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SYSTEMIC LEVELS IN NEURODEVELOPMENTAL DISORDERS

Lee A. Teufel-Prida and Juan A. Lopez Prida

Neurodevelopmental disorders are broadly defined as disorders that manifest or appear in the developmental period. More specifically, neurodevelopmental disorders can be defined as a series of complex traits that emerge as a result of genetic determinants interacting with various poorly understood environmental components resulting in a diverse clinical presentation (Cristino et al., 2014). This broad category of disorders is a new introduction to the *Diagnostic Statistical Manual of Mental Disorders* (5th ed.; *DSM-5;* American Psychiatric Association [APA], 2013) and represents significant attention and focus to the area of neurodevelopment. Because neurodevelopmental disorders are generally associated with the developmental period, this group of disorders is associated with infancy, childhood, and adolescence. Most commonly, the onset and diagnosis of a neurodevelopmental disorder occurs in childhood. Despite the onset of neurodevelopmental disorders appearing in childhood, one should note that these disorders rarely experience a remission or relapse and are considered to be a stable set of symptoms over time (World Health Organization, 2014), and thus neurodevelopmental disorders appear throughout the individual's life span.

DSM-5 AND FAMILY SYSTEMS

Neurodevelopmental disorders impact not only the individual diagnosed with the disorder, but also the family of the individual diagnosed. Because neurodevelopmental disorders are commonly diagnosed in childhood, it is the parent or caregiver of the individual with a neurodevelopmental disorder who seeks assistance through a physician, psychologist, counselor, social worker, or teacher. Parents and family members are often the first to notice differences in their child. Parents are also asked to regularly monitor their children's development through scheduled pediatric well-child care visits at developmentally critical

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periods in a child's growth and development. See the Periodicity Schedule for a comprehensive schedule of well-child care visits, specifically recommendations for preventive pediatric health care at American Academy of Pediatrics' (2015) website. The American Academy of Pediatrics' (2010) recommendation that all pediatricians screen for developmental delays serves to increase awareness about developmental issues and preventative measures that may be taken early in a child's life to increase the likelihood of developmental milestones being achieved. However, the reality is that few pediatricians use standardized assessments when assessing for developmental delays (Sand et al., 2005). Thus, parents and caregivers need to be able to accurately and regularly communicate with medical providers to ensure care for their child in need and advocate for services to assist their child.

Neurodevelopmental Disorders as Significant Focus of Attention

The *DSM-5* represents a shift in clinical and research focus toward neurodevelopment. Systemic clinicians are now regularly asked questions about the assessment, diagnosis, and treatment of neurodevelopmental disorders, whereas, in the past, neurodevelopmental disorders were treated primarily by medical professionals in neurology or pediatrics or perhaps a psychologist with expertise in neuropsychology. The Children's Health Care Act of 2000 represented a specific shift in attention by authorizing the Centers for Disease Control and Prevention (CDC) to create the Autism and Developmental Disabilities Monitoring Network. This network, which is funded by the CDC, works to estimate the number of children with Autism Spectrum Disorder (ASD) and other developmental disabilities in the United States. For example, research from tracking estimated prevalence rates from 1991 to 2010 in the Greater Atlanta, Georgia metropolitan area suggests that the incidence of Intellectual Disability and hearing loss among 8-year-old children remained about the same with some minor increase in vision impairment. Similarly, in the same population of 8-year-olds with cerebral palsy in Atlanta, the incidence remained about the same from 1993 to 2010. In sharp contrast, the estimated incidence of ASD among 8-year-olds in Atlanta increased 269% from 1996 to 2010 (CDC, 2015). Even more specifically, the National Institutes of Health (NIH) estimates that in 2012 Autism received approximately $192 million in science, actual research projects funded, and NIH budget, whereas in 2012 Attention Deficit Hyperactivity Disorder (ADHD) received approximately $60 million in science, actual research projects funded, and NIH budget. The trend to fund and research Autism continues with $216 million estimated to be spent in 2017 for science, actual research projects funded, and NIH budget compared to $43 million for ADHD, $33 million for Fetal Alcohol Syndrome, $40 million for Fragile X syndrome, and $5 million for Tourette syndrome. Given the increase in research and treatment attention on neurodevelopmental disorders and neurodevelopment in general, the role of family members is a factor to consider in systemic treatment.

