem-solving (e.g., communicating effectively with peers), (c) challenging distorted thinking in school situations (e.g., believing a teacher "hates me" after being prompted to turn in missing homework), and (d) conducting exposures in collaboration with the student's CBT therapist.

A major challenge for school staff is to determine the level of accommodation appropriate for each anxious student. With too few accommodations, some youth become overwhelmed and vulnerable to poor academic performance and/or school refusal. On the other hand, overaccommodation may reinforce anxious behaviors and lead to greater anxiety over time. Consider the case of Ryan, an 11-year-old boy with a severe fear of vomiting that he developed in fifth grade after seeing a peer throw up in the classroom. At the onset of his phobia, his teachers thought it best not to let him leave the classroom when he felt anxious that someone might vomit; he felt trapped and started to have frequent panic attacks, which then led to meltdowns every morning before school in an effort to stay home. The next year, his guidance counselor addressed this under-accommodation by working out a plan with his sixth grade teachers to allow him to be excused to the guidance office when needed. The teachers did so, but not wanting to repeat his fifth grade experience, they also extended their accommodation of Ryan by often asking him if he was feeling okay, telling him to leave the classroom preemptively if they thought class material might trigger his fear, and encouraging him to see the school nurse whenever he said he did not feel well (who would then check his temperature and his throat and assure him he was not sick). Though the teachers were well meaning, these extra accommodations only increased Ryan's fear of vomiting by reinforcing his belief that he could not handle references to vomit or being sick and making him believe he needed external affirmation from the nurse that he was healthy. The guidance counselor ultimately had a meeting with the teachers and Ryan's parents together and created a gradual plan to reduce excessive reassurance, "trigger warnings," and passes to leave the classroom, which Ryan then worked on with the guidance counselor in their meetings.

Thus, the goal is to start with the level of accommodation needed to maximize the anxious student's school attendance and engagement but to gradually reduce these accommodations with the cooperation of the student and his/her parents as the student's anxiety improves through treatment. For example, a socially anxious elementary school student may be exempt from reading aloud in class at the beginning of the year, but as the year progresses, the student will work on gradually increasing class participation to the point of being able to read aloud. Similarly, a high school student may initially be permitted to complete written instead of oral reports; as the student works with his therapist and guidance counselor on managing his social anxiety, he may start to give short presentations to the teacher alone, then to small groups of students, and then to his classroom as a whole. By gradually reducing avoidant behaviors, youth learn they can handle the situation and its accompanying anxiety, but are not so overwhelmed that they refuse the situation altogether.

In some cases when a student is presenting with a severe anxiety disorder or intermittent school refusal due to anxiety, a more programmatic approach is needed and acquired through a 504 plan or an individualized education plan (IEP). Though this varies by school, these programs often consist of a modified schedule, with students attempting to attend their mainstream classes but having the option to go to a "home base" classroom instead where students work independently with the support of special education teachers and counselors, as well as daily check-ins with guidance counselors and ad hoc counseling as needed. The goal of these types of programs is to keep students engaged in school but to gradually increase the amount of time spent in mainstream classes and decrease reliance on support staff for emotional and academic assistance. If this level of school accommodation is still inadequate, then therapeutic school placement should be considered.

School-Based Prevention and Early Intervention Programs

Recently, researchers have evaluated the effectiveness of cognitive behavioral interventions for anxiety delivered within school settings (see [41] for review). School staff members are in a good position to identify those youth who may benefit from anxiety intervention, and school-based CBT may increase access to care for youth who are unlikely or unwilling to receive it in clinic settings. Further, given the high prevalence of anxiety, CBT programs may be provided to all students in an effort to prevent development of later or more severe anxiety disorders.

Studies have examined three different types of school-based programs: universal prevention (provided to all students in an effort to prevent anxiety disorders), indicated prevention (provided to students with certain risk factors or elevated symptoms of anxiety), and targeted intervention (provided to students meeting criteria for an anxiety disorder). The majority of universal prevention programs have implemented the FRIENDS protocol [4], a cognitive behavioral intervention that teaches relaxation skills, cognitive identification and restructuring, seeking support from family and peers, and gradual exposure to anxiety-provoking stimuli. The initial trial of the FRIENDS protocol involved three schools, which were randomized to three different conditions: psychologist-led FRIENDS, teacher-led FRIENDS, and standard curriculum. All available students ($N = 489$, ages 10–12) were included in the trial; those receiving CBT participated in ten weekly sessions (75 min) plus two booster sessions. Results showed that those in either of the FRIENDS conditions had lower self-reported anxiety symptoms compared to those in the standard curriculum [4]. Subsequent universal prevention trials based on the FRIENDS protocol (with varied intervention durations) have shown similar results within the same general age range [13, 51, 58], though a couple of studies have found that the intervention has not outperformed usual curricula [17, 40]. There is also some indication that students have greater improvements in anxiety symptoms when the program is administered by mental health clinicians compared to teachers [51]. Future universal anxiety prevention trials would benefit from a wider range of outcome measures (i.e., clinician-administered interviews, parent report) and longer follow-up periods.

A number of studies have also examined the efficacy of early intervention (indicated or targeted) for children and adolescents with elevated anxiety symptoms or mild to moderate disorders; these studies used school-based group CBT protocols, with most showing significant improvements in anxiety symptoms at follow-up compared to those receiving no intervention [11, 12, 18, 34, 37, 39]. Among the earlier studies, Dadds and colleagues [11, 12] screened 7- to 14-year-olds for anxiety via self-report and teacher nomination. Parents of those with elevated symptoms were then given a structured interview examining the presence/absence of anxiety disorders. Children with mild to moderate anxiety disorders or with subclinical features of an anxiety disorder were offered participation in the study; 128 children were randomized to either ten sessions of group CBT (plus three parent sessions) or monitoring only. Both groups showed improvement at posttreatment, but those receiving CBT had lower rates of anxiety disorder diagnoses at 6-month and 24-month follow-up (no significant difference at 12-month follow-up). Those in the intervention group had a 20% greater reduction in anxiety disorder rates after 2 years compared to those in the monitoring-only group [11]. Another comprehensive school-based intervention for adolescents (ages 13–17) with a diagnosis of social phobia (including off-campus social events and help from pro-social peers) also found significantly lower posttreatment rates of diagnosis among those receiving CBT (33%) versus those in a waitlist control group (94%); improvements in anxiety disorder symptoms were maintained at 9-month follow-up [37].

Overall, school-based cognitive behavioral prevention and early intervention programs show promise as effective and accessible alternatives to clinic-based treatment, at least for those with more mild to moderate anxiety severity. Future research must examine how to disseminate these interventions more widely while maximizing cost-effectiveness.

Summary

Anxiety disorders are common in children and adolescents and can lead to significant interference in school and social functioning. Anxiety disorders frequently co-occur with other anxiety disorders as well as other psychiatric disorders such as depression, ADHD, and substance use disorders. Particularly when untreated, anxiety disorders are associated with poorer social skills development, social adjustment, and peer acceptance. Further, youth with anxiety disorders often avoid a range of feared school activities, which may lead to decreased engagement in school curriculum, poorer academic performance, and even school refusal.

A comprehensive school-based assessment for youth anxiety includes measures that screen for anxiety and related symptoms from multiple reporters (child, parent, and teachers) as well as behavioral observation. Youth with elevated scores on these measures or other signs of interfering anxiety should then be referred to a clinician or program with expertise in anxiety disorders for further assessment and intervention. Cognitive behavioral therapy (CBT) has been shown to be particularly efficacious for youth anxiety disorders, though children and adolescents with more severe anxiety may require a combination of CBT and pharmacotherapy.

This chapter also outlines the appropriate level of school accommodations for youth with anxiety, with the goal of gradually reducing avoidant behaviors. We also described advances in school-based prevention and early intervention programs for anxiety, most of which employ a CBT approach. These programs show promise in preventing development of anxiety symptoms and/or reducing symptoms of anxiety disorders. Overall, identifying distressing or impairing symptoms of anxiety in children and adolescents as early as possible may circumvent later adverse consequences and promote optimal academic and social functioning (Table 11.1).

Table 11.1 Summary of interventions and accommodations for anxious students

In-school interventions	Outside-of-school interventions
• Generate a 504 plan to formalize school supports • Request a school evaluation to determine special education eligibility • Regular meetings with guidance counselor or school psychologist to work on – Academic problem-solving – Social problem-solving – Challenging unhelpful thinking • Crisis management: allowing student to take breaks as needed from classroom or academic material during periods of acute anxiety • Gradual reduction of breaks or excused absences by encouraging gradual exposure to anxiety-provoking situations • School-based cognitive behavioral therapy (CBT) groups for anxiety (e.g., FRIENDS protocol) • Small social groups to improve communication skills and reduce anxiety when interacting with peers (e.g., “lunch bunch”)	• Neuropsychological assessment for learning disorders that may be contributing to anxiety • Cognitive behavioral therapy (CBT) to improve anxiety management skills • Pharmacotherapy for moderate to severe anxiety disorder (in combination with CBT) • Social skills group training

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Disruptive Behavior Disorders

12

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Introduction

Disruptive behavior disorders (*DBDs*) are psychiatric disorders in which the hallmark feature is behavior that violates the rights of others and/or brings an individual into conflict with others or with society. Some examples of such behaviors include rule-breaking, defiance, aggression, and destruction of property. They may also be referred to as *externalizing disorders*, due to their outward focus, in contrast to *internalizing disorders*, in which individuals typically focus negative mood and behaviors inward. The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), classifies oppositional defiant disorder (ODD) and conduct disorder (CD) (together with intermittent explosive disorder, pyromania, and kleptomania, which won't be discussed here) as *disruptive*, *impulse-control*, *and conduct disorders* [1]. This chapter will discuss ODD and CD, which are commonly considered disruptive behavior disorders, and will also briefly cover disruptive mood dysregulation disorder (DMDD), which sits at the intersection of the mood and behavior disorders and should be considered when diagnosing ODD and CD.[1]

ODD, CD, and DMDD share symptoms and some can co-occur. Much of the difference between them is due to the prominence of some symptoms over others in the DSM-5. While many of the behaviors associated with disruptive behavior disorders (e.g., irritability, lying, etc.) may also be exhibited by a typically developing child on occasion, it is the increased frequency, persistence, and pervasiveness across situations, as well as impairment in functioning, that will distinguish disordered functioning from more typical presentation of these behaviors. Table 12.1 provides a broad comparison of these three disorders, which may be helpful as you proceed through this chapter.

In the next section, we briefly review the symptoms associated with each of these three disorders, as well as what we know regarding neurocognitive features, risk factors, and the prognosis of each. We then focus our discussion on how to assess the impact of disruptive behavior disorders on learning and how best to intervene to minimize such impact.

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[1] More information on DMDD can also be found in Chap. 10 on "Mood Disorders."

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Table 12.1 Comparison of prominent types of dyscontrol and common symptoms of oppositional defiant disorder (ODD), conduct disorder (CD), and disruptive mood dysregulation disorder (DMDD)

Prominent type of dyscontrol	**ODD**	**CD**	**DMDD**
Poorly controlled behaviors	X	X	
Poorly controlled emotions	X		X
Common symptoms	**ODD**	**CD**	**DMDD**
Chronic angry, irritable, or negative mood	X		X
Recurring temper outbursts, inconsistent with developmental stage	X		X
Defiance of rules or authority figures	X	X	
Stealing or deceit		X	
Destruction of property		X	
Serious violation of rules		X	
Verbal/physical aggression		X	X

Oppositional Defiant Disorder (ODD)

Symptoms and Diagnosis

Although it is a disorder often identified or diagnosed because of oppositional and defiant behaviors, ODD can include poor control of behaviors *and/or* emotion. Emotional symptoms of ODD include an angry and irritable mood, which may result in a child exhibiting frequent temper tantrums, acting touchy or easily annoyed, and expressing anger or resentment. Behavioral symptoms include argumentative and defiant behavior, such as arguing with authority figures, defiance or refusal to comply with rules, deliberately annoying others, blaming others for mistakes or misbehavior, and/or vindictiveness [1].

In order to meet the criteria for a diagnosis of ODD, a child must have many of these symptoms, frequently and for a significant length of time. The symptoms must cause the child distress or interfere with social relationships, including relationships with family and/or peers, or the symptoms must negatively impact functioning in social, educational, or occupational domains. Finally, the behaviors must not occur solely during a psychotic episode, use of substances, depressive episodes, or manic episode. If the criteria for DMDD are also met, the diagnosis of DMDD overrides the diagnosis of ODD [1].

Prevalence

The chance that a person will meet the criteria of ODD at some point in his or her lifetime is around 10%. ODD is slightly more common in boys than girls (1.4:1) and is usually diagnosed in late preschool or early elementary school [1, 2]. Although there is no age limit for a diagnosis of ODD, it is typically considered a disorder of childhood, and it is extremely rare for ODD to first emerge in adulthood.

Co-occurrence and Prognosis

Research on rates of co-occurrence tells us that children diagnosed with ODD are more likely to also have a diagnosis of attention deficit hyperactivity disorder (ADHD), anxiety or depressive disorders, learning and language disorders, or substance use disorders compared to the general population. This may be because neurocognitive differences that are related to ODD (e.g., in the amygdala and prefrontal cortex, which will be described later) contribute to other sets of symptoms as well. However, it may also be due to the fact that there is some overlap in symptoms that contribute to diagnostic classification. For example, a child's inability to sit still in class when told to do so may contribute to a diagnosis of ADHD (for hyperactivity) and ODD (for defiance); a child's chronic touchiness may contribute to a diagnosis of depression (for irritability) and ODD (for loss of temper). When a child is diagnosed with multiple disorders, it can be overwhelming and confusing to parents, educators, and providers. It can be hard to know which problems are primary and should be the focus of an intervention.

About 70% of children seem to "outgrow" ODD as they get older [2]. For others, ODD could predict conduct disorder, antisocial personality disorder, or other behavioral disorders. Children with ODD are also at greater risk for developing other disorders later on, such as depression, anxiety disorders, or substance use disorders [2, 3].

Environmental Risk Factors

While it is unlikely that any single risk factor will "cause" a person to develop disruptive behavior disorders, it is typically a combination of biological and environmental factors that put a person at higher risk for developing these disorders. There are a number of known environmental risk factors for ODD; however, one must keep in mind that much of the research on risk factors is *correlational*, telling us only that a certain factor is associated with higher prevalence of the disorder, rather than clearly establishing that a factor *causes* the disorder.

Some of the environmental factors known to be associated with ODD include hostile parenting practices, abuse or neglect, lack of supervision, uninvolved parents, inconsistent discipline, and familial instability [4]. ODD is more prevalent for children from families of lower socioeconomic status [5]. However, rather than poverty itself, it is likely the environmental factors mentioned above, which are known to be more common in low-income homes, that are contributing to the disorder.

Additionally, research has found racial and ethnic disparities in diagnosis, such that African American, Hispanic, and Asian American youth are less often diagnosed with ADHD and more often diagnosed with disruptive behavior disorders than non-Hispanic, white youth [6]. It is currently unclear whether cultural biases in clinicians' diagnoses may contribute to this difference and if so, to what degree. Other factors that may contribute are racial or ethnic differences in the type of treatment visited, in treatment-seeking behaviors, or in parent knowledge or beliefs. Regardless of cause, it will be critical to monitor and correct prior misdiagnosis.

Biological and Neurocognitive Risk Factors

Research suggests that individuals with ODD may have significant brain differences compared to individuals who don't meet the criteria for ODD. For instance, some studies have found that individuals with ODD have abnormalities in the prefrontal cortex, which is responsible for decision-making and personality, and the amygdala, which is responsible for memory, decision-making, and emotion regulation [1]. These brain differences could explain why individuals with disruptive behavior disorders often exhibit a lack of sensitivity to punishment [7]. One study referred to this as a *motivational inhibition deficit* [8], finding that children with ODD (or CD) were more likely to ignore the high probability of punishment and continue seeking a reward even if punishment was likely.

Clues to brain differences like these also come from studies in which children are asked to perform various neurocognitive tasks, in order to identify performance differences between children with and without ODD. Although the neurocognitive research on ODD is only in its earliest stages, preliminary evidence points to deficits in *executive functions*, the broad set of skills that enable humans to plan, focus attention, remember, and juggle multiple tasks. More specifically, children with ODD (as well as CD) show poorer ability in the executive areas of flexibility (e.g., switching between ideas), inhibition (e.g., stopping before behaving impulsively), working memory (e.g., holding and manipulating multiple ideas at once), planning (making decisions for action by thinking through outcomes), and regulation of negative emotions such as frustration and irritability [7, 9]. Deficits in these executive functions may cause children to respond aggressively when angry and to defy adult expectations without thinking through the consequences of doing so.

In addition to executive functioning, other studies have found that children with ODD may have more difficulty than other children processing social cues [4, 10]). Children with social skill difficulties may inaccurately perceive others' expectations for their behavior or misperceive others' negative responses to disruptive behaviors. If a child can't perceive that others are displeased with his or her behavior, this will interfere further with the typical relationship between negative feedback and behavior change.

Finally, a few studies suggest that children's externalizing behaviors, including those that contribute to ODD (and CD) can be impacted by language skill deficits [11]. Language skills that may impact disruptive behaviors include receptive skills such as understanding directions and expressive skills such as being able to express needs or feelings in words.

Conduct Disorder (CD)

Symptoms and Diagnosis

While there is some overlap of CD and ODD symptoms, such as defiance of authority figures, the behaviors exhibited by individuals with CD tend to be more severe and problematic to society than those of ODD. An individual with a diagnosis of CD exhibits a long-standing pattern of aggressive, destructive, deceitful, or rule-breaking behavior, which might include initiating physical fights, physical cruelty to animals or people, use of a weapon with intent to injure, sexual assault, fire setting, theft, and frequent truancy [1]. If a person with CD exhibits poor emotional control, it is of much less prominence than the observed poor behavioral control.

In order to meet the criteria for a diagnosis of CD, an individual must engage in many of these behaviors, frequently and for a significant length of time. An individual's symptoms must significantly impair their social, academic, and/or occupational functioning. In addition, if the individual is over the age of 18 and meets the diagnostic criteria for antisocial personality disorder, this overrides a diagnosis of CD.