The Role of Neurodevelopment in Families

Parents are impacted by the increased attention on neurodevelopment. Due to research in the area of neurodevelopment and efforts to ensure that children meet developmental milestones, parents are increasingly aware of the importance of healthy and unobstructed neurodevelopment. As the definition of neurodevelopment evolves, emerging research continues to show that neurodevelopment is the interaction between genetic inheritance and the environment. Ultimately, genes and the environment are refereed by nongenetic influences to make up the brain from conception to adulthood (Fine & Sung, 2014). Because of this interaction between genes and the environment, parents have a crucial part to play

in the likelihood of neurodevelopmental disorders whether they are conscious or aware of the part they play or not. For example, a parent with a Specific Learning Disorder, Impairment in Reading (otherwise known as Dyslexia; APA, 2013, p. 67), may be aware that his or her child is at increased likelihood of also having a Specific Language Disorder due to the genetic components of the disorder (Fisher & DeFries, 2002). The biological origination of specific learning disorders according to the APA (2013) is the interaction of genetic, epigenetic, and environmental factors. Dyslexia's behavioral manifestation is difficulty in learning specifically printed words (APA, 2013), and a person would be aware of challenges given school reports and possible educational or psychological assessments. A person with dyslexia may also be aware that a biological relative also struggled in school. Yet, parents with no known neurodevelopmental disorder may be concerned about ASD due to increased media or research attention around this disorder. In addition, there are multiple nonspecific risk factors for ASD. The lack of clear risk factors may lead a parent to wonder about his or her role in ASD. Both parent examples display the role that neurodevelopment and neurodevelopmental disorders, risk factors specifically, play in families.

Families may be curious about how to promote healthy neurodevelopment. Likewise, families may wonder what causes abnormal neurodevelopment. To understand the root cause of the neurodevelopmental disorder or the etiology of the neurodevelopmental disorder is a key element to understanding neurodevelopment as a whole (Thome, Drossos, & Hunter, 2013). Families play a role in the etiology of neurodevelopmental disorders given that most neurodevelopmental disorders have multiple causal sources, including genetics. The etiological contributors include genetic, biological, psychosociological, and environmental (Environmental Protection Agency, 2015). See Table 1.1 for a list of various contributors or causes of neurodevelopmental disorders. Families and counselors have an opportunity to impact these contributors in a positive or negative fashion.

Neurodevelopmental Versus Neurocognitive

Neurodevelopmental disorders can be mistaken for neurocognitive disorders. The important distinction between neurodevelopmental and neurocognitive disorders is that neurodevelopmental disorders emerge in the developmental period of life versus neurocognitive disorders, which are acquired during the life span (APA, 2013). Counselors should make careful assessment of the behaviors associated with the disorder and the age of onset when making a diagnosis. For example, a traumatic brain injury (TBI) can occur at any age with prevalence being high in childhood (Faul, Xu, Wald, & Coronado, 2010), but the associated symptomatology and the fact a TBI is acquired make it a neurocognitive disorder and not a neurodevelopmental disorder. TBI in children may appear as issues in cognition or challenges academically and even meeting developmental milestones. More specifically, a TBI is the direct result of an accident or is an acquired impairment, whereas a neurodevelopmental disorder is not acquired; rather it is part of a person's innate biological and behavioral makeup. Thus, when making a differential diagnosis, an understanding of when the symptoms appeared and if an injury occurred is an important factor in final diagnosis.

Neurodevelopmental Disorders in the *DSM-5*

The chapter in the *DSM-5* on neurodevelopmental disorder categories includes Intellectual Disability (intellectual developmental disorder), Communication Disorder, Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Specific Learning Disorder, and Motor Disorders. See Table 1.2 for a list of all the disorders associated with neurodevelopmental category. In the *DSM-5,* there are notable changes associated with some of the

TABLE 1.1 Neurodevelopmental Disorder Causes

	Genetic causes	Fragile X syndrome Down's syndrome Rett's syndrome ICF syndrome ATR-X syndrome Angelman syndrome Other single genetic lesion syndromes
	Biological causes	Prenatal disorders Arrested hydrocephalus Perinatal disorders Prematurity Peripartum ischemic Encephalopathy Fetal distress syndrome Postnatal disorders Anoxemia at birth Postnatal infection Primary neoplasm
	Illness or disease	
	Nutritional factors	
	Psychosocial	Emotional trauma Neglect abuse Abuse/maltreatment Antenatal maternal stress
	Environmental	Exposure to toxins known and unknown Alcohol, tobacco, drugs Mercury Lead Polychlorinated biphenyls Dioxins Pesticides Ionizing radiation Aluminum[a] Acetaminophen[a] In utero exposure to toxins known and unknown Poverty
Family life	Emotional	Lack of attachment Poor family dynamics Divorce and remarriage Foster care

[a]Causality questioned; empirical evidence may be biased.