Prevalence

The chance that a person will meet the criteria of CD at some point in his or her lifetime is around 9.5% [12], and it is more common during adolescence than childhood. CD is more prevalent in males, and there are sex differences in the presentation of symptoms, with males more commonly exhibiting fighting, stealing, vandalism, and trouble in school and females more commonly exhibiting lying, truancy, running away, substance use, and prostitution [1]. Although there is no age limit for a diagnosis of CD, it is rare for CD to first emerge in adulthood.

Co-occurrence and Prognosis

CD commonly co-occurs with ADHD and/or ODD, and having more than one of these disorders predicts poorer response to treatment [1]. There is a developmental relationship between ODD and CD; individuals diagnosed with CD most likely would have met the diagnosis for ODD at some point (however, as noted in the section on ODD, the majority of individuals with ODD will not develop CD). Prior to DSM-5, an individual could not be diagnosed with both CD and ODD at the same time (CD overrode a diagnosis of ODD). However, new research evidence is inconsistent with previous notions that ODD is simply an early form of CD, so DSM-5 allows ODD and CD to co-occur if appropriate. A careful diagnosis should be made to ensure accuracy if a provider believes a child should meet the criteria for both disorders. CD also frequently co-occurs with learning disorders, anxiety disorders, depressive or bipolar disorders, and substance use disorders.

Unfortunately, few children with severe conduct disorder receive mental health treatment. Many become involved with the justice system before they have the chance to seek treatment, and others cannot afford treatment. If CD is not treated, or is treated unsuccessfully, 40% of individuals will continue to exhibit problematic behaviors into adulthood, which may lead to a diagnosis of antisocial personality disorder [13].

Environmental Risk Factors

There are many known environmental factors that increase risk for CD. As mentioned in the section on ODD, most research on risk factors is *correlational*, telling us only that a certain factor is associated with higher prevalence of the disorder, and not that a factor *causes* the disorder. Additionally, much of the research on risk factors is on risk for delinquency, which is related, but not equivalent, to CD. Both are presented here.

Like ODD, CD is more prevalent for individuals of lower socioeconomic status [14–16]; however, rather than poverty itself, it is likely social and psychological factors that are known to be associated with poverty that are contributing to the disorder. For example, unemployment, poor educational facilities and opportunities, disrupted family life, exposure to violence, exposure to delinquent peers, and living in a community where delinquency is considered acceptable all put an individual at a higher risk for developing CD [14]. There are also interpersonal factors that are associated with delinquency, including peer rejection, parental neglect, inconsistent discipline, overly harsh discipline, lack of supervision, and physical or sexual abuse [17].

Biological and Neurocognitive Risk Factors

Research in behavioral genetics suggests that CD has a significant biological basis; a family history of criminality and substance use disorders increases an individual's risk of being diagnosed with CD. Twin studies tell us that family transmission of CD is due to both genes and the influence of delinquent family members, but the extent to which genes, environment, and the interaction of these influence CD is still unclear [18, 19]. Genetic influences probably contribute many of the structural and functional brain differences for individuals with CD, while both genetic and environmental influences may contribute to some of the social tendencies seen in individuals with CD, such as lack of remorse or moral awareness of the self, deficits in cognitive and emotional regulation, and a tendency to see neutral events as hostile [20].

Our current understanding of the biological and neurocognitive factors related to CD is largely based on a body of literature examining differences between those who engage in delinquent behaviors and those who do not. Relatively few studies have examined individuals with CD who do not *also* have ODD and/or ADHD; thus, it is currently difficult to make many conclusions regarding biological and neurocognitive correlates that are associated only with the delinquent behaviors that are the focus of CD, rather than possibly related to other symptoms (like irritability or impulsivity) that are prominent in individuals with ODD or ADHD. Despite this, a few key findings are highlighted below.

First, there seem to be basic physiological differences between individuals who exhibit, and do not exhibit, aggression and conduct problems. On average, individuals who exhibit these behavior symptoms have lower resting heart rate, higher heart rate reactivity, and reduced resting electrodermal activity, suggesting that differences in the autonomic nervous system may contribute to these externalizing behaviors [21].

Second, a vast literature suggests a relationship between childhood aggression and social skill deficits. Deficits identified as correlates of aggressive behavior are in multiple areas of social cognition, including emotion attribution accuracy, anger attribution, empathy/perspective-taking, social-information processing, social problem-solving, and emotion knowledge [22–25]. Since verbally and physically aggressive behavior can play a significant role in the diagnosis of conduct disorder, social skill deficits should be considered as a possible contributing factor when assessing individuals with CD.

Third, there is a robust association between low IQ and delinquency in children, and there is evidence that low IQ leads to delinquency, rather than the other way around [26, 27]. Exactly how IQ may cause delinquency remains unclear. One hypothesis is that there is an indirect and simple relationship; low IQ leads to school failure because children who fail in school are more likely to turn to delinquent behavior. However, another hypothesis is that IQ is, among other things, an index of *executive functioning*, that is, how well an individual can pay attention, inhibit impulses, and monitor his or her own behavior. Thus, an executive functioning deficit that leads an individual to score poorly on an IQ test may also lead an individual to engage in impulsive, delinquent behaviors. This is consistent with other research that has found direct associations between executive functioning and delinquency. For instance, one study found clear deficits in *motivational inhibition*; children with CD (or ODD) were more likely to ignore the high probability of punishment and continue seeking a reward [8]. Additionally, a review of research suggests that children with CD (as well as ODD) show poorer ability in the executive areas of flexibility (e.g., switching between ideas), inhibition (e.g., stopping before behaving impulsively), working memory (e.g., holding and manipulating multiple ideas at once), and planning (making decisions for action by thinking through outcomes; [9]). Deficits in these executive functions may cause children to respond aggressively when angry and to break rules and social convention without thinking through the consequences of doing so.

Of note, some studies find that the relationship between executive functioning and CD is entirely accounted for by symptoms of co-existing ADHD [28, 29], while others find that this relationship exists independently of ADHD symptoms [30, 31]. Future research will need to clarify the extent to which executive functioning and symptoms of CD are directly related or whether this association is simply because executive functions are impaired in ADHD and ADHD commonly co-occurs with CD.

Despite the confusion caused by overlapping patterns of neurocognitive functioning between patients with ADHD and CD, brain imaging studies show distinct differences in what regions of the brain seem to be affected across these disorders. For ADHD, the inferior frontal, striatal, parietotemporal, and cerebellar regions and networks are implicated; these are related to controlling impulses, maintaining attention, and coordinating timing. In contrast, for CD, the lateral orbital and ventromedial prefrontal cortices, superior temporal lobes, and amygdala are implicated; these are related to decision-making, motivation, and emotional reactivity [32]. As brain imaging technologies improve, we expect imaging research to clarify how neurocognitive differences lead to differences in behavior, possibly providing clues to help us design better treatments.

Disruptive Mood Dysregulation Disorder (DMDD)

Symptoms and Diagnosis

Disruptive mood dysregulation disorder is characterized by chronic, severe, persistent irritability or anger, in combination with frequent temper outbursts that are not typical for a child's developmental stage and that are out of proportion to the situation. DMDD should only be diagnosed in children between 6 and 18 years old, the mood disruption cannot occur solely during a major depressive episode, and impairment must occur in two settings (e.g., home and school), with severe impairment in at least one setting [1]. DMDD is classified as a depressive disorder in DSM-5 and is also discussed with mood disorders in this book, but it is included here because it is important to consider a diagnosis of DMDD if a child's primary symptom is persistent irritability or anger. Although irritability is one symptom in ODD, the persistence and prominence of irritability (even between temper outbursts) are what typically differentiate DMDD from ODD. If a child meets the criteria for DMDD, even if the behavioral symptoms of ODD are present, only DMDD should be diagnosed [1]. If a child meets the criteria of DMDD and also has a pervasive pattern of behaviors that violate rules and the rights of others, that individual may be diagnosed with both DMDD and CD.

DMDD has only been a diagnosable disorder since the latest revision of the *Diagnostic Statistical Manual* (DSM-5) in 2013. DMDD was added to DSM-5 in order to distinguish between children who are chronically irritable from children who have cyclic irritability, the latter of which may warrant a diagnosis of bipolar disorder [1, 33]. This distinction reduces the likelihood of incorrectly using treatments known to be effective for children with bipolar disorder, but which may not typically be effective for children with DMDD. At this time, not enough research has been done on DMDD to provide reliable information on prevalence, etiology, risk factors, and prognosis.

The Impact of DBDs on School Functioning

As outlined in the sections above, research suggests that children with disruptive behavior disorders may have brain differences, and corresponding neurocognitive skill deficits, compared to other children. Because of the particular brain areas that are implicated in these disorders, the most common areas of difficulty for children with disruptive behavior disorders include flexibility, inhibition of impulses, decision-making, and emotion regulation. Thus, when we consider the association between disruptive behavior disorders and school functioning, we must consider that these underlying skill deficits may affect school functioning both directly (poor skills make it harder to meet academic expectations in school) and indirectly (poor skills lead to disruptive behaviors and punitive responses to those behaviors, which in turn have a negative impact on academic functioning). Figure 12.1 illustrates these two pathways (marked A and B), and the following vignette provides an example.

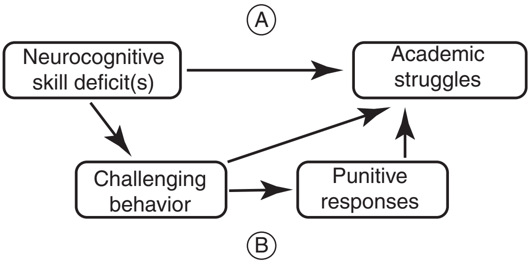

Fig. 12.1 Two pathways by which skill deficits impact school functioning

Vignette: Brandon

Brandon is a ninth grader in an inner-city school who is in danger of failing a number of classes. Brandon misses a lot of instruction because teachers often send him to the principal's office or to the guidance office due to disruptive behaviors in class. Brandon has been sent out of biology class six times in the last 2 weeks for refusing to sit down, disrupting other students, and talking back to the teacher, Ms. Channing.

Ms. Channing's Perspective: I've been teaching ninth grade biology for 10 years, and I've never had more trouble with a student than I have had with Brandon. All the students know as soon as they walk into my classroom, they are supposed to sit down and do the Do Now assignment that I have written on the board, to get them thinking about what we did the day before and what we will be learning that day. I only have 60 min with them, and I have to make use of every single minute to get through the curriculum!

It seems like every day, Brandon walks into my class, talking with his friends, laughing and joking, and refuses to sit in his seat and do the Do Now. Not only does he defy my instructions to get his own work done, but he also disrupts others so they can't get it done either! I can't imagine why he won't just do it. At the beginning of the year, I would remind him nicely and give him some warnings. But now it's October and I'm just fed up. I admit that I have yelled at him a number of times, and I've sent him out of class a lot. When I do, he often talks back and has even punched the wall. It's very tense between us.

Brandon's Perspective: Biology class is the worst! I don't mind learning the stuff, and I even think the work is pretty easy. But I just can't sit down in that class! It's right after lunch, so I'm coming off chilling and laughing with my friends, all hyper and happy and full from lunch. Then I walk into that class and it's, like, all serious and quiet, and everyone is starting on the Do Now assignment that's written on the board. If I sit down right then, I swear I'll fall asleep.

So usually what happens is that I come in, and I still have all this energy, and my friend Kevin is there, and we're still talking about whatever we were talking about at lunch, and I'm standing up by the lab tables on the side. But as soon as the bell rings, Ms. Channing yells at me to sit down and do my Do Now. Last week I had enough of her yelling at me; I punched the wall on my way out. Now I'm in even more trouble.

As we can see in this vignette, Brandon is exhibiting behaviors (labeled by Ms. Channing as defiant and disruptive) that could be explained by specific neurocognitive deficits. First, Brandon appears to have some difficulty with cognitive flexibility, switching into classroom-appropriate behavior when coming from the less structured lunchroom environment. Second, despite a long history of punishing responses from Ms. Channing, Brandon keeps engaging in disruptive behaviors, suggesting that he may have trouble with planning and making decisions in the face of an undesirable reward-punishment balance. Finally, Brandon responds to frustration by yelling at his teacher and punching the wall, signs that he may have difficulty regulating emotions and inhibiting impulsive behaviors. Brandon's assessment results are consistent with these skill deficits, all of which fall in the broad domain of executive functioning.

These skill deficits are likely to impact Brandon's school functioning via the two pathways mentioned above and illustrated in Fig. 12.1. First, executive skills such as flexibility, decision-making, and inhibition/emotion regulation have been shown to be necessary for successful completion of academic work [34]. For instance, flexibility, or the ability to switch back and forth between ideas, is needed when writing or comprehending complex text such as dialogue or persuasive essays. Good planning and decision-making skills are critical in labs and projects with multiple steps. Inhibition and emotion regulation skills are necessary for maintaining high performance during oral reports or tests. Thus, a student like Brandon who has skill deficits in these areas may have academic struggles that can be directly traced back to these trouble areas (see the pathway marked "A" in Fig. 12.1).

Second, for Brandon, these same specific neurocognitive skill deficits lead to disruptive behaviors that appear defiant and aggressive. For instance, Brandon's inability to switch into classroom mode after lunch combined with his inability to make decisions based on an accurate reward-punishment balance results in behavior that looks like he is willfully defying Ms. Channing's rule about immediately completing the Do nows. Brandon's difficulty managing his emotions and inhibiting his impulses result in yelling and punching behavior that looks intentionally threatening or aggressive. Educators' punitive responses to oppositional, defiant, or rule-breaking behaviors can inadvertently compound the negative impact of neurocognitive skill deficits on school functioning (see the pathway marked "B" in Fig. 12.1). In the case of Brandon, he is already having difficulty completing work due to trouble being flexible, making decisions, and regulating his emotions. Then, in response to his "defiance" and "aggression," he is frequently sent out of class, thus resulting in more missed instruction and opportunities to learn. Additional downstream effects of Brandon's behaviors will continue to negatively impact his functioning and the chance that he will catch up academically: the tension between Ms. Channing and Brandon makes it less likely that Brandon will stay after school to request extra help and less likely that Ms. Channing will go out of her way to offer it. Thus, through these pathways, the underlying neurocognitive skill deficits that we have identified impact Brandon twofold: First, they directly impact his ability to complete academic work successfully, and second, they lead to behaviors and punitive responses that then decrease the likelihood that he will get the adequate instruction he needs to catch up.

Assessing Disruptive Behavior Disorders

The first step in assessment of a suspected disruptive behavior disorder is to conduct a thorough exam to rule out physical causes of any recent changes in behavior or emotional symptoms and a full symptom assessment to consider any co-occurring mental health concerns. Although the behavioral symptoms prominent in ODD and CD generally do not respond to medication, it is important to discuss with the child's family any co-occurring symptoms or disorders that may benefit from medication. For instance, co-occurring symptoms of ADHD, mood disorders, or anxiety may respond to medication, which may reduce the severity of the symptoms or their impact on day-to-day functioning. In some cases, after medicating attention, mood, or anxiety symptoms, behavioral symptoms are resolved, and providers learn that behavioral difficulties were secondary to another underlying disorder.

The diagnosis of a disruptive behavior disorder is determined based on relatively easily observable and quantifiable symptoms. Thus, findings from structured neuropsychological assessments are not usually necessary for confirming a diagnosis of ODD or CD (except to rule in or out other disorders). However, neuropsychological assessments are still quite useful when disruptive behavior disorders are the primary diagnosis, since results can provide critical information about *which* underlying neurocognitive skill deficits may be contributing to the observed behavior symptoms, in order to provide a better understanding about probable academic impact and necessary intervention. In our vignette, Brandon refused to sit, defied teacher's requests to complete work, yelled at the teacher, and punched a wall. His behaviors, which seemed defiant, disruptive, and aggressive, were identified as likely downstream effects of difficulties with cognitive flexibility, decision-making, inhibition of impulses, and emotion regulation. Another child exhibiting the *same symptoms* could have been doing so because of deficits in receptive language processing, working memory, and social skills. Thus, it is critical to understand, for each child, the area(s) of lagging neurocognitive skill(s) that may be related to the symptoms.

Since research tells us that common neurocognitive culprits for disruptive behavior disorders include executive functions (cognitive flexibility, problem-solving, response inhibition, working memory), emotion- and self-regulation, language skills, and social skills, it is useful to know which assessment tools may provide information on deficits in these skills areas, to guide you as you review assessment reports. Table 12.2 provides a list of common tools that assess these skill domains. When reviewing assessment reports with a parent, pay particular attention to results on these tools and others that assess deficits in these specific areas. Table 12.2 includes both behavior rating scales (i.e., a parent completes a checklist of symptoms commonly exhibited due to this skill deficit) and measures of performance (i.e., the child performs a neurocognitive task thought to be a test of a particular skill). Of note, it is not unusual for behavior rating scales to be somewhat inconsistent with direct measurement of performance (e.g., [35]). If this is the case, you might consider a deficit identified by either a behavior rating scale *or* via performance as enough evidence to suggest that the child may benefit from an intervention that remediates or accommodates that particular skill.

Some assessment reports will include a summary of the ways in which these skill deficits may be contributing to disruptive behavior disorders, but many will not. Thus, you may choose to educate the child's guardian or school team regarding the ways in which reported neurocognitive skill deficits may be impacting academic functioning through the two pathways presented in Fig. 12.1. The child's family should then make a plan with their school team (teachers, administrators, and counselors) to *remediate* or *accommodate* these lagging skills, to decrease both the direct and indirect impact of these skill deficits on school functioning. *Remediating* may include a school plan to train specific skills through practice, for instance, having the child work with an adult to learn to slow down decision-making processes, to inhibit impulses, or to learn to pay better attention to social cues. *Accommodating* may

Table 12.2 Common assessment tools that provide information regarding skill deficits that may contribute to disruptive behavior disorders

Skill domain	Rating scales	Performance-based measures
Cognitive flexibility	Behavior Rating Inventory of Executive Function (BRIEF), shift scale	Stroop Task/color-word interference test; Trail Making Test; Wisconsin Card Sorting Test (WCST); Shifting Attention Test
Problem-solving	Behavior Rating Inventory of Executive Function (BRIEF), plan/organize scale	Twenty questions; Rey-Osterrieth complex figure; Tower of London test; mazes
Reward processing	Behavior Rating Inventory of Executive Function (BRIEF), task monitor scale; reward responsiveness scale	Various computer-based gambling tasks (uncommon in standard assessments)
Response inhibition	Behavior Rating Inventory of Executive Function (BRIEF), inhibit scale	Continuous Performance Test (CPT); Stroop Task/color-word interference test
Working memory	Behavior Rating Inventory of Executive Function (BRIEF), working memory scale	Digit span backwards; letter-number sequencing
Emotion- and self-regulation	Behavior Rating Inventory of Executive Function (BRIEF), emotional control scale; Child Mania Rating Scale (CMRS)	Sensory Integration and Praxis Tests (SIPT); emotional go/no-go task (uncommon in standard assessments)
Language and communication	Children's Communication Checklist (CCC); Behavior Assessment System for Children (BASC), functional communication scale	Verbal scores on various IQ tests; Boston Naming Test; various picture-vocabulary tests; Clinical Evaluation of Language Fundamentals (CELF); Autism Diagnostic Observation Schedule (ADOS)
Social skills	Social Responsiveness Scale (SRS); Social Skills Improvement System (SSIS); Behavior Rating Inventory of Executive Function (BRIEF), self-monitor scale; Behavior Assessment System for Children (BASC), social skills scale	Perception of Emotions Test (POET); Autism Diagnostic Observation Schedule (ADOS)

include making plans for those times when lagging skills are most likely to result in challenging behaviors, for instance, giving a child who struggles with flexibility extra time to get settled after moving from unstructured to structured times or providing visual cues of expectations and expected positive outcomes. Table 12.3 provides more information on remediation and accommodation strategies that can be recommended for each of the skill areas, as well as the names of some common approaches used in schools.

Addressing Disruptive Behavior Disorders Outside of School

To have the best chance of successfully treating disruptive behavior disorders, to reduce the impact on functioning, and to prevent lasting problems, the child's guardian should be encouraged to address disruptive behavior disorders from multiple perspectives and across multiple settings. Thus, in addition to targeting symptoms appropriate for medication and making a plan to remediate or accommodate lagging neurocognitive skills in the school setting, you may recommend that the family receive ongoing support from a mental health professional. Such support may help the family address any of the environmental risk factors or family factors that may be contributing to disruptive behaviors (e.g., exposure to conflict or peers who are engaging in deviant activity) or that may be a result of the disruptive behaviors (e.g., high parent-child conflict). This mental health professional may also work directly with the child and family to try to address some of the disruptive behaviors that are occurring. The most common techniques for doing so are behavioral, or operant, approaches. These approaches, often referred to as "parent management training," or PMT, focus on making behavioral expectations clear, then using a system of reinforcement (i.e., rewarding the child for

Table 12.3 Recommended accommodations and common interventions for skill deficits that contribute to disruptive behaviors

Skill domain	Remediation and accommodation strategies	Interventions, approaches, and curricula
All or multiple skills	Be sure expectations are clear, consistent, and realistic based on the child's skill level Do not target the challenging behaviors themselves for intervention (e.g., "What will you do instead of hitting next time?") but rather the skills deficits that lead the child to have difficulty meeting expectations and that lead to the challenging behavior (e.g., "It seems hard for you to deal with the frustration of losing that game. What can we do to grow that skill?") Provide a small learning environment with reduced teacher/student ratio, so teachers can understand the child's triggers and are aware of cognitive strengths and challenges Provide education about student's own cognitive strengths and weaknesses to make difficulties and episodes of dysregulation feel more predictable, controllable, and changeable Provide access to a resource room where the student can get direct assistance from an attentive adult	Collaborative Problem Solving® Tools of the Mind
Cognitive flexibility	Teach strategies to integrate new information into student's current knowledge base by thinking about how new information builds on older concepts Maintain familiar places, people, or routines Give ample warning of transitions or changes	Cognitive behavioral therapy SuperFlex®
Problem-solving	Offer help generating multiple reasonable solutions to real-world problems, thinking through pros and cons of each solution, and picking one that will work Provide additional structure for activities that other children may be able to self-direct, e.g., explicit written directions for unstructured tasks; breaking larger tasks into a list of smaller tasks	Collaborative Problem Solving® I Can Problem Solve (ICPS)
Response inhibition	Assign preferential seating (in the front and/or near the teacher) Provide multiple, gentle reminders of expectation when off task Assign shorter homework with a focus on skill mastery rather than practice Extend time to complete tests and assignments	Stop and Think
Working memory	Provide more repetitions of material Directly teach verbal memory strategies that do not come naturally (e.g., chunking or clustering, mnemonic devices) Provide individualized help planning and breaking down larger assignments and organizing homework and school materials Make *written* lists whenever multiple ideas need to be weighed, for instance, a list of possible solutions to a problem prior to evaluating which would work best	Cogmed
Emotion- and self-regulation	Provide frequent motor breaks Allow age-appropriate "fidgets" (e.g., stress ball, thera-band) for motor activity while seated Identify activities the student finds helpful in regaining emotional control when dysregulated (e.g., deep breathing, listening to music over headphones, or writing a creative story) Direct student to engage in regulating activities at early stages of dysregulation Provide shorter periods of learning Allow space to move within the classroom while student attends to material being presented Provide headphones or earplugs, or access to a room without auditory distraction, when completing individual assignments and tests Engage student in rhythmic, repetitive activities when dysregulated	Occupational therapy Sensory integration therapy The Incredible Years® Zones of regulation

(continued)

Table 12.3 (continued)

Skill domain	Remediation and accommodation strategies	Interventions, approaches, and curricula
Language and communication	Use visual aids to assist with verbal learning or organizing of tasks, e.g., visual cues, charts, lists, and illustration of tasks Utilize educated guessing if student is having trouble identifying needs or thoughts	
Social skills	Explain nonverbal behavior Explicitly describe student's impact on others	Skillstreaming Social Thinking Social skills group therapy Social Stories

engaging in a desired behavior or removing attention when a child engages in an undesired behavior) to shape the child's behavior, with the intention of decreasing disruptive behaviors and increasing positive, pro-social behaviors. While PMT programs have the most empirical support for treating disruptive behavior disorders [36], there is limited research on whether PMT provides lasting benefits. Additionally, you will note that the target of PMT is the disruptive behavior itself, which research suggests may be downstream from the neurocognitive deficits. One promising treatment approach that attempts to target both the behavior and the neurocognitive skill deficits, and has similar results to PMT, is Collaborative Problem Solving [37, 38]. This approach, which includes teaching a caregiver to solve problems together with the child, is one to consider, as it has increasing empirical support in decreasing disruptive behaviors and improving caregiver and family outcomes [39].

Vignette: Brandon (Continued)

Brandon's mother asked to have a joint meeting with the school psychologist and Ms. Channing. In that meeting, the school psychologist reviewed the following assessment results:

IQ testing indicated that Brandon's intelligence is in the average range, and an educational assessment provided no evidence of a specific learning disorder. Neuropsychological testing suggested significant impairments in multiple areas of executive functioning. Teacher and parent ratings on the Behavior Rating Inventory of Executive Functioning (BRIEF) were in the clinically significant range for all three Behavior Regulation Index subscales: inhibit, shift, and emotional control. Brandon's performance on the Wisconsin Card Sort (many perseverative errors) suggested impairments in cognitive flexibility, and his performance on the continuous performance task (many commission errors) suggested significant difficulty inhibiting responses. All measures of language skills, social skills, working memory, and attention fell in the normal range.

The school psychologist explained to Ms. Channing the ways in which Brandon's pattern of neurocognitive functioning may be impacting both his ability to get work done and the disruptive behaviors he had been exhibiting.

The team agreed that Brandon clearly understands the classroom expectations for entering the classroom and getting right to work and that Brandon is able to accurately predict the consequences when he doesn't meet those expectations (zeroes on the assignment, being sent out of class for being disruptive). Thus, it was determined that behavioral/operant approaches were unlikely to increase compliance because they would not improve his ability to adhere to those expectations. Together, the team discussed a plan for gradually remediating the neurocognitive skills that were found lagging, and in the meantime they discussed accommodations in Brandon's classes.

To accommodate Brandon's difficulty with flexibility, Ms. Channing began handing Brandon a clipboard with the Do Now assignment as he walked into the classroom and allowed him to complete the Do Now assignment while pacing the back of the classroom. This helped him to transition to the classroom environment, and by the end of the Do Now assignment, Brandon found he was ready to sit in his seat. Brandon's new ability to complete these assignments, and the lack of disruption to other students, resulted in decreased conflict between Brandon and Ms. Channing, and his difficulties with emotional control were no longer a liability in the classroom. With more time in class, Brandon was exposed to more content, and his quiz and test grades in Biology showed marked improvement.

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Part IV

Special Considerations

Special Education: Laws and Procedures

13

H. Kent Wilson and Eileen M. Hagerty

History of Special Education and the Individuals with Disabilities Education Act (IDEA)

In 1975, Congress passed Public Law (PL) 94–142, The Education for All Handicapped Children Act ("EAHCA"), which established for the first time that all eligible students with disabilities in states that accepted funding under that statute had the right to a "free appropriate public education" (FAPE). This law was the foundation for special education funding and services nationally. Amendments to the law in 1990 renamed it the Individuals with Disabilities Education Act (IDEA). IDEA was most recently reauthorized in 2004.

Before the EAHCA, many children with disabilities were denied access to an appropriate education. State institutions were often the eventual home of individuals with significant disabilities [5], where such individuals received basic care but not education or rehabilitation. In 1970, only one in five children with disabilities was educated in US public schools. Laws in many states excluded students with intellectual disabilities (e.g., mental retardation), physical disabilities (e.g., deafness/blindness), and emotional disabilities from school.

In the 1950s, the federal government began laying the groundwork for serving youth with disabilities by enacting legislation that supported the training of educators to work with individuals with disabilities (e.g., Training of Professional Personnel Act of 1959) and the provision of modified materials for individuals with disabilities (e.g., Captioned Films Act of 1958). Further, in 1965, the Elementary and Secondary Education Act and the State Schools Act provided grants to states to assist in educating children with disabilities. In addition, court decisions such as Pennsylvania Association for Retarded Citizens v. Commonwealth in 1971 and Mills v. Board of Education of the District of Columbia in 1972 helped to establish that states are responsible for educating youth with disabilities, on the grounds that failure to do so deprives such individuals of their right to "equal protection of the laws" under the Fourteenth Amendment to the US Constitution. With these court decisions and the eventual passage of the EAHCA, education for individuals with disabilities became recognized formally as a civil right [4].

According to the US Department of Education [5], IDEA and its predecessors have resulted in

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more children with disabilities receiving intervention in neighborhood schools with improved outcomes. In 2008, 95% of all students with identified disabilities were educated in their local neighborhood schools. From 1996/1997 to 2007/2008, DOE data indicated an increase of 16 points in the percentage of students with disabilities graduating from high school and a 21-point decrease in the percentage of students with disabilities dropping out of school. Furthermore, more students with disabilities are pursuing postsecondary education (up from 14.6% in 1987 to 31.9% in 2005).

Principles of IDEA

The basic premise behind IDEA is that all eligible students with disabilities in states that accept federal special education funds have the right to receive an appropriate public education at no cost to the family (a "free appropriate public education," or FAPE). Note that while all states that accept federal special education funds must comply with IDEA, states may provide greater protection for students and parents[1] than IDEA requires. As is sometimes stated, IDEA provides "a basic floor of opportunity," which a state is free to exceed. This chapter will review regulations and procedures that are set forth in federal law. The reader should refer to their state's department of education for information about state-specific regulations and procedures.

As the reader can quickly determine, many acronyms and technical terms are used in special education, which can cause confusion for families. Please see Table 13.1 for a guide to the most commonly used terms that relate to education for youth with special needs.

What is a FAPE for one student may be different for another, because each student has unique needs. FAPE is closely connected with another important principle behind IDEA, that of the least restrictive environment (LRE). The latter principle mandates that students with disabilities be educated to the maximum extent appropriate with nondisabled peers and that they be removed from the regular education environment only when the nature or severity of their disability requires it (20 U.S.C. § 1412(a)(5)(A)).

When a student is eligible for special education services, a Team (i.e., a formally designated group comprised of the youth's parents, teachers, and other school personnel) must first determine what a student requires to have an *appropriate* education. To be appropriate, the educational plan must be reasonably calculated to allow the student to make meaningful academic and functional progress. After determining the student's program (educational services that the student will receive), the Team determines the student's placement (environment in which the services will be provided), which must be the least restrictive environment in which the student can make effective progress. For example, for a student with a mild learning disability, supplemental aids in the classroom and specialized instruction a few times per week outside of the classroom, all provided within the student's neighborhood public school, could be sufficient. In contrast, a student with a severe learning disability who has not made progress in inclusion settings may require a more restrictive setting (e.g., a private school outside the district, specializing in educating students with specific learning disabilities) to make effective progress.

Eligibility for Special Education

IDEA states a general requirement that states ensure provision of FAPE to eligible students between the ages of 3 and 21. For students aged 3 through 5 and 18 through 21, however, this

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[1] IDEA defines "parent" to include a natural or adoptive parent; a foster parent, unless prohibited by state law from serving as a parent; a guardian (but not the state, if the child is a ward of the state); an individual acting in the place of a natural or adoptive parent (including a grandparent, stepparent, or other relative) with whom the child lives, an individual who is legally responsible for the child's welfare; or an individual in accordance with IDEA as a surrogate parent. "Parent" is used in the same sense in this chapter. "Parent" should also be understood to refer to a student who has reached the age of majority and is not under guardianship and is therefore acting on his or her own behalf.

Table 13.1 Glossary of key terms

Term	Definition
Section 504 plan	Most often used for students with disabilities who are not eligible for special education, this document specifies the accommodations, modifications, services, and/or placement that the student will receive to ensure the student access to the learning environment, comparable to that of nondisabled students
Accommodations	Services and/or supports that are provided to help a student with a disability access the general education curriculum and validly demonstrate their learning, without altering curricular materials (e.g., providing extra time to take a test)
Direct services	Services that are delivered directly to the student with a disability. The location where the service is delivered (e.g., general education classroom versus substantially separate setting) and the frequency and duration of the service delivery (e.g., how many minutes per cycle) should be specified in the student's IEP
Disability	Under IDEA, a child must be identified as having a disability in one of the following areas to be eligible to receive special education services: autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairments (e.g., ADHD), specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment. In some states, "developmental delay" may also be used as an eligibility category for children aged 3 through 9 (or any subset of that age range)
Free appropriate public education (FAPE)	An educational right, first established by PL 94–142 and renewed by IDEA, requiring that eligible children with disabilities (in states that accept IDEA funding) receive special education and related services at public expense, under public supervision and direction, which is appropriate to their learning needs and is designed to allow them to make effective educational progress
Inclusion	Any setting whereby a student with a disability is integrated with and has an opportunity to learn or engage with nondisabled peers in general education settings (e.g., classroom, cafeteria, electives)
Indirect services	Consultation services that are provided to parents/guardians or school staff to help them to understand and meet the needs of students with disabilities. As with direct services, the location, frequency, and duration of service delivery should be specified in the student's IEP
Individualized Education Program (IEP)	A document that governs a disabled student's education if the student is eligible for special education services. Among other things, it sets out the services that the student will receive, provides goals by which progress will be measured, and details how a student will access programming and assessments in the least restrictive environment
Individuals with Disabilities Education Act (IDEA)	Renewed in 2004, IDEA is the name of federal legislation, codified at 20 U.S.C. §§ 1400–1482, which ensures the rights of students with disabilities (in states that accept IDEA funding) to receive an appropriate education and establishes the procedures to maintain that right
Local education agency (LEA)	A public board of education or other public entities authorized by a state to exercise administrative control or direction of, or to perform a service function for, public elementary or secondary schools in a city, county, township, school district, or other political subdivisions of the state (or for a combination of school districts or counties, if state law permits)
Least restrictive environment (LRE)	Principle established in IDEA and its predecessors, requiring that eligible students with disabilities receive their education in settings with nondisabled peers to the maximum extent appropriate
Modifications	Changes that are made to the content of curricular materials and/or to performance expectations that are individualized to the needs of a student with a disability (e.g., reducing the number of test items that a student is expected to complete or providing the student with a simplified text)
Related services	Developmental, corrective, and other supportive services that are required to assist a child with a disability to benefit from special education (e.g., speech-language pathology, occupational therapy, physical therapy); may also include transportation
Special education	Specially designed instruction, at no cost to the parent, to meet the unique needs of a child with a disability

(continued)

Table 13.1 (continued)

Term	Definition
Stay-put	A term (also known as the right to placement pending appeal; codified at 20 U.S.C. § 1415(j)) referring to a student's right to continue receiving the educational program and placement specified in the last agreed-upon IEP in the event of a dispute regarding a currently proposed program or placement. In some states, a due process hearing must bee commenced in order for stay-put to attach.
Substantially separate	Also called a self-contained classroom; a setting where individuals with disabilities receive services apart from their nondisabled peers
Team	A group that makes decisions regarding special education eligibility, services, and placement. The group consists of parents/guardians, at least one of the child's regular education teachers (if the child is or may be participating in regular education), at least one special education teacher or provider, an individual who can interpret and review assessment results, and a school district representative who is qualified to provide or supervise special education and who knows the resources available to the district. Other individuals and agencies with knowledge or special expertise regarding the child may attend at the request of the school district or family. The student may also participate, if appropriate

obligation does not apply if it would be inconsistent with state law or practice regarding the provision of public education to individuals in those age ranges. Thus, for example, graduation from high school generally terminates a student's eligibility for special education. For students who have not graduated from high school, many states end eligibility at some point during a student's 21st year or on the 22nd birthday. Some states end it earlier, however, and at least one state allows eligibility until the student turns 26.

IDEA imposes a "child find" obligation, meaning that states are required to ensure all children with disabilities who reside within the state are identified, located, and evaluated. A child need not be attending public school in order to be evaluated and found eligible for special education, as the "child find" obligation extends to students who are homeschooled or attending private schools. State law generally determines which local educational agency ("LEA," or school district) is responsible to evaluate a student and, if the student is found eligible, to fulfill IDEA's obligations to him or her. Often the responsible LEA will be the district in which the student resides; for private school students, however, IDEA designates the district where the private school is located as the responsible one. Note that under federal law, a "parentally placed private school student" (i.e., one whose parents did not unilaterally place him or her in private school, as discussed below) has the same right to evaluation and determination of eligibility as any other student, but is not entitled to receive FAPE in the private school setting. Such students have a more limited right, as a group, to provision of "equitable services."

Students may be identified and evaluated in any grade and at any age, as long as state law requires the provision of educational services to students in that age range. Some states permit referrals in advance of the age of eligibility. For example, if the lower end of the age range is 3, a state may permit referral during the child's second year so that the student may be evaluated, and, if the student is eligible, services may be proposed and ready to begin once the child turns 3.

In order to be eligible for special education services, (1) a student must have a disability falling within one or more of the disability categories recognized by IDEA, as a result of which (2) the student is not making progress in the general curriculum and (3) the student requires special education (or, in some states, a related service, discussed below). See Fig 13.1, detailing the steps for eligibility graphically. IDEA's disability categories consist of intellectual disability, hearing impairment (including deafness), speech or language impairment, a visual impairment

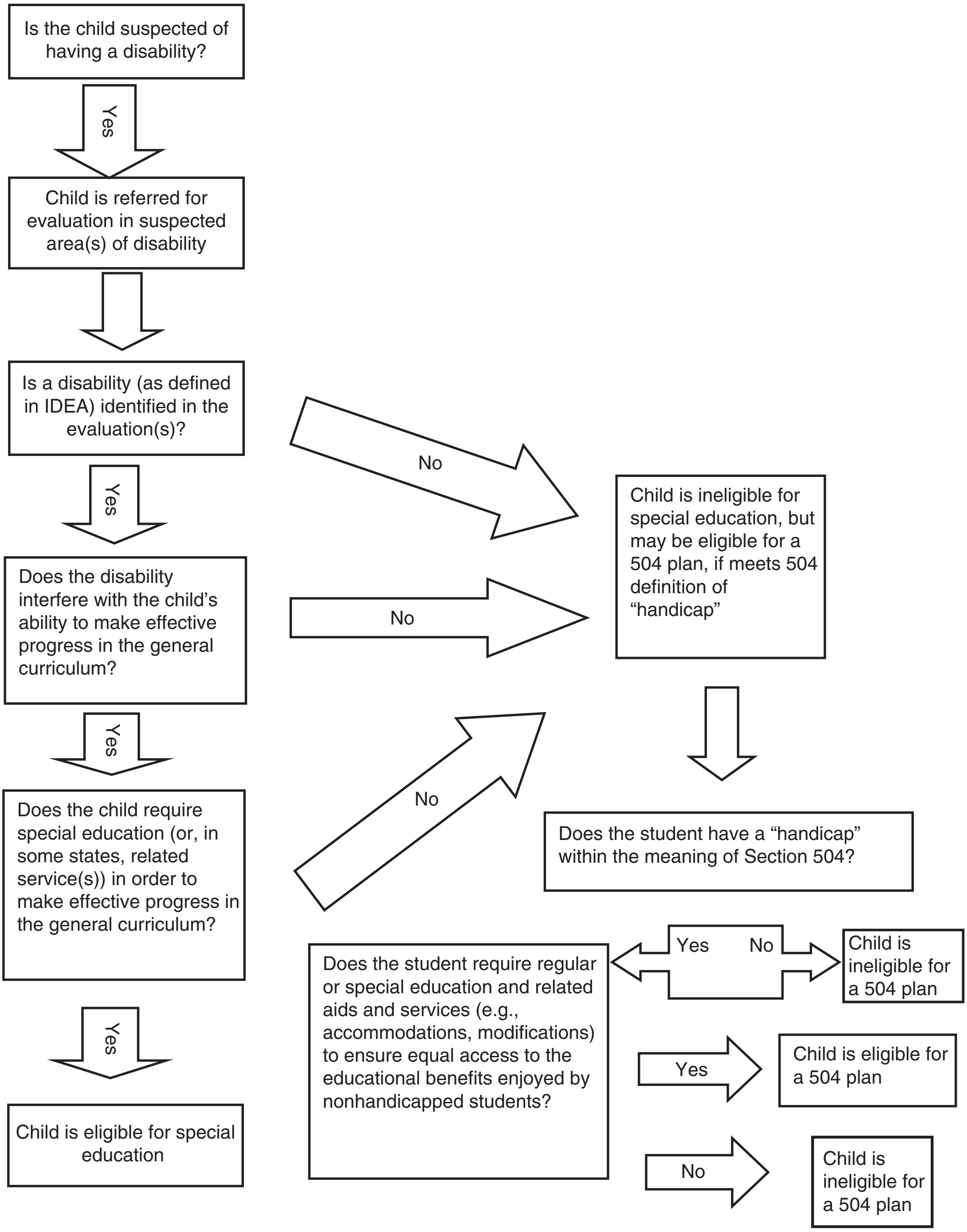

Fig. 13.1 Flowchart for special education eligibility decisions

(including blindness), serious emotional disturbance, orthopedic impairment, autism, traumatic brain injury, other health impairments (under which attention deficit disorders fall), specific learning disability, deaf-blindness, and multiple disabilities. Each state may also permit, though not require, LEAs to use the term “developmental delay” as an eligibility category for children aged 3 through 9 (or a subset of that range, such as ages 3 through 5) who have identified delays in physical, cognitive, communication, social, emotional, or adaptive development. IDEA specifies that a child cannot be identified as having a disability primarily because she or he speaks a language other than English and does not understand or speak English adequately and/or because the child has not received appropriate instruction in reading or math.

While some students’ disabilities may already have been identified by an outpatient provider (e.g., a diagnosis made by a pediatrician, psychiatrist, or psychologist), the student must be formally referred to the school district for an evaluation to determine whether that student is eligible for special education. IDEA provides that a parent, state agency, or LEA may refer a student for evaluation. State law may permit referrals by other types of individuals. Regardless of the referral source, the responsible LEA is required to obtain the parent’s written consent before a special education evaluation can begin (with certain exceptions, such as for students who are wards of the state and whose parents cannot be located).

The parents’ consent must be informed consent, which is another keystone of IDEA. Thus, at this and other points within the special education process, the parent must be given prior written notice, including a description of the action that the LEA proposes or refuses to take; an explanation of the reasons and basis for the proposal or refusal, including all relevant factors; a description of other options that were considered, and the reasons why those options were rejected; and a statement alerting the parents to the fact that they have certain procedural rights. Parents must be given a written statement of their procedural safeguards on the student’s initial referral for evaluation and, if the student is found eligible, at least once per year after that.

If the parents fail to consent to an initial evaluation, IDEA permits (but does not require) a school district to use dispute resolution processes such as mediation and due process hearing (both discussed below) to obtain substituted consent to evaluate, unless doing so would be inconsistent with state law regarding parental consent. If the student is homeschooled or attending private school at the parents’ expense, this consent override procedure does not apply.

IDEA dictates that evaluations must be provided in all areas of suspected disability and that they be provided at no cost to the parent. Formal assessments are required, together with a written report. A screening by a teacher or specialist to determine appropriate instruction does not constitute an evaluation. Assessments must be individualized, be administered in the language and form most likely to yield accurate information, and use a variety of tools and strategies to gather relevant information. Test instruments must be technically sound and must not be racially or culturally discriminatory. They must be given in accordance with the test maker’s instructions, by personnel who are appropriately trained in the area being assessed. A district may not rely on any single measure or assessment as the sole criterion for determining eligibility or for determining the child’s educational program.

There can be as many different types of assessments as there are student needs. Psychological assessments are quite common, as they provide information about a student’s cognitive abilities (e.g., intelligence), which is relevant to the student’s academic potential. A psychological assessment may also help to identify and describe emotional/behavioral factors that may be interfering with learning. Tests of academic achievement help to establish whether the child is achieving adequately for his or her age. Testing by a speech-language therapist, occupational therapist, and/or physical therapist may occur if there are suspected needs in any of those areas. For students with sensory impairments, a teacher of the visually impaired, teacher of the deaf and hard of hearing, audiologist, and/or orientation and mobility specialist may conduct an assessment. If the student has behavioral issues, a behavioral specialist may perform a functional behavioral assessment ("FBA"). An assistive technology evaluation will be relevant for many students. A medical assessment or home assessment may be proposed. An observation in the classroom (or, if the child is not in school, in another age-appropriate environment) is required if the student is suspected of having a specific learning disability and is often performed in other contexts as well.

Once assessments are completed, a Team meeting is held to review the evaluations to determine the student's eligibility for special education and, if the student is eligible, to develop an Individualized Education Program ("IEP"). IDEA specifies the members of the Team. Parents are always members of the Team; the Team may meet without the parents only if the district has made multiple, documented attempts via various means to secure their attendance. The Team must include at least one regular education teacher (if the child is or may be in regular education), at least one special education teacher or provider, a school district representative who is qualified to provide or supervise special education and knows what services and resources are available to the school district, someone to interpret the evaluation results and explain what services may be needed (oftentimes the individual who completed the evaluation), and, when a student is suspected of having a specific learning disability, at least one person qualified to conduct individual diagnostic examinations of children, such as a school psychologist, speech-language pathologist, or remedial reading teacher. Other individuals with knowledge or expertise regarding the student (e.g., an independent evaluator, private service provider, or representative of another agency involved with the child) may participate in the meeting at the invitation of the parents or district. The student may be invited "whenever appropriate" (20 U.S.C. § 1414(d)(1)(B)(vii)). Because transition planning (planning for life after special education) must begin no later than the first IEP to be in effect when the child is 16, the student will often be invited beginning at age 15 and may be invited before that. If the student is a minor, or has reached the age of majority but is under guardianship, it is up to the parent or guardian to determine whether the student will attend.

At the Team meeting, the members of the Team review all relevant information and evaluation results to determine whether the student is eligible for special education services, using the three criteria discussed above. If the student is eligible, the Team uses the evaluation results to develop the IEP, which is a written document that outlines the Team's proposal for the student's educational programming. Special education services begin once the parent consents to the IEP.

Individualized Education Program (IEP)

An IEP is a formal proposal regarding the services/supports that an eligible student will receive. Each IEP must be individualized to meet the student's unique needs. The IEP is first developed when a student is determined to be eligible for special education services and is reviewed and revised at least annually. The annual review date depends on the IEP's expiration date, which may or may not coincide with the beginning or end of the academic year. An IEP must be in effect for all eligible students as of the start of each school year.

The IEP is developed in a Team meeting with the participation of parents and educators, as discussed above. IDEA provides parents with specific safeguards to ensure that they have the opportunity to participate in Team decisions and that they are part of the group that determines the student's program and placement. The IEP must include the following information: (1) the student's present levels of academic and functional performance; (2) measurable annual goals; (3) a description of how the student's progress will be monitored and reported; (4) documentation of the special education and related services, direct and indirect, which the student will receive; (5) a description of the extent to which the student will not participate with nondisabled children in the regular classroom: (6) a list of accommodations and modifications that the student requires; (7) a plan for how the student will participate in statewide and districtwide testing; and (8) transition planning (if applicable). These components are described below. While the format and content of an IEP may differ among states (with some states requiring additional information), each of these components must be included.

Required Components of an IEP

1. Present levels of performance: All IEPs must provide information about a student's current level of performance. This includes a student's current academic achievement as well as functional performance in areas related to the disability. In addition to information that may be provided by classroom teachers, present levels of performance can include data gathered from key evaluation results and input from other Team members (e.g., concerns raised by parents). This component of the IEP provides a yardstick from which progress can be measured.
2. A statement of annual goals: The Team must identify specific goals focusing on the student's special education needs. These goals should address areas that require development/intervention to make progress in the general education curriculum, as well as other educational needs that result from a student's disability (e.g., a student with high-functioning autism may be doing well academically but have social learning needs related to his/her disability). The number and content of the goals depend on the student's individual needs. For example, a student with a specific learning disability in reading may only require a goal in reading. In contrast, a student with an intellectual disability may require multiple goals in such areas as life or adaptive skills, academics, social skills, and behavior. Goals must be measurable and must be appropriately ambitious, in light of the student's circumstances. For students who take alternate statewide and districtwide assessments, the goals must include benchmarks or short-term objectives. (Some states require benchmarks for all special education students.) For example, if the annual goal is that a student will demonstrate a particular skill 100% of the time, and if the student currently displays the skill only 20% of the time, benchmarks may be set at 40%, 60%, and 80%.
3. A description of will be measured and reported: IDEA requires that the IEPs describe how the child's progress toward each of the annual goals will be measured and state when periodic progress reports are provided. IEP reports may be issued concurrently with report cards, but IDEA does not require them to be.
4. Special education and related services to be provided for the student: The IEP must state what special education and related services will be provided, how frequently and with what duration each will be delivered, the projected date on which each service will begin, and the setting in which each service will be delivered.
    (a) Consultation services (often called *indirect services*) are not provided directly to a student but are instead provided to parents or school staff to inform programming to meet a student's goals. For example, the IEP for a student with autism who has sensory processing problems may specify that an occupational therapist will consult with classroom teachers to help support sensory needs in the classroom.
    (b) Special education services in the general education classroom (often called the *inclusion setting*) are services that are delivered to the identified student within the general education classroom. These could include, for example, having an occupational therapist work with students with fine motor disabilities on handwriting in a small group in the general education classroom or having a special education teacher or paraprofessional present to support students with reading difficulties during an English/Language Arts class.

   (c) Special education services outside of the general education classroom represent the most restrictive level of service. Some students receive only one service (e.g., tutoring in reading or a related service such as occupational, physical, or speech-language therapy) outside the regular education setting. Others may spend a greater portion or all of their time in a specialized setting, up to and including attendance at a separate public or private special education school.

5. An explanation of the extent (if any) to which the student will not participate with nondisabled children in the regular classroom: Typically, this would include not only the amount of time spent outside the regular classroom but the reasons why the student's needs require instruction or related services in the separate setting.
6. A list of accommodations and/or modifications necessary to support student achievement and functioning: An IEP must describe how a student's disability will be accommodated in all educational settings. Accommodations include supports that allow students with disabilities access to the curriculum. For example, for a student with an attention-deficit/hyperactivity disorder (ADHD), accommodations may be necessary to support attention (e.g., seating the student closer to the teacher and away from distractions) and to reduce hyperactivity (e.g., providing frequent breaks for the student to move). Modifications involve changes to the materials or curriculum to enable the student to access the material (e.g., providing a student with a reading disability with an easier passage to read for a history lesson or reducing the number of math problems a student will be required to complete).
7. A description of how the student will participate in statewide and districtwide assessments: In the past, students with disabilities did not consistently participate in statewide and districtwide assessments that were used to measure student and school achievement. IDEA requires that students with disabilities participate in state and district assessments that are required of nondisabled peers; however, the Team specifies in the IEP how the student with the disability will participate in these assessments. The IEP should indicate whether the student requires accommodations during assessments. If so, those accommodations should be specified and should generally be similar to those used in other educational settings. Due to the severity of their disabilities, some students are not able to take district or state assessments in a standard format; instead, they participate in an alternate assessment through which the student will be required to demonstrate knowledge and skills related to the general curriculum. In that case, the IEP needs to specify that the student will take an alternate assessment and must explain why the student cannot take the standard assessment and why the selected alternative method is appropriate.
8. Transition planning: IDEA requires that, beginning with the IEP that will be in effect when a student turns 16, the Team must engage in transition planning to help the student prepare for adult life. Transition planning can begin at an earlier age if mandated by the state or if determined to be appropriate by the Team. When transition planning is required, the IEP must include measurable postsecondary goals related to training, education, employment, and (if appropriate) life skills. The IEP should also describe transition services that are needed to reach those goals.

Response to and Implementation of the IEP

At or after the Team meeting, parents are provided with a written copy of the IEP, which details the components described above. For an IEP to be implemented, the parent or adult student (if applicable) must give written consent to the proposed program. Once the IEP is accepted in whole or in part, the district must immediately begin providing the accepted services. If there is a dispute (i.e., a parent disagrees with what is being proposed), then IDEA sets out several processes for dispute resolution, discussed later in this chapter. If an IEP is already in place (i.e., the dispute emerges after a student has already been found to be eligible for special education and has been receiving services through an IEP), then the student has a “stay-put” right to continue receiving the services delineated in the last agreed-upon IEP until the dispute is resolved. In some states, the filing of a formal due process hearing request is required in order to trigger this right. If there is a dispute about an initial IEP, then special education services will not begin until the parent has provided consent. If the parents refuse to consent to the initial provision of services, or later revoke consent for provision of all special education and related services, the district may not use IDEA’s dispute resolution processes to try to override their decision. The district may, however, use those dispute resolution procedures if the parent has not denied or withdrawn consent to all special education services, but only to some. In appropriate cases (e.g., if the district believes that the denial of services would constitute abuse or neglect), the district may have recourse under the state’s child welfare statutes.

Annual Review of the IEP

Once a student has been found to be eligible for special education services, IDEA requires that the Team meet at least annually to review the student’s progress and to update the IEP. At this annual review, the major components of the IEP will be reviewed and revised according to the student’s needs at that time. Parents may request an IEP meeting at any time, though IDEA does not require a district to agree to such a request. An IEP may be amended at any time during the period that it covers, either by agreement of parents and district or through the Team process. If new information becomes available (e.g., an evaluation completed by an independent party) and is shared with the Team, then the Team must consider that information and may amend the IEP (e.g., increase reading tutorials after an independent evaluation identifies limited progress in reading).

Unlike the case with initial evaluations, if a parent refuses consent to a proposed re-evaluation, the district may use IDEA’s dispute resolution procedures (mediation and/or due process hearing) to seek the parents’ agreement to the evaluation or to obtain an order from an independent hearing officer that would grant substituted consent (overriding the parents’ refusal). Similarly, although a district may not use IDEA’s dispute resolution procedures to challenge a parent’s refusal of an initial program of special education or initial placement, it may use those procedures to seek approval of subsequently proposed programs or placements that the parents have rejected. The parents’ withdrawal of all consent to the provision of special education, however, will prevent a district from proceeding either to seek consent to an evaluation or to seek approval of a rejected program or placement.

Re-evaluation

While the Team meets yearly to review the IEP, IDEA mandates that a re-evaluation be completed at least every 3 years (starting from the date of initial eligibility) to assess whether a student continues to be eligible for special education services and to continue to inform programming. The standard for determining eligibility is the same as for initial evaluations, except that instead of asking whether the student is failing to make progress as a result of the disability, the Team considers whether the student would fail to make progress if he or she were not receiving special education services and supports.

A re-evaluation follows the same procedures as the initial evaluation described above (e.g., parental consent is required, all areas of special needs should be assessed, and so on). On a re-evaluation, however, IDEA permits the Team, after review of existing evaluation data, to determine that no additional data are needed to determine the student’s continuing eligibility and educational needs. The Team is required to inform the parents of that conclusion and of their right to request an assessment; if the parents exercise that right, the assessment must proceed.

Re-evaluations can occur more frequently than every 3 years, but not more than once per year unless the parents consent. A re-evaluation must be conducted any time that a parent or teacher requests it. IDEA requires that an LEA perform a re-evaluation before determining that a student is no longer eligible for special education, unless the reason for ineligibility is because the student is graduating from high school or reaching the maximum age for special education. In that case, the district must provide a summary of the student's academic and functional performance, together with recommendations as to how to meet postsecondary goals. Section 504 regulations (also applicable to the IEP process) require re-evaluation before any significant change in a student's placement.

Determining Placement

After developing an IEP, the Team determines the student's placement, which is the location where the student will receive his or her services. As noted earlier, under the principle of LRE, the Team begins by considering whether the student's educational needs can be met in a general education setting in a student's home/neighborhood school. If it is determined that appropriate services are unavailable in that setting or if the student is not making effective progress in that setting, then the student may be placed in a "more restrictive" setting. Every district is required to have available a continuum of placement options to meet students' individual needs. The following is a brief description of various types of placements and circumstances when each may be indicated.

Full Inclusion

A full inclusion setting is one whereby a student with a disability spends most or all of his or her time in a general education classroom (i.e., one composed mainly of nondisabled peers). Students with disabilities in these settings often require classroom and testing accommodations (e.g., seating near the teacher or extended time for tests) to access educational programming. If they receive direct services, most or all will be provided in the general education classroom, often in what is called a co-taught or collaborative classroom. For example, a student with a mild language disorder may need instruction in an inclusion English/Language Arts classroom that is staffed both by a general education teacher and a special education teacher, with the latter providing additional instruction/support as needed to students with disabilities (e.g., checking in to clarify complex vocabulary and reviewing instructions that the general education teacher gives).

Partial Inclusion

When a student's learning needs cannot be appropriately addressed in a general education classroom, then direct services (like tutorials, speech therapy, occupational therapy) are provided in a specialized setting, containing only nondisabled peers. A student who is receiving his or her education in a partial inclusion program will receive some educational programming in regular education settings but will receive other services in a separate setting. For example, a student with a moderate to severe language disorder may require such substantial modifications to the curriculum or such specialized methodology for language-based subjects (such as English/Language Arts and reading) that the student will need to receive ELA and reading instruction in a special education classroom. However, that student may be able to access other subjects (e.g., mathematics, science, and electives) without extensive curriculum modification or specialized methodology and thus receives these components of his or her education in regular education settings in accordance with the LRE principle.

Substantially Separate Placement

In some cases, due to a student's disability or multiple disabilities, the student is unable to make effective progress in any part of the general education setting; such students often also have specific academic, social, emotional, behavioral, or adaptive learning needs that cannot be appropriately addressed in a general educational classroom. For such students, more restrictive, substantially separate, settings away from nondisabled peers are necessary in order to provide the student with the intensive, specialized instruction that he or she requires. In many cases, substantially separate programs exist within the student's neighborhood public school whereby individuals with significant disabilities (such as a significant intellectual disability, autism, emotional disturbance, or severe language-based learning disability) receive all core educational instruction in a self-contained special education classroom but still have opportunities for inclusion through electives, lunch, recess, or extracurricular activities. If an appropriate program is not available within the student's local public school, the student may be placed in a different school within the district that has an appropriate program. If programming appropriate for a given student does not exist within the district, then the district must make the required programming available either through creation of programming (hiring qualified staff, determining an appropriate peer group, etc.) or by placing the student in an appropriate setting outside of the district, such as a public or private special education school. In appropriate cases, a student may be placed in a public or private residential program (discussed further below). Even if a student is placed outside the district, the LEA remains ultimately responsible for ensuring the provision of a FAPE to the student.

Unilateral Placement

When parents and district disagree about a student's eligibility, program, or placement, the parents have the right to place the student in a program of their choice at their own expense and to seek reimbursement from the district. IDEA contains particular requirements as to the method of giving notice (either at the last Team meeting before the child is removed from the district or in writing at least 10 business days before removal), contents of the notice, and exceptions to the notice requirement. Parents, in choosing a program, are not held to the same requirements as an LEA would be regarding licensure, staff qualifications, and so on. However, if the matter goes to litigation, the parents will need to show that the LEA's proposed program did not offer the student FAPE and that their alternative program appropriately met the child's needs.

Measuring Progress and Placement Decisions

Determining whether the student is making effective progress will be an important aspect of most Team meetings. The determination of what is "effective" or "meaningful" progress is an individualized one that takes into account the individual's disability, his or her potential, and the amount of progress one might reasonably expect within the span of time under discussion. Report cards, IEP progress reports, and statewide or districtwide assessment results can all be useful in assessing whether a student is making progress. Similarly, a review of results of curriculum-based assessments (which measure achievement in the curriculum) and other relevant norm-referenced assessments (which measure performance relative to a normative group, such as individuals who are the same age) can aid such a determination. Often it is helpful to consult with experts in the particular area of disability. For example, a neuropsychologist who specializes in learning disabilities can provide a professional opinion regarding a student's current needs, the adequacy of the student's current program, and (if there is sufficient data to review) the level of the student's progress in that program. Consultation with relevant experts can be particularly helpful for parents to ensure that their child's program has articulated appropriate goals, has provided appropriate services in an appropriate setting, and is measuring the student's progress in a systematic and meaningful manner.

The Team ultimately makes the determination whether a proposed program or placement will allow the student to make effective progress. When the parties disagree about the student's program or placement (e.g., if parents believe that a child requires a more restrictive setting than educators propose), there are a variety of steps that can be taken to resolve disputes.

Dispute Resolution

Disputes most commonly occur when parents reject an IEP in whole or in part or reject a placement. However, disputes can arise regarding almost any aspect of the special education process, including failure to find a student eligible for special education, failure to implement an accepted IEP, failure to follow IDEA's requirements for discipline of special education students, and failure to comply with IDEA's procedural requirements (e.g., failure to conduct an annual review or 3-year re-evaluation in a timely manner, failure to develop an IEP when required, failure to comply with "stay-put"). Dispute resolution options run the gamut from informal negotiation to formal evidentiary hearings and appeals.

Informal Negotiation

When a dispute arises, the quickest and most cooperative resolution method is for the parents and district to discuss the matter with each other. The district may reconvene the Team for this purpose, or the parties may find it more productive to discuss the matter less formally, through letters or e-mails, telephone calls, or an informal (non-Team) meeting. If the parties have attorneys, or if the parents have a lay advocate, those individuals may become involved in negotiations also. If the parties reach a consensus on some or all of the items at issue, the terms should be reflected in a new or amended IEP and/or in a written settlement agreement.

State Complaint Procedures

IDEA requires all states that accept federal special education funding to establish a state administrative complaint process. Each state educational agency ("SEA") must establish a process for the filing of written complaints against a public agency (i.e., a school district or the state itself) for violation of any of IDEA's special education-related requirements. The violation must have occurred not more than 1 year before the filing of the complaint. In general, the SEA must investigate such complaints and must issue a written decision within 60 days after receiving a complaint; however, the state's procedures must allow for a longer time when exceptional circumstances exist or when the parties agree to an extension to pursue alternative dispute resolution options. If the SEA finds a failure to provide appropriate services, the SEA must address that failure, including requiring appropriate corrective action (e.g., compensatory services or monetary reimbursement) for the student at issue and ensuring appropriate future provision of services for all children with disabilities within the state.

The state complaint process is distinct from the due process hearing (discussed below). If the matters at issue in the state complaint are (or become) the subject of a due process hearing, then the SEA must set the state complaint aside until the due process hearing is concluded. If the state complaint concerns some issues that are part of a due process hearing and some that are not, the SEA must set aside the portions of the complaint that are covered by the due process hearing request but must proceed with those that are not within the scope of the hearing.

Discrimination Complaints Through the Office for Civil Rights

The Office for Civil Rights ("OCR") of the US Department of Education investigates complaints of discrimination in education based on race, color, national origin (which may include religion), age, sex, and disability. It also investigates claims based on retaliation for the exercise of an individual's rights under any of the laws that OCR is charged with enforcing. Disability-related discrimination claims may be based on Section 504 of the Rehabilitation Act of 1973 ("Section 504") or Title II of the Americans with

Disabilities Act of 1990 (“ADA”). Because all students who are eligible for special education under IDEA are protected by Section 504, parents of special education students may use the OCR complaint process for claims involving discrimination (e.g., denial of equal access to an educational benefit enjoyed by nondisabled students) or retaliation. Generally, complaints must be filed within 180 calendar days, although OCR may decide to waive that deadline in appropriate circumstances.

If OCR accepts a complaint, it will conduct an investigation and will issue a letter of finding, determining whether or not there is sufficient evidence to support a finding that the respondent failed to comply with the law. If a finding of noncompliance is issued, OCR attempts to help the parties negotiate a voluntary resolution agreement. If the parties are unable or unwilling to do so, OCR will either initiate administrative enforcement proceedings to suspend, terminate, or refuse to grant or continue federal financial assistance to the respondent or will refer the case to the US Department of Justice.

OCR will dismiss any complaint whose allegations are the subject of a pending complaint before (or were previously resolved by) another federal, state, or local civil rights enforcement agency. This includes state complaints (discussed above) and due process hearings (discussed below). In addition, OCR will dismiss any allegations that could have been raised in a proceeding currently pending before such an agency, even if not actually asserted there.

Mediation

IDEA 2004 noted the need for “expanded opportunities” for parents and district “to resolve their disagreements in positive and constructive ways” (20 U.S.C. § 1400(c)(8)). To that end, IDEA requires all states that accept federal special education funding to establish procedures allowing parties to resolve disputes through a mediation process. The process is voluntary (i.e., no party can be compelled to mediate; mediation occurs only if both parties agree to participate). Mediation must be provided by qualified, impartial mediators, and all costs must be borne by the state. Mediation must not be used to delay any parental rights, including the right to a due process hearing (discussed below).

Mediation is informal and is generally designed not to require the participation of attorneys (although attorneys may be present at a party’s option). Mediation is non-binding, meaning that if mediation does not succeed in resolving all issues in dispute between the parties, each party retains all of its rights under state and federal special education law, including the right to a due process hearing. Mediation may be scheduled at any time after a dispute arises, including while a due process hearing request is pending. Discussions that occur during mediation are confidential and may not be used as evidence in a subsequent due process hearing or court proceeding.

If the parties reach an agreement at mediation, they must enter into a written, signed mediation agreement that sets out the agreed-upon terms. The agreement must contain a provision regarding the confidentiality of discussions during mediation (as discussed above). The agreement must also state that it is enforceable in any state court of competent jurisdiction or in federal district court.

Due Process Hearing

A due process hearing is a formal administrative proceeding, which IDEA requires all states that accept federal special education funding to make available. IDEA has an exhaustion requirement, meaning that the parties to a special education dispute must complete the administrative process before they may resort to court. (See discussion of appeals to court below.)

The hearing process begins when one party files a complaint with the agency designated by the state (which may be the SEA, LEA, or another state agency), requesting a due process hearing. The complaint, which is confidential, may set forth “any matter relating to the identification, evaluation, or educational placement of the child, or the provision of a [FAPE] to such child” (20 U.S.C. § 1415(b)(6)(A)). The complaint may be filed by any party, including a parent, a school district, or (less commonly) another state agency or a private special education school. The due process complaint must be filed within 2 years of the date when the complainant knew or should have known about the facts forming the basis of the complaint, unless state law has an explicit time limitation governing such complaints, in which case the state statute of limitations applies. The time limitation will not apply to a parent who was prevented from requesting a hearing due to the LEA's specific misrepresentation that it had resolved the problem forming the basis of the complaint or its withholding of information that IDEA required it to provide the parent (such as prior written notice of the basis for a district's decision or the more general notice of procedural safeguards, required to be furnished at least annually, both of which are discussed above).

A party that receives a hearing request must send a written response to the other party within 10 days, specifically addressing the allegations in the hearing request. An LEA need not send a response if it has already provided prior written notice, as required by IDEA, regarding the subject matter of a parent's complaint. If the LEA has not previously provided prior written notice, then its response must include all of the elements of that notice (an explanation of why the LEA proposed or refused to take the action raised in the due process complaint; a description of other options considered and the reasons why those options were rejected; a description of each evaluation procedure, assessment, record, or report forming the basis for the proposed or refused action; and a description of any other factors relevant to the proposed or refused action).

A party receiving a hearing request may challenge the sufficiency of the request by filing a notice with the independent hearing officer (IHO) within 15 days of receiving it. The IHO must rule on the sufficiency of the request within 5 days. A party may amend its hearing request if the other party agrees or if the IHO permits amendment (the latter may only occur 5 or more days before the hearing date). An amendment resets all timelines, including those for the resolution process, described below (if applicable). The party filing the hearing request will not be permitted to raise issues at hearing that are not specified in the hearing request, unless the other party agrees.

Within 15 days after receiving a parent's hearing request, the district must convene a "resolution session." This is a meeting between parents and district to attempt to resolve the dispute prior to hearing. The district's attorney may not attend the resolution session unless the parents are bringing an attorney. If the parties reach agreement at the resolution session, they enter into a written, signed resolution agreement that is enforceable in a state court of competent jurisdiction or in federal district court. The parties may agree to waive the resolution session or to use mediation instead. A resolution session is not required when an LEA (or anyone other than a parent) files a due process complaint.

If the dispute is not resolved within 30 days of the LEA's receipt of a parent's hearing request, an evidentiary hearing takes place before an IHO. This deadline, like most of the other procedural deadlines connected with the hearing process, may be extended by order of the hearing officer. In certain situations, such as the disciplinary context (discussed below), IDEA provides for expedited hearings.

The IHO need not be a lawyer, but must be knowledgeable about state and federal special education laws and regulations. He or she must also possess the knowledge and ability to conduct hearings and render decisions. The IHO may not be an employee of the SEA or of the LEA responsible for the child.

At least 5 business days before the hearing, each party must disclose to all other parties "all evaluations completed by that date and recommendations based on the offering party's evaluations that the party intends to use at the hearing" (20 U.S.C. § 1415(f)(2)(A)). At hearing, the IHO may bar introduction of any evaluations or recommendations that have not been so disclosed, unless the other party consents. Compliance with the 5-day rule does not mean that the evaluations and recommendations are automatically admissible. Unless the parties agree otherwise, the party proffering this evidence must still introduce it through testimony of the expert evaluator.

At hearing, all parties have the right to be accompanied by counsel and by knowledgeable non-attorneys if permitted by state law. All parties may present evidence, confront and cross-examine witnesses, and compel the attendance of witnesses through subpoenas. Parents also have the rights to have the child who is the subject of the hearing present and to open the hearing to the public. A written (or, at the parents' option, electronic) verbatim record of the hearing must be made and furnished to the parents at no charge.

Most states have regulations and/or rules that describe the conduct of due process hearings in detail. State rules and regulations may also set out various prehearing procedures (e.g., discovery, prehearing conferences, motion practice). As with the substantive FAPE obligation, a state must comply with the "floor" of rights specified in IDEA but is free to provide greater protection to parents and students if it chooses to do so. In specific cases, one should always refer to state as well as federal statutes, rules, and regulations.

Following the hearing, the IHO issues a written (or, at the parents' option, electronic) decision, which must be provided to the parents at no charge. The IHO must issue and mail the decision to the parties within 45 days after the expiration of the 30-day resolution period (discussed above), although the IHO may grant extensions of the 45-day period at a party's request. The decision must be made "on substantive grounds based on a determination of whether the child received a [FAPE]" (20 U.S.C. § 1415(f)(3)(E)(i)). Parents may raise procedural violations, but the IHO may find that the child did not receive FAPE on that basis only if a procedural violation "impeded child's right to [FAPE]," "significantly impeded the parents' opportunity to participate in the decision making process regarding the provision of a [FAPE]" to the child, or "caused a deprivation of educational benefits" (20 U.S.C. § 1415(f)(3)(E)(ii)).

If the IHO finds a denial of FAPE, he or she may order various types of relief. Remedies may include an order finding the child eligible for special education and requiring the development of an IEP (if the dispute concerned eligibility), requiring changes in the child's IEP and/or placement, and/or requiring compensatory education (services to be provided to the student in the future to make up for past violations). In addition, if the parents have placed the student unilaterally in a different setting at their own expense and have notified (or been excused from notifying) the district of their intent to seek reimbursement, and if the IHO finds the district's proposed program inappropriate and the unilateral placement appropriate, the IHO may require the LEA to reimburse the parents for the cost of that placement.

Appeals from IHO Decisions

Some states have a two-level system of review, providing for an initial hearing by the LEA, with a right of appeal to the SEA. Under this model, a state review officer ("SRO") is required to conduct an impartial review of the IHO's findings and decision and to make an independent decision after completing that review. The SRO may receive additional evidence if necessary. The SRO must issue and mail a decision to the parties within 30 days after receiving a request for review, unless it extends that deadline at a party's request.

If any party is dissatisfied with the IHO's decision (in a state where LEAs do not conduct original hearings) or with the SRO's decision (in a state where LEAs conduct original hearings), that party may appeal by filing a civil action in a state court of competent jurisdiction or in federal district court. The action must be filed within 90 days after the date of the decision appealed from, unless the state has an explicit time limitation for bringing such actions, in which case the state's limitation period applies.

On appeal, the court must receive the records of the administrative proceedings, hear additional evidence at the request of a party, and grant such relief as the court determines is appropriate. The reviewing court does not retry the case. In general, a court will consider additional evidence only if it is relevant and if it could not have been produced at the administrative hearing. As noted above, a party must exhaust its administrative remedies before proceeding to court; therefore, the court will only consider issues that were litigated to conclusion before the IHO (and, where relevant, before the SRO).

There is no deadline for issuance of a court's decision in a special education case. After the trial level court issues its decision, at least one level of appellate review (sometimes more) will be available. While the parties are pursuing appeals, IDEA's "stay-put" provision (discussed above) provides that, except in certain disciplinary situations, the student has the right to remain in his or her last agreed-upon educational placement (at the district's expense) unless the parties agree otherwise. The parents are not responsible for the cost of a stay-put placement even if they ultimately fail to succeed on appeal.

IDEA permits the courts to award attorneys' fees to parents who prevail on appeal. A party prevails if that party succeeds on any significant issue in litigation, thereby achieving at least some of the benefit the party sought in bringing suit. Thus, a parent need not succeed 100% in order to have a claim for fees. However, if the parents obtain only a partial victory, then their award of fees will generally be reduced to reflect their degree of success.

If the district or SEA is the prevailing party, an award of fees is not routine. A court may require the parents or their attorney to pay the district's or SEA's attorney's fees only in certain circumstances of egregious misconduct: if the litigation was "frivolous, unreasonable, or without foundation" or if it was presented "for any improper purpose, such as to harass, to cause unnecessary delay, or to needlessly increase the cost of litigation" (20 U.S.C. §1415(i)(3)(B)(i)).

Discontinuing Special Education Services

Special education services can be discontinued for several reasons. First, parents have the right to revoke their assent to the provision of special education services in writing at any time. The school district must honor the parents' request, although the district must provide the parents with prior written notice before discontinuing services. If the parents request termination of services, the district will no longer be required to provide FAPE. However, revocation of consent does not negate past acts (thus, for instance, a district is not required to expunge all references to special education from the child's record). As with parents' denial of initial consent to provision of services, the district may not use IDEA's dispute resolution processes to seek to override the parents' revocation of consent. In an appropriate case, the district may have recourse under the state's child welfare statutes.

Termination of special education services can also be proposed by the Team. The district must re-evaluate the student before the Team can conclude that he or she is no longer eligible, unless the reason for termination is because the student is graduating or aging out (see below). If the parents disagree with the Team's finding of ineligibility, IDEA's stay-put provision will require the district to continue providing services. (Note that in some states the parents must invoke their due process hearing rights in order for stay-put to apply.)

A student's eligibility for special education ends when the student graduates from high school or reaches the maximum age for provision of public education under state law, whichever occurs earlier. If the student's eligibility will be ending because the student is graduating from high school or aging out, the termination of services need not be preceded by an evaluation, although the district must provide the student with a summary of his or her academic achievement and functional performance, including recommendations to assist the student in meeting his or her postsecondary goals.

Special Topics to Consider for Students with Disabilities

504 Versus IEP

Section 504 of the Rehabilitation Act of 1973 ("Section 504") is a federal civil rights law aimed at preventing discrimination on the basis of disability (or, in the statutory language, "handicap") in many arenas that receive federal financial assistance, including preschool, elementary, and secondary education programs. Section 504, like IDEA, includes a FAPE guarantee and a child find obligation. School districts (as well as private schools that receive federal funding) are required to identify students who meet Section 504's definition of disability and to provide accommodations, modifications, services, and placements necessary to allow such students access to their education, thereby placing such students on an equal footing with nondisabled students. The elements that the student requires are summed up in a Section 504 plan, which bears some resemblance to an IEP but for which the law specifies far fewer requirements (e.g., a 504 plan need not even be written, although the better practice is that it be).

All students who qualify for IEPs are also protected by Section 504, but the reverse is not the case. If a student has an IEP, he or she will generally not have a separate 504 plan. By regulation, compliance with IDEA's FAPE requirement by means of an IEP will satisfy Section 504's FAPE requirement. FAPE under Section 504 centers on the concept of *access* to education, while FAPE under IDEA turns on the concept of effective *progress*. Although Section 504 provides students and parents with some procedural rights, those available under IDEA are more robust.

A determination of Section 504 eligibility, like the determination of special education eligibility, is preceded by an evaluation and a Team meeting. However, the requirements as to the composition of the Team and the tasks the Team must perform are different (generally, less specific) under Section 504. The eligibility standard is also different, being much broader under Section 504. A student will be considered "handicapped" under Section 504 if he or she "has a physical or mental impairment which substantially limits one or more major life activities" or has a record of or is regarded as having such impairment (34 C.F.R. § 104.3(j)(2)(i)). "Major life activities" include "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working" (*Id.* § 104.3(j)(2)(ii)). (This list is not exhaustive.) In assessing the degree of the student's limitation, the school may not take into account the effect of "mitigating measures" (e.g., medication, hearing aids, prosthetics), except for ordinary eyeglasses or contact lenses.

Section 504 plans are commonly used for students who require only accommodations, modifications, and/or related services to obtain access to education. Section 504 plans can encompass more extensive services, however, up to and including public or private residential placement. *See* 34 C.F.R. § 104.33(c)(3). Supports and services under Section 504 must be provided at no cost to the parent or guardian. Students eligible under Section 504 must be re-evaluated periodically, but Section 504 does not specify the interval. Section 504 does require a procedure for an impartial hearing with the opportunity for participation for parents and representation by counsel and a review procedure. These procedures may be (but are not required to be) the same as the hearing and review procedures under IDEA.

Response to Intervention

Response to intervention ("RTI") is an approach that grew from a provision in IDEA 2004 permitting a Team, in determining whether a child has a specific learning disability, to "use a process that determines if the child responds to scientific, research-based intervention" (20 U.S.C. § 1414(b)(6)(B)). More generally, RTI can refer to a multitiered system of supports ("MTSS") designed to identify, monitor, and assist students who are struggling in regular education and to assess whether a child should be referred for a special education evaluation. Although RTI may be useful in assessing a child's eligibility, it cannot be used to delay or deny a special education evaluation.

Independent Educational Evaluations

Parents may obtain an independent educational evaluation ("IEE") of their child at their own expense at any time. An independent evaluation is one performed by a qualified examiner who is not employed by the agency responsible for the child's education. Parents also have a right to obtain a publicly funded IEE if they disagree with an evaluation performed by or for a public agency, such an as LEA or SEA. In response to a parent's request for a publicly funded IEE, the agency must, "without unnecessary delay," either file a due process complaint requesting a hearing to show that its evaluation was appropriate or arrange for the evaluation to take place (34 C.F.R. § 300.502(b)(2)). A publicly funded IEE must use the same criteria that the agency uses for its own evaluations, including as to the location of the evaluation and the qualifications of the examiner. Some states have their own standards as to how quickly the public agency must file for hearing in this situation and/or the amounts that publicly funded independent evaluators may be paid.

Regardless of whether the IEE was obtained at public or private expense, the Team must consider it, if it meets agency criteria, in any determination regarding the provision of FAPE to the child. Such an evaluation may be offered as evidence by any party as evidence at a due process hearing. A hearing officer may also request an IEE as part of a due process hearing. In that event, the IEE must be publicly funded.

Participation in Nonacademic Activities

IDEA and Section 504 both require that students with disabilities receive an equal opportunity to participate in nonacademic and extracurricular services and activities. These are defined under IDEA to include "counseling services, athletics, transportation, health services, recreational activities, special interest groups or clubs sponsored by the public agency, referrals to agencies that provide assistance to individuals with disabilities, and employment of students, including both employment by the public agency and assistance in making outside employment available" (34 C.F.R. § 300.107(b)). The definition under Section 504 is similar. Under IDEA, the student is entitled to receive "supplementary aids and services" to ensure participation in these types of activities, if the Team deems such services appropriate and necessary. Thus, for example, an IEP could provide for an aide to accompany a student to a school-sponsored after-school activity, if the Team found that participation in the activity was necessary for FAPE and the aide was necessary for the child's participation.

Related Services/Transportation

IDEA states that, in order to be eligible for special education, a student with a disability must, as a consequence of the disability, require "special education and related services" (20 U.S.C. § 1401(3)(a)(ii)). "Related services" are defined as "transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education," including "speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services for diagnostic or evaluation purposes," together with "school health services and school nurse services, social work services in schools, and parent counseling and training" (34 C.F.R. § 300.34(a)). Assistive technology may, depending on the circumstances, be considered to be special education, or a related service, or a supplemental aid or service.

If a student, because of a disability, requires only a related service and not special education, then the student is not eligible for special education under IDEA unless the related service is considered to be special education under state law (34 C.F.R. § 300.8(a)(2)(ii)). Thus, a student who only requires, for example, occupational therapy will be considered eligible for special education in some states, but not in others. If a student is eligible for special education, his or her IEP must describe all of the related services that the child will receive.

Transportation may include travel to and from school, travel between schools, travel in and around school buildings, and specialized equipment (such as adapted vehicles). Even if a child does not require specialized equipment, the LEA must provide transportation as a related service if transportation is required to assist the child to benefit from special education (e.g., if the child would otherwise have no way to get to his or her placement). If a student with disabilities does not need transportation as a related service, Section 504 requires the LEA to provide the student with the same transportation that it provides to nondisabled children.

All related services that an eligible student requires, including transportation, must be provided at no cost to the family.

Extended School Year

Extended school year ("ESY," or summer) services must be provided if the Team determines that such services are necessary in order for the child to receive FAPE. This determination, like virtually all others that the Team makes, is an individualized one. Public agencies are prohibited from "[l]imit[ing] extended school year services to particular categories of disability" or "[u]nilaterally limit[ing] the type, amount, or duration of those services" (34 C.F.R. § 300.106(a)(3)). Thus, for example, an LEA or SEA could not categorically state that students with autism may receive summer services but students with learning disabilities cannot. Likewise, an LEA or SEA could not legally promulgate a policy stating that no student will receive more than 4 weeks' worth of services in any given summer.

One of the criteria on which Teams often focus, in determining a child's need for summer services, is known as the "regression/recoupment" standard. The Team examines the likelihood that the student will lose skills (regress) over the summer and the amount of time it would take the student to recover (recoup) such skills once school resumes in the fall, if the child were not to receive ESY services. The more significant the likely effect on the child's learning, the more likely it is that the Team will specify summer services in the IEP.

Residential Services

As mentioned above, LEAs are required to make a continuum of placements available to meet the needs of special education students. Residential placements (together with home- and hospital-based placements, discussed below) are considered among the most restrictive. Thus, before placing a student in a residential program, the Team must consider less restrictive options; residential placement should occur only if the Team concludes that other educational models are not appropriate to meet the student's needs. Disputes can arise over whether residential placement is necessary to meet the child's *educational* needs or whether some other reason (e.g., family dysfunction) is making it difficult for the student to live at home. In the former situation, the LEA will be responsible for all costs, including room and board. In the latter, another agency, such as a state social services agency, may be fully or partially responsible.

Home-Based and Hospital-Based Services

A program consisting entirely of home-based or hospital-based services is perhaps the most restrictive of all, as the student is generally educated without any peers in such settings. A home- or hospital-based special education program will often be a temporary measure, until such time as the student is physically and/or emotionally able to attend school. Home-based services are also sometimes used for young children who require intensive 1:1 services before they can participate effectively in educational settings with peers (e.g., severely impaired preschool-age students on the autism spectrum).

Home-based services may also form part of a student's special education program, supplementing the instruction that he or she receives in school. For example, students on the autism spectrum or students with intellectual disabilities may need specialized home-based instruction in order to learn or to generalize skills in such areas as activities of daily living, community participation, self-care skills, play, and emotional and/or behavioral regulation. Home-based services may also include parent counseling and training, which are related services that are often necessary to assist with generalization of skills to the home environment.

Discipline

IDEA sets out specific protections for special education students in the disciplinary context. These protections take effect when the student has been removed from school for more than 10 consecutive school days or for a total of more than 10 nonconsecutive school days during a school year under circumstances that constitute a pattern (e.g., multiple incidents involving substantially similar behaviors). Before the 11th school day is reached, the LEA may discipline a special education student in the same way that it would a regular education student. As of the 11th day, however, the LEA may remove the student from his or her placement only under certain circumstances. Two concepts are relevant: "special circumstances," governing three defined types of serious misbehavior, and "manifestation of disability," governing everything else.

In "special circumstances," the LEA may remove a special education student immediately to an "interim alternative educational setting" ("IAES") for up to 45 school days, without regard to whether the behavior is a manifestation of the child's disability. The three types of special circumstances are: (1) if the student possesses a weapon at school, on school premises, or at a school function; (2) if the student knowingly possesses or uses illegal drugs, or sells or solicits a controlled substance, at school, on school premises, or at a school function; or (3) if the student inflicts serious bodily injury on another person at school, on school premises, or at a school function. ("Weapon," "illegal drug," "controlled substance," and "serious bodily injury" are all defined by reference to other federal laws.) The IAES is determined by the Team.

In all other circumstances, the Team must reconvene to conduct a manifestation determination, and the student may be disciplined only if his or her behavior is found not to be a manifestation of the student's disability. Behavior will be considered a manifestation if the misconduct "was caused by, or had a direct and substantial relationship to, the child's disability" or resulted directly from the LEA's failure to implement the child's IEP (20 U.S.C. § 1415(k)(1)(E)). In that event, the Team must arrange for a functional behavioral assessment ("FBA") if one had not already been performed, develop or review the child's behavioral intervention plan, and return the student to his or her placement, unless the parents and district agree on a change in placement.

If the parents disagree with a manifestation, determination, or with any decision of the Team regarding placement, or if the LEA believes that maintaining the student's current placement is substantially likely to result in injury to the child or to others, the parents or district may file a due process hearing request, which must be considered on an expedited basis. The hearing officer may order a student returned from an IAES to his or her prior placement and may also order a student to attend an IAES for up to 45 school days (even in the absence of the three special circumstances described above) if the IHO determines that continuing the child's current placement is likely to cause injury.

The LEA remains obliged to provide FAPE to special education students even when they are suspended or expelled. Thus, a student who is attending an IAES, or a student who is excluded from school because his or her behavior was not a manifestation of his or her disability, is nevertheless entitled to continue receiving special education (and, if applicable, regular education and/or related services), albeit in a different setting.

In certain situations, the LEA will be deemed to have knowledge of the fact that a student is eligible for special education, even though it has not formally found the student eligible yet. Such students are entitled to the same protections that special education students receive in the disciplinary context.

Transition Services

As discussed above, transition planning must form part of every IEP discussion for older students, starting with the IEP that will be in effect when the student turns 16. Transition services are defined as a coordinated, results-oriented set of activities designed to improve the student's functional and academic achievement in order to facilitate his or her movement to post-school activities. The postsecondary goal may include higher education, vocational education, employment (with or without supports), adult services, independent living, and/or community participation. The IEP's transition-related goals and transition services must be individualized, just like any other portion of the IEP. The US Department of Education has issued detailed guidance about transition planning (see references below for "A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities"). Teams should think creatively in considering options for transition services. These may include, for example, concurrent enrollment in a 2- or 4-year college or university; vocational assessment; social pragmatics training; development of employment-related skills; volunteer or paid work experience; mentorships; learning to use public transportation and otherwise to navigate the community; development of independent living skills such as shopping, managing money, and/or managing medical needs; and development of self-advocacy skills. For more information about the needs of transitional age-youth, see Chap. 14.

Disclaimer The information contained herein is not, nor is it intended to be, legal advice. Consult an attorney licensed in your state for advice regarding individual situations.

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The transition from adolescence to adulthood is a critical developmental period marked by continuing educational and social-emotional growth, as well as shifts in expectations that accompany the roles and responsibilities of adulthood. Transition age youth, sometimes referred to as emerging adults or secondary-aged youth, are individuals between the ages of 16 and 25 who face the unique developmental challenges associated with entry into adulthood. Young people must take on distinct developmental tasks in order to progress toward becoming healthy, socially connected, and productive adults. New educational goals emerge as the expectations of adult employment and financial independence begin to take hold. Development in the frontal cortex of the brain promotes increased maturity in problem-solving, decision-making, and self-control during this period. However, emerging adults must also tackle society's growing expectations for self-sufficiency and responsibility taking. They experience shifts in their relationships as well, including increased emotional and psychological independence from caretakers, more stable and productive relationships with peers, and opportunities for adult sexual and romantic relationships. This transition from adolescence to adulthood has been described as "the age of possibilities," a time when a wide array of life directions remains possible [1]. For most youth, this transition period is also the time when they are given increased independence and control over their lives, with greater opportunity to follow their own interests and desires [1].

Unfortunately, these characterizations of emerging adulthood do not always hold true for transition age youth with developmental or learning disabilities. For many, anticipated milestones of higher education, employment, independence, and adult relationships are not easily attained. As they struggle to find their place in the adult world, young people with developmental or learning challenges may find the transition to adulthood fraught with uncertainty, setbacks, or disappointment.

Despite their need for increased support during this critical time, transition age youth often have difficulty accessing appropriate services. In fact, they show significantly lower rates of service utilization than both younger adolescents and older adults [17]. Even when relevant educational, vocational, or mental health supports are available, transition age youth may find them to be poorly matched to their particular needs [4]. This chapter begins by describing the unique challenges of individuals with developmental or learning disabilities during their transition to early adulthood, followed by a review of best

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practices for support in areas of education, career development, social-emotional development, and daily living.

Challenges of Transition Age Youth with Disabilities

Shifting Capacities and Expectations

Transition age youth differ, both biologically and psychologically, from younger adolescents and older adults. From a cognitive standpoint, this stage of development is characterized by growing capacities in areas of abstract or hypothetical thinking, self-awareness, future-oriented planning, decision-making, and social judgment. Control over behavioral impulses and emotions also increases substantially during this time. Perhaps the most salient cognitive changes during the transition years relate to a group of skills known as executive functions.

Executive functions are orchestrated by activity within the prefrontal cortex of the brain, and they generally encompass those cognitive processes that underlie self-regulation and goal-directed behavior. Executive functions are essential to everyday tasks such as organizing, planning, problem-solving, following rules, and adjusting to new situations. Broadly speaking, they depend on three types of brain function: working memory, mental flexibility, and self-control. Working memory governs our ability to retain and manipulate distinct pieces of information over short periods of time, while mental flexibility helps us to sustain or shift our attention in response to different demands or to apply different rules in different settings. Self-control enables us to set priorities and resist impulsive actions or responses. These capacities are germane to many core competencies of adult life.

Even for youth without developmental or learning disabilities, executive functions are among the last of the cognitive capacities to emerge. In fact, studies of neurotypical brain development suggest that higher-level executive functions develop throughout an individual's 20s with mastery not occurring until nearly age 30 [6]. By contrast, the expectations of adulthood emerge quite suddenly, even overnight, when a young person reaches the age of majority and is legally considered to be an adult. This sudden initiation into the responsibilities and choices of adulthood is inconsistent with the gradual and highly individualized trajectories of brain development and even more so for youth with disabilities. As a result, emerging adults with developmental or learning disabilities face societal expectations that are incongruent with their individual capacities.

The executive function demands of typical adult life are myriad. Individuals must get up in time for their morning routine, eat, and get to school or work, either by car, foot, or public transportation. Day-to-day demands such as grocery shopping, preparing meals, doing laundry, cleaning house, budgeting, paying bills, and making doctor's appointments all place significant demands on executive functioning. Similarly, one's ability to sustain or shift attention, organize information, and plan problem-solving is crucial to success at school or in the workplace. When executive functioning deficits are present, even highly intelligent young people can struggle with the most elementary aspects of daily living. Life at home or in the dorm may be impacted by procrastination, disorganization, and poor follow through in important areas such as self-care, cleanliness, appointments, and daily responsibilities. In the academic realm, students who have excelled throughout their life may experience abrupt declines in their school performance at college, once parents or other adults are no longer present to scaffold their study habits and daily routine. In the workplace, emerging adults with executive functioning challenges are more likely to make careless errors, lack dependability, fall short of expectations, or communicate with coworkers in an inconsistent or haphazard fashion.

Many young adults with ADHD, for example, are intelligent, resourceful, and innovative thinkers with much to offer the world around them. However, those with significant executive functioning deficits may struggle to meet the increased demands that accompany their transition to young adulthood. Particularly if disability-related challenges are poorly recognized, others may find the young person's lack of success to be puzzling, frustrating, or even purposeful. Indeed, emerging adults with ADHD are often wrongly characterized as lazy, irresponsible, and even obstinate. Like many individuals with developmental or learning disabilities, their successful transition to young adulthood depends greatly upon the availability of well-matched expectations and support.

Education and Employment

Among the most critical tasks of emerging adulthood is the transition from high school to postsecondary education or employment. However, for students with learning difficulties, even the initial steps of decision-making about educational or career options can be daunting. Students without access to appropriate role models, counselors, or mentors may question what, if any, educational options will be available to them after high school. Those with severe learning challenges may recognize that college enrollment is not feasible but may know very little about other opportunities for technical or job-related training after high school. College-bound students with dyslexia or other specific learning disabilities may worry that appropriate learning supports will not be available at their school of choice but may lack the information or guidance needed for locating schools well suited to their needs. Co-occurring social or emotional challenges, or difficulties with self-esteem, may exacerbate this already-stressful period of uncertainty and change.

Even after decisions have been made, the transition to a new school or job may be tumultuous. In both higher education and postsecondary employment, the transition beyond high school is often characterized by a loss of support. This is because, for most students, the institutional structures and legal mandates of secondary education do not extend beyond the high school years. Throughout their schooling, well-supported students are likely to have experienced their special education programming as a "one-stop shop" meeting all their needs for academic interventions, accommodations, and in some cases social-emotional support. Thus far, the onus for identifying and supporting their needs has fallen upon their school district. Following graduation, however, these special education mandates fall away and are replaced by less stringent ones, which focus primarily on preventing discrimination with regard to their access to education or employment. In addition, the onus of responsibility now falls to the young person or their family, who may find themselves ill-prepared for seeking the supports they need.

Students who enroll in postsecondary education following high school face many new opportunities and challenges. About 67% of students with learning disabilities opt to pursue postsecondary education of some type following high school, with 71% of these attending a 2-year or 4-year college and 36% attending vocational or technical schooling [3]. This transition often brings new freedoms and opportunities, in both coursework and day-to-day life, but it also presents new and unfamiliar challenges that may occur all at once. Academic and learning demands may shift, as students encounter larger class sizes, less contact with teachers, and more sophisticated material, as well as increased autonomy in their study habits and daily routines. The executive functioning challenges described above, which are common in many different types of learning disabilities, may affect a student's success in balancing educational demands with other activities of daily life (e.g., socializing, self-care, hobbies). For those who attend school away from home, they may be balancing these freedoms and responsibilities on their own for the first time.

For many, the transition to higher education is accompanied by shifts in family and peer relationships. For students who move further from home, separation from family may be a source of anxiety or stress. At the same time, increased proximity with peers brings about new social demands, such as the need to negotiate with a roommate, make decisions about behaviors such as alcohol use, or confront issues surrounding sexual identity and romantic relationships. With the increased autonomy of adult relationships comes the rising expectation that a young person will self-advocate to ensure that their needs are met. Accommodations that were readily available in high school must often be sought out by students, either through formal means or informally from teachers and advisors. Poor self-advocacy can have damaging impact on a student's prospects of success. Students who experience stigma surrounding their disability, struggle with communication skills, or lack social assertiveness may have particular difficulty getting the support they need to succeed in higher education.

The prospect of adult employment, whether it occurs immediately following high school or after additional postsecondary education or training, presents many opportunities for the emerging adult. Employment is a central component of adult life for most individuals, providing not just financial support, but also a social network and a sense of worth as a productive member of society [12, 21]. Given its importance in adulthood, it is not surprising that achieving employment is the primary transition goal of the majority of secondary students receiving special education [2]. However, transition age youth with developmental or learning disabilities may face unique challenges along the path to employment. In the early stages of developing their career interests, individuals must begin to recognize the importance of their learning profile in selecting an appropriate path. While poorly matched options may be more obvious, they may have greater difficulty identifying career paths that are well suited to both their interests and their abilities. Even those with well-informed career paths may lack important information about the particular educational or training needs associated with them? Further, many young people begin their search for employment without important job-seeking skills, such as researching an available position, compiling resumes or applications, weighing financial considerations, and interviewing.

Emerging adults with learning disabilities face the same challenges as any adult who begins a new job but also the added challenges of overcoming the difficulties associated with their disability. The disability-related challenges experienced in the workplace are unique to a given individual and may vary widely depending upon the type and severity of an individual's learning challenges. Common challenges include difficulties with reading comprehension, writing skills, time management, and organization skills, as well as trouble processing information quickly or accurately. For individuals with disabilities that are not readily apparent to others, learning challenges are less likely to be recognized and supported in the workplace. These individuals must decide whether to disclose their disability at work and whether to seek support or accommodations for their special needs. In some cases, they may choose not to share details of their disability for fear of being stigmatized or underestimated. Higher functioning young adults may appear to have all of the skills needed for success, only to surprise colleagues or supervisors with on-the-job difficulties that seem unexplained or even willful. Others may spend inordinate amounts of time and effort compensating for their disability, often to the detriment of their personal well-being and job satisfaction.

Emerging adults with more severe developmental or learning challenges may face a different set of challenges on the job. The impact of their disabilities may be ever-present in their interactions with supervisors and coworkers, and stigmatizing reactions from others may be more commonplace. Those whose disabilities are more impairing may require formal assistance to succeed in the workplace. For instance, young adults with developmental disorders, such as mild to moderate intellectual disability, may require additional time and supervision to master job-specific skills and may have difficulty applying these skills to new or unfamiliar situations. They may also require additional support in developing everyday skills that are necessary for success in most work settings, such as giving or following instructions, answering or placing telephone calls, or understanding social boundaries.

Given the lifelong nature of most developmental and learning disabilities, it stands to reason that individuals who receive special education services would benefit from similar support in their post-secondary education or employment pursuits. However, research indicates that far fewer continue to receive support for their disability after high school. For instance, a national longitudinal study by the US Department of Education found that, among college students who had received special education support during their K-12 years of education, only 19% continued to access disability-related support during their college years. Rates of disability-related support in postsecondary employment were also low, with only 26% reporting that their employer was aware of their disabilities and a mere 7% reporting that they received job-related accommodations or support [13]. Even among students who have received special education support for their disabilities, the transition to postsecondary education and employment may involve significant challenges as well as difficulty accessing appropriate support.

Social, Emotional, and Daily Living Challenges

In addition to the many practical and skill-based tasks faced by transition age youth, social and emotional needs are also paramount during this time. Emerging adulthood is a time of dramatic change, as individuals experience diverse and uniquely timed personal milestones that may include finishing high school, enrolling in college, beginning a career, and forming long-term romantic relationships. These life events bring significant changes to a young person's relationships with others, as well as the introduction of new social roles and expectations. Many young people leave their parents' home for the first time during this period, and this separation from primary caregivers means they must begin to manage the demands of daily life on their own. Relationships with peers become an increasingly important source of support, and young people face the task of establishing and maintaining a network of friendships. Individuals with developmental or learning disabilities may face challenges in this regard. For instance, those with communication impairments may have difficulty engaging effectively with others, while young adults with executive functioning challenges may lack skills necessary for initiating, planning, or following through on opportunities for socialization. Some individuals, such as those with autism spectrum disorders or nonverbal learning disabilities, may have underlying social skills deficits that impact important areas such as reciprocal conversation, nonverbal communication, perspective-taking, or conflict resolution. In some cases, these deficits may be severe and impact a young person's ability to understand social norms, respect personal boundaries, or prevent exploitation by others.

The interpersonal challenges noted above are also likely to influence a young person's success in intimate or romantic relationships, and issues related to sexuality may also be present for young people with disabilities. Like all young people, transition age youth with potentially stigmatizing sexual identities, such as those who identify as gay, lesbian, bisexual, or transgender, may face additional psychosocial stressors. There is also growing recognition that young people with certain types of disabilities, such as autism spectrum disorders or significant intellectual disabilities, may struggle with aspects of sexuality development [20]. Young people on the autism spectrum may have greater difficulty understanding or communicating about feelings of intimacy and attraction, and they may be less likely to understand or subscribe to prevailing norms surrounding gender, gender roles, and sexuality [14]. For some individuals with disabilities, societal stereotypes may be an obstacle to their development of a positive sexual identity [8]. Most often, in mainstream culture, people with disabilities are characterized as either asexual or in some cases sexually vulnerable. Even though they are likely to experience the same desires and behaviors as all young people, individuals with disabilities are often denied access to sex education or other important resources for sexual health. Despite promising efforts by some organizations and advocacy groups, positive sexual identity development is likely to be more challenging for transition age youth with disabilities than for their nondisabled peers.

In addition to its burgeoning social demands, the period of transition to adulthood is also one of heightened risk for mental health problems.

Forty-six percent of the adult population will experience a psychiatric or substance use disorder in their lifetime, and three fourths of those affected experience the onset of their difficulties before the age of 25 [10]. Rates of psychiatric diagnoses also increase during the transition to adulthood, with 12-month prevalence rates for psychiatric diagnosis jumping from 22% to 40% between the ages of 15 and 21 [11, 16]. Mood disorders, such as major depression, are the most prevalent mental illnesses among transition age youth. Anxiety disorders may begin at an earlier stage of development, but their impact can become more severe and widespread as young people face the demands of early adulthood. In addition, several types of severe mental illnesses, including schizophrenia and bipolar disorder, tend to onset during the transition years, most likely for reasons that are biological.

Compared to transition age youth as a whole, those with developmental or learning disabilities appear to be at even greater risk of developing mental health problems. In addition to shared biological risk factors, the increased mental health problems experienced by those with developmental or learning disabilities may be in part due to the psychosocial stressors associated with disability. Individuals with disabilities face greater adversity and are more likely to experience setbacks in school, employment, or other domains of life. Experiences of stigma, negative self-evaluation, and accompanying problems with self-esteem may take additional tolls on mental health. Importantly, emerging adults with developmental or learning disabilities may also lack the skills or resources needed for coping with stress or other negative emotions. Individuals on the autism spectrum, for example, often struggle to interpret their internal states, making emotional insight and problem-solving more challenging. Young people with language or communication deficits may have difficulty seeking assistance or empathic support from others, while individuals with ADHD may find themselves more prone to impulsive emotional reactions or regretful decisions during times of stress. The linkages between disability-related challenges and mental health are likely to be reciprocal for transition age youth. Those with disabilities are more likely to struggle during the transition to adulthood, resulting in experiences of stress and failure that have the potential to compromise their mental health. If these outstrip a young person's capacity for coping, more persistent mental health problems may emerge. Inversely, mental health problems are a source of strain and disruption, likely to interfere with a young person's success in managing the demands of emerging adulthood. For this reason, the transition to adulthood must involve not only the development of skills for employment and daily living but also the capacities necessary for sustaining one's social and emotional well-being.

Increased independence and autonomy with day-to-day activities is an important aspect of the transition to young adulthood. Yet, individuals with more significant developmental or learning disabilities may require additional support in developing the skills needed to live independently at home and in their community. Areas of competency include self-care, domestic tasks, cooking and nutrition, safety awareness, functional communication and literacy, money management, engagement in social and leisure activities, and access to community spaces, as well as spiritual, cultural, or civic involvement. Individuals without disabilities often acquire these skills gradually over the course of their development without dedicated training or support. However, those with developmental or learning disabilities may require specific training or support to develop the skills they need for optimal independence in adulthood.

Supporting Transition Age Youth and Their Families

During the period from adolescence to early adulthood, young people face rapid changes in developmental demands, educational or employment expectations, social relationships, and factors affecting mental health. As with any developmental period, this confluence of new demands yields the potential for setbacks or challenges. The growing awareness of the unique needs and potential pitfalls of emerging adulthood is promising. Nonetheless, young people who find themselves in need of assistance during this pivotal stage of development continue to struggle with accessing support. The barriers to access are myriad. Among the most commonly cited obstacles to support is the lack of coordination between child and adult services. As they approach the end of their eligibility for child services, most commonly at age 18, young people often face a so-called “cliff” in which they may be forced to sever relationships with trusted providers and systems of support. Transition age youth in need of assistance frequently find themselves in the gap between child-serving and adult-serving systems. After “aging out” of child-based supports, they struggle to identify and connect with adult-based services appropriate to their needs. This may be particularly true for certain populations of young people, including youth who come from underserved communities, age out of foster care, or are involved in the juvenile justice system. Young people who are members of racial, ethnic, or sexual minority groups may face additional disparities that affect their access to services.

With a lack of coordinated systems to address the gaps between child and adult services, it is not surprising that many emerging adults report that ideal supports are either inaccessible or unappealing [4, 5]. This dearth of available support is likely to be especially problematic for transition age youth with developmental or learning disabilities, who are at particular risk of poor outcomes in the areas of education, employment, social-emotional adjustment, and independent living. The sections that follow offer a review of best practices for supporting transition age youth with disabilities in each of these domains.

Educational Programming

Adolescents with developmental or learning disabilities have a legal right to transition-related services. Under federal law, students receiving special education services as part of an Individualized Education Program (IEP) are entitled not only to a free appropriate public education but also to transition-related services that prepare them for further education, employment, and independent living. By age 16 (or earlier in some states), a student’s annually revised IEP document must include a discussion of his or her transition needs. If assessments in areas such as literacy, numeracy, employment, or independent living skills identify specific areas of need, the student’s educational planning team is tasked with developing a formal transition plan. This plan becomes a part of the student’s IEP and includes measurable goals and services, which are updated annually to reflect progress toward benchmarks that are to be met prior to the discontinuation of educational services. In some states, transition planning includes a strategic planning tool known as an Individualized Learning Plan (ILP), which helps youth identify and achieve their postsecondary goals. Transition planning may encompass any number of goals and services depending upon a student’s particular needs. Special education students pursuing standard high school diplomas are eligible for transition services up until their date of graduation. Those with more significant impairment who must pursue alternative options such as a certificate of completion or high school equivalency exam (GED) are entitled to transition services that extend beyond their high school graduation and most commonly until age 22.

For students with learning disabilities, transition goals are most often designed to prepare for postsecondary pursuits such as college enrollment, further career/technical training, or employment. Students may benefit from several types of assistance in this regard. Those pursuing higher education after graduation may require additional guidance in identifying schools or programs that are well suited to their learning differences, particularly since information about the quality and availability of disability support services at a given school may not be readily available. For instance, disability-specific guidance for a student with dyslexia might include assistance in narrowing a large list of potential college options down to those who offer the necessary learning supports. Many students with disabilities lack awareness of specialized postsecondary education options, despite the growing number of programs and schools devoted exclusively to students with learning disabilities [e.g., The University of Arizona's Strategic Alternative Learning Techniques (SALT) Center, Curry College's Program for Advancement of Learning (PAL), Beacon College]. Students may also benefit from assistance in identifying financial options to fund their postsecondary education. The Office of Federal Student Aid (FSA) in the US Department of Education awards about $150 billion a year in grants, work-study funds, and low-interest loans to approximately 13 million students. A counselor may assist the student in completing the Free Application for Federal Student Aid (FAFSA), which is the first step toward getting financial assistance.

Transition planning for students with disabilities should also include support for career development. Whether they seek employment immediately after high school or following additional postsecondary education, students with learning disabilities need guidance in weighing potential career paths. Ideally, standardized interest and aptitude assessments should be administered and then interpreted by an individual with expertise in the student's particular disability. For example, the student with dyslexia mentioned above might benefit from career counseling to help in narrowing her diverse set of career interests to those best suited to her learning profile. Standardized questionnaires may identify her desire for a career that is active, hands-on, and project-based, while tests of aptitude may show particular strengths in quantitative and spatial abilities. Pairing these results with a strong understanding of the student's dyslexia-related challenges, an effective career counselor could guide the student toward her expressed interest in engineering, while helping her to understand that she may be more likely to struggle with a reading-intensive career path such as veterinary medicine. Career guidance may be equally important in helping a student to identify the postsecondary educational or training needs associated with a particular career. For instance, a student with a well-established interest in automotive repair may need assistance to identify local technical institutes or community colleges offering certifications in the field, as well as guidance in completing any prerequisite courses during high school. In some cases, transition plans may include initial training in a student's chosen field through a high school vocational program. Field-specific vocational training or work experience can be especially valuable for students with developmental or learning disabilities, since it offers an early start at gaining mastery in a chosen field.

In addition to preparing students for specific educational or career endeavors, transition planning should also ensure that students have the skills needed to function at their full potential in day-to-day life. For students with significant cognitive or developmental delays, transition goals may focus on the development of skills in functional literacy or numeracy, self-care, domestic tasks, everyday social interactions, or participation in the community. For students whose disabilities are less impairing, the barriers to independent adult functioning may differ. For instance, even highly intelligent and academically successful students with learning disabilities may approach their graduation from high school without the study skills necessary to succeed in college. Given the prevalence of co-occurring executive functioning challenges, many require specific training in areas such as organization, planning, and time management. For students who are hearing or vision impaired, assistive technology is likely to be crucial to their success beyond high school, and transition-related services should include training in relevant devices or tools. One important transition goal that may be overlooked for students with disabilities is that of self-advocacy. In the years following high school, young people must become increasingly independent in identifying and accessing the supports they need. Successful self-advocacy will depend not only on their willingness to seek help when needed but also their self-awareness, assertiveness, and knowledge about their particular learning differences. In addition to their active involvement in transition planning, young people should be provided with opportunities for understanding and communicating about their disability, as well as coaching designed to improve their initiative and confidence in seeking the supports they need. These individual capacities become increasingly important as they approach the transition to adulthood.

Career Development and Employment

The development of skills for successful adult employment is paramount during the transition years. For individuals with more significant disabilities, preparations for adult employment should begin well before their transition out of secondary education. In fact, support for postsecondary employment is a federally mandated part of transition planning. If longer-term services and support for adult employment are anticipated, a student's transition plan should include what are known as *pre-employment transition services*. Pre-employment transition services involve collaboration between adult vocational rehabilitation (VR) agencies and the student's school, and they are designed to provide a continuum of services as the student approaches eligibility for adult VR services. By law, adult VR agencies must reserve at least 15% of their federal funds for pre-employment transition services. These services encompass five main areas: (1) job exploration counseling to assist students in honing career interests and identifying relevant career opportunities, (2) work-based learning experiences that may include internships or on-the-job training experiences, (3) counseling regarding postsecondary educational or training opportunities, (4) workplace readiness training to develop social and independent living skills relevant to employment, and (5) instruction or peer mentorship in self-advocacy skills. These pre-employment services can be provided to students with significant disabilities, regardless of whether they are ultimately found eligible for adult vocational rehabilitation services.

For students with more significant needs who are found to be eligible for VR services, an Individualized Plan for Employment (IPE) is mandated. Under federal law, state agencies are responsible for providing VR services outlined by an IPE created with the support of vocational rehabilitation counselors or agents (Rehabilitation Act of 1972, 2018). While specific administration of VR services varies from state to state, families or individuals can contact state-run disability services agencies or the US Social Security Administration (SSA). An IPE specifies individualized services that will be necessary for the individual in preparing for, securing, and sustaining employment outcomes that are well matched to an individual's needs. The services included in an IPE vary widely depending upon the student's needs and eventual employment goal. Some youth may require specific instruction or training in general skills needed to survive in the workplace, such as accurately following or giving directions, answering or placing telephone calls, displaying appropriate workplace etiquette, and understanding social boundaries. Once career interests and opportunities have been honed, the student's plan may include necessary vocational or skills training, as well as community-based opportunities for job training.

On-the-job training is one type of community-based work experience, in which an individual learns a specific skill that is taught by an employer in the work environment. As part of their IPE, an individual may also become involved in other agencies or programs relevant to their eventual field of employment. For instance, the US Department of Labor administers two well-known programs, Job Corps and YouthBuild, which provide integrated vocational, academic, and employability skills training. Job Corps programs offer career technical training in over 100 career areas, while YouthBuild programs focus on the construction trades. In some cases, students may qualify for these programs as early as age 14 with services extending to age 21. Even after attaining necessary skills and training, transition age youth may require assistance in searching for and obtaining employment. For students with more significant disabilities, job search and placement services may be specifically provided to them as part of their transition or employment plan. In other cases, an individual may be provided with training in skills necessary for seeking employment, such as searching available jobs, compiling resumes or applications, weighing financial considerations, and job interviewing.

While long-term employment is the ultimate goal of all transition age youth with developmental or learning disabilities, specific employment outcomes are likely to vary depending upon the severity of an individual's disability and may include competitive integrated employment (i.e., in more typical environments with both disabled and nondisabled employees), supported employment (i.e., short-term job training or support while the individual gains mastery toward integrated employment), or customized employment (i.e., job tasks that are tailored to the individual on a long-term basis). Access to supported and customized employment can be supported through the VR services described above. Vocational counselors/agents in the federal (e.g., SSA) or state-run agencies designated by the Rehabilitation Act of 1973 [18] are available to support individuals and their families.

Social, Emotional, and Independent Living Skills Supports

In addition to the academic, occupational, and vocational demands of early adulthood, individuals with developmental and learning challenges may also struggle to manage the growing demands on their social, emotional, and independent living skills. The challenges of emerging adulthood may overtax individuals' capacities for coping, while those with more significant developmental delays may have difficulty acquiring the skills needed for independence in day-to-day activities. To be effective, services for transition age youth must address not only their academic and vocational needs but also their development of social-emotional competencies and daily living skills.

As noted previously in this chapter, delays in social competencies are a hallmark of some neurodevelopmental disorders (e.g., intellectual disability, autism spectrum disorders). Thus, some young people with disabilities may have difficulty communicating effectively, engaging in to-and-fro conversation, picking up on social cues, or navigating large group dynamics. In such cases, social skills training should begin early and may be provided for some students through their special education program. There are several evidence-based social skills training curriculums that extend to young adulthood. For instance, the Social Thinking curriculum [22] is a research-validated social skills training program used frequently with groups of children, adolescents, and young adults with social skills concerns. Additionally, therapists and social skills coaches are available to bolster social skills on a more individualized level. Ideal targets of individual treatment may focus on specific social skills deficits (e.g., reading nonverbal cues) or may help an individual prepare for a particular social event (e.g., a social gathering or first date). Even when social skills deficits are less pronounced, emerging adults with developmental or learning disabilities may benefit from the support of an individual therapist as they navigate demands such as separation from parents, deeper romantic relationships, and increased need for assertiveness. Some may need assistance in connecting with social activities in their community, and this may be especially important for transition age youth who have more significant cognitive and social impairments. For all young people, the transition to early adulthood coincides with the desire for increased autonomy, independence, and separation from caregivers. Emerging adults who need higher levels of supervision and support may be frustrated by the lack of opportunities for asserting their independence. Community-based social and recreational programs can be critical in providing the chance for increased independence from caregivers in supported settings. The list of national agencies and organizations below may be valuable in locating opportunities for daily living support, as well as opportunities for healthy recreation and leisure activities (Table 14.1).

As previously noted, transition age youth also face increased risk for mental health problems, such as depression, anxiety, and substance abuse. This is especially true for young people with developmental and learning differences. Through

Table 14.1 Selected national agencies, organizations, and resources

Domain	Agency or organization	Web address
Independent living	National Rehabilitation Information Center	http://www.naric.com
	National Council on Independent Living	http://www.ncil.org
	Government Benefits	http://www.benefits.gov/
	Social Security Administration	https://secure.ssa.gov
Housing	Technical Assistance Collaborative	http://www.tacinc.org
	US Department of Housing and Urban Development	http://www.projectaction.org/
Recreation	Disabled Sports USA	http://www.dsusa.org
	Mobility International USA	http://www.miusa.org
	National Center on Accessibility	http://www.ncaonline.org
	National Center on Health, Physical Activity and Disability	http://www.nchpad.org/
	National Library Service for the Blind and Physically Handicapped	www.loc.gov/nls
	United States Adaptive Recreation Center	www.usarc.org

their respective departments of mental health or developmental services, many states have created specific mental health initiatives designed to help bridge the gap between child and adult mental health services. The coordination of mental health services for emerging adults has been more challenging at a national level, but promising efforts are underway. An interagency workgroup known as the Federal Partners in Transition (FPT) was formed in 2005 and is tasked with developing shared goals and outcomes to be coordinated across the many federal programs that support young people in their transition from school to adulthood. Recent grant programs through the Substance Abuse and Mental Health Services Administration (SAMHSA), including Project AWARE and Healthy Transitions, have sought to improve access to mental treatment and support services for youth ages 16–25. At this time, however, mental health services for individuals with disabilities vary greatly by region. Those working with transition age youth should be aware of relevant agencies, services, and mental health providers in their particular region, so that they can best assist young people and their families in accessing appropriate care.

Providers play an important role in identifying and locating the resources necessary to support a young person's progress toward independence. Up-to-date assessment of current functioning is critical to informing applications for and implementation of transition services due to the unique demands of the transition-age period and ongoing changes in cognitive, emotional, and social development. Youth with more significant developmental disorders, such as intellectual disability or autism spectrum disorders, should be referred to their state's intellectual and developmental disability agency, which will evaluate their eligibility for services. The application for eligibility should be completed prior to age 18 and often requires documentation from providers regarding the individual's disability or disabilities, as well as the associated impact on day-to-day functioning. Youth with a significant co-occurring mental health condition may be eligible for services through their state's department of mental health. In cases where an individual is likely to require additional assistance for financial stability, the provision of Social Security benefits may be important, and families should be encouraged to have the emerging adult screened by Social Security system before he or she reaches age 22.

For some young people with developmental or learning disabilities, their independence in early adulthood rests heavily upon their capacity for daily living at home and in their community. Living on one's own can be quite demanding as the young person learns to manage a range of new responsibilities, such as handling living expenses, making medical decisions, performing household tasks, and navigating life in their community. Today, many young people depend upon their caregivers for longer periods, often remaining or returning to live at home well into their 20s. For young people with more significant disabilities, needs surrounding day-to-day living support may be more intensive or long-term. In such cases, in-home services may be necessary to provide assistance or supervision in areas such as self-care, household tasks, and safety awareness. In-home training in adaptive skills is especially beneficial, since it allows the young adult to learn and practice a given competency within the setting where it will be performed. Community providers, national agencies including the National Council on Independent Living, and government agencies such as the Social Services Administration (SSA) can provide such resources. Many individuals who need significant support at home remain in the care of parents or other family members, and these caregivers benefit from the availability of respite care. Respite care provides parents or other caregivers with short-term home care services that offer temporary relief, improve family stability, and reduce the risk of abuse or neglect. The provision of these services varies by region, but national respite care databases online can provide information about local agencies registered to provide such services. Living at home with parents may not be a feasible or desirable long-term option for all individuals in need of daily support. In such cases, young people may transition to supportive group homes or assisted living facilities that are staffed with counselors and other workers who help the residents live on their own. Home-based or residential services can be paid for in many ways, including private payment or state programs for people with disabilities.

Support with legal issues may also become paramount for transition age youth with disabilities. Although the legal age for adult decision-making and competency falls largely at 18 years, many young people lack the skills needed for independence in both decision-making and day-to-day living. Several issues may arise with regard to their competency for decision-making in legal, financial, medical, or other matters. In such cases, there are guardianship and conservatorship options that are available, which assist the individual in establishing the appropriate balance of autonomy and surrogate assistance for decision-making. Both guardians and conservators are individuals appointed by the court to make decisions for persons unable to do so because of an illness, injury, or disability. More specifically, guardians are appointed to make healthcare and other non-monetary decisions, while conservators are appointed to take care of a person's finances. The court may appoint either a guardian, a conservator, or both depending on the needs of the individual, and in cases where both guardianship and conservatorship are needed, these roles can be appointed to the same or different people. While the appropriateness of conservatorship versus guardianship is dependent on the unique personal and situational needs of the individual, conservatorship is generally necessary when handling large amounts of money (i.e., >$24,000 annually). National organizations, such as the National Guardianship Association, are helpful resources for families who must navigate these legal options. The transition to young adulthood brings about the need to interface with many adult agencies and legal institutions, and families are likely to require additional support and guidance from providers in identifying and accessing services that are most appropriate to their needs.

Assessment of Transition Age Youth

Given the complexity and diversity of challenges faced in emerging adulthood, comprehensive and up-to-date assessments of a young person's functioning are crucial to providing supports that are well targeted to an individual's unique transition needs. From an educational standpoint, individuals with developmental and learning disabilities may have received psychoeducational evaluations as part of the special education planning process. In addition to their initial evaluation of eligibility, students receiving special education services are entitled to a comprehensive reevaluation, sometimes referred to as a core evaluation, at least every 3 years. While parents may request additional evaluations at any time, many students approach their high school graduation without up-to-date assessments of their needs. Students undergo rapid cognitive, emotional, and social changes during their final years of secondary education. Thus, regardless of their specific timeline of eligibility and reevaluation, all students with special needs should receive comprehensive evaluations within 2 years of their anticipated graduation. Ideally, reevaluation of current functioning and difficulties should be conducted proximal but prior to youth's transition out of high school and used to guide transition planning and further educational and/or vocational supports (discussed in detail below).

The domains of assessment and specific measures used will vary based on an individual's needs and transition goals but are mandated to be validated, reliable, and administered in standardized manner by trained and knowledgeable personnel. Standardized assessment of an individual's cognitive abilities (often referred to as neuropsychological, psychological, or psychoeducational testing) may cover domains such as intelligence, language, memory, attention, executive functions, and perceptual/motor abilities, as well as aspects of day-to-day functioning. Intellectual testing often forms the cornerstone of cognitive assessment, since it examines core reasoning and processing abilities known to be predictive of success in school, work, and daily life. Common tests of intellectual ability include the Wechsler Intelligence Scales, the Kaufman Intelligence Tests, the Stanford-Binet, and the Woodcock-Johnson Tests of Cognitive Abilities. Particularly for individuals with intellectual disability, these global tests of cognitive ability provide important information about the degree of impairment that can be expected in early adulthood. Assessment of independent living skills, such as functional literacy, numeracy, self-care, home or community living, and everyday social interactions, is equally important in characterizing an individual's capacity for independence. These are often assessed via standardized and norm-referenced rating scales, which may be completed by a family member, caregiver, educator, or in some cases the individual themselves. Widely used assessments of daily living skills include the Adaptive Behavior Assessment Scales, the Vineland Adaptive Behavior Scale, and the Independent Living Scales.

Some of the most important questions for emerging adults relate to their careers, and there are a range of well-validated assessment tools for determining an individual's occupational interests as well as their work-related capabilities. Standardized assessments have long been used to help young people find career paths suited to their interests and skills. For example, the Strong Interest Inventory (SII) is a valid and reliable assessment of occupational interests originally published in 1927, which has been widely used for decades to assist adolescents and adults in identifying career paths suited to their interests and skills [9]. The current version provides scores on over 200 Occupational scales, as well as 30 Basic Interest scales, 6 General Occupational Themes, and 5 Personal Style scales (SII; [7]). Other widely used assessments of vocational interests include the Self-Directed Search and the Career Key. Standardized assessment of individual's occupational and vocational skills may be equally important in identifying career paths well suited to their particular strengths and challenges. Such evaluations may include standardized tests of aptitude in areas such as language or mechanical abilities, as well as performance tests that assess an individual's ability to perform specific job-like tasks in actual and contrived work environments. Widely used tests of vocational aptitude include the Differential Aptitude Test, the Armed Services Vocational Aptitude Battery, and the Occupational Aptitude Survey and Interest Assessment.

For individuals planning to pursue secondary education, updated assessments of learning disabilities are often required by college and university disability services in order to provide classroom support and accommodations. These assessments typically consist of measures of overall intellectual functioning (e.g., Wechsler Adult Intelligence Scales) and academic ability (e.g., Wechsler Individual Achievement Test), as well as tests of neurocognitive and executive functions such as attention, working memory, self-monitoring, and planning/organization. The dramatic reduction in structure and monitoring that comes with the transition from high school to college is especially difficult to navigate for individuals with deficits in executive functions commonly associated with learning disabilities and neurodevelopmental disorders such as ASD and ADHD. Targeted assessment of executive functioning via cognitive tests (such as the Delis-

Kaplan Executive Function System) or behavioral rating scales (Behavior Rating Inventory of Executive Function) can provide recommendations for school-based accommodations and support, as well as insight to youth and their families in developing strategies for success.

The most recent reauthorization of the Individuals with Disabilities Education Act (IDEA), known as the Individuals with Disabilities Education Improvement Act (IDEIA 2004), reinforced the role of assessment in transition planning by including specific language regarding age-appropriate Transition Assessments. Comprehensive Transition Assessments that are well targeted, based on reliable and valid assessment methods, begin early, and are provided at regular intervals can play a key role in ensuring that an individual's transition needs are met. While states vary in the interpretation and implementation of these Transition Assessment requirements [15], the National Technical Assistance Center on Transition (NTACT), funded by the US Department of Education, provides assistance and guidelines to state and local agencies implementing evidence-based Transition Assessment practices. According to the NTACT guidelines, a Transition Assessment with the goal of facilitating student success in postsecondary environments should answer three basic questions: (1) Where is the student presently? (2) Where is the student going? (3) How does the student get there? [19]. Transition Assessments can include both informal and formal assessments in four major domains: academic functioning, self-determination, vocational interest and aptitude, and adaptive behavior and independent living (NTACT 2016). Formal measures may include standardized, norm-referenced tests of intellectual ability, academic achievement, adaptive behavior, and career interest described above, as well as standardized assessments of personality (e.g., 16 Personality Factor Questionnaire) and self-determination (e.g., American Institutes for Research Self-Determination Scale). These formal instruments may be supplemented with informal measures that provide descriptive information and relate more directly to the student's personal interests and goals but lack formal norming procedures and standardization. Transition Assessments are a relatively new yet rapidly progressing area of specialized evaluation. Legislation such as the IDEA/IDEIA as well as federal initiatives like NTACT supports the development and implementation of evidence-based Transition Assessments that can provide crucial information and support for emerging adults and their families.

Conclusion

The needs of transition age youth are both unique and numerous. In addition to shifting developmental capacities and expectations, emerging adults often face educational and employment milestones, as well as new social and emotional demands. In each of these domains, young people with developmental and learning disabilities are likely to face unique challenges in their transition to adulthood. Supports related to education, employment, social functioning, mental health, and daily living skills are especially important for this population of young people. The growing recognition of this critical stage of development, as well as the unique needs of youth with disabilities, is promising. However, institutions and agencies that provide such services are large, complex, and slow to adapt. As a result, many young people and their families face the transition to young adulthood with trepidation and uncertainty. A knowledgeable provider, who is well-versed in the needs of transition age youth, as well as the landscape of available support services, can be an invaluable resource during this critical period of youth development.

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