TABLE 1.2 Neurodevelopmental Disorders

Category/Disorder	Subtype/Disorder

Intellectual Disability	• Intellectual Disability (intellectual developmental disorder)
	  ▪ Mild
	  ▪ Moderate
	  ▪ Severe
	  ▪ Profound
	• Global Developmental Delay
	• Unspecified Intellectual Disability (intellectual developmental disorder)

Communication Disorders	• Language Disorder • Speech Sound Disorder • Childhood-Onset Fluency Disorder (Stuttering) • Social (Pragmatic) Communication Disorder • Unspecified Communication Disorder
Autism Spectrum Disorder	• Specify if: associated with medical or genetic condition or environmental factor; associated with neurodevelopmental, mental, or behavioral disorder • Specify severity: amount of support required • Specify if: with or without intellectual impairment, with or without accompanying language impairment, with catatonia

Attention-Deficit/ Hyperactivity Disorder	• Combined presentation
	• Predominantly inattentive presentation
	• Predominantly hyperactive/impulsive presentation
	  ▪ Specify: in partial remission
	  ▪ Specify severity: mild, moderate, severe
	• Other Specified Attention-Deficit/Hyperactivity Disorder
	• Unspecified Attention-Deficit/Hyperactivity Disorder

Specific Learning Disorder	• Specify if:
	  ▪ With impairment in reading
	  ▪ With impairment in written expression
	  ▪ With impairment in mathematics
	• Specify severity: mild, moderate, severe

Motor Disorder	• Developmental Coordination Disorder
	• Stereotypic Movement Disorder
	  ▪ Specify if: with self-injurious behavior, without self-injurious behavior
	  ▪ Specify if: associated with known medical or genetic condition, neurodevelopmental disorder, or environmental factor
	  ▪ Specify severity: mild, moderate, severe

(*continued*)

TABLE 1.2 Neurodevelopmental Disorders (continued)

Category/Disorder	Subtype/Disorder
	• Tic Disorders ▪ Tourette's Disorder ▪ Persistent (Chronic) Motor or Vocal Tic Disorder ▪ Provisional Tic Disorder ▪ Other Specified Tic Disorder ▪ Unspecified Tic Disorder
Other Neurodevelopmental Disorders	• Other Specified Neurodevelopmental Disorder • Unspecified Neurodevelopmental Disorder

disorders within the neurodevelopmental chapter. Specifically, the term *mental retardation* has been replaced with intellectual disability (intellectual developmental disorder). The shift to intellectual disability comes as a result of use by persons in the medical community, counselors, educators, and advocacy groups. In addition, the term *intellectual disability* aligns with a federal statue in the United States (Rosa's Law, 2010). Rosa's law removed terms such as mental retardation and mentally retarded from educational, federal health, and labor policies. These terms were replaced with the deemed people-first language of "individual with an intellectual disability" and "intellectual disability." The noted additional terminology (Intellectual Developmental Disorder) is associated with the *ICD-11*, which recognizes disorders.

In addition, the *DSM-5* disorders under the Communication Disorders subsection include Language Disorder (LD), Speech Sound Disorder, Childhood-Onset Fluency Disorder (Stuttering), and the new disorders: Social (Pragmatic) Communication Disorder, and Unspecified Communication Disorder.

In a similar move to combine disorders into overarching and theoretical categories, the specific learning problems from the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; APA, 1994)—reading, math and writing, as well as learning disorder not otherwise specified—were replaced with a category called "Specific Learning Disorder." One can still acknowledge the more common types of describing reading deficits as dyslexia and specific types of mathematics deficits as dyscalculia. The *DSM-5* continues to recognize motor disorders as Developmental Coordination Disorder, Stereotypical Movement Disorder, Tourette's Disorder, Persistent (Chronic) Motor or Vocal Tic Disorder, and Other Specified and Unspecified Tic Disorder. The criterion for tic disorders is standardized. Major attention is paid to the description for stereotypical movement disorder. This reflects the importance the motor disorders category has in the diagnosis of self-injurious behavior. Nothing in particular changed from the *DSM-IV* to *DSM-5* regarding motor disorders; the *DSM-5* did add a new Z code of personal history of self-injury. When making this diagnosis of stereotypic movement disorder, the system clinician is required to specify with or without self-injurious behavior and to specify any associated medical or genetic condition, neurodevelopmental disorder (e.g., intellectual disability/intellectual developmental disorder), or associated environmental factors (e.g., intrauterine drug exposure).

In a parallel move to combine and focus the classification, APA (2013) in the *DSM-5* notes ASD as encompassing the previous *DSM-IV* Autistic Disorder (Autism), Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. ASD is a single condition with severity of symptoms noted in two

core domains. These two domains that are measured for symptom severity are deficits in social communication and social interaction, and restricted, repetitive behaviors, interests, and activities, otherwise known as restrictive, repetitive behaviors (APA, 2013).

ADHD is a neurodevelopmental disorder due to the brain developments associated with ADHD, such as impulse control, attention, planning, and stimulation. Specifically, individuals with ADHD exhibit delays in brain maturation (Sripada, Kessler, & Angstadt, 2014). It appears that the lag in connection development may help to explain the reason for distractibility and behavioral inhibition in persons with ADHD. The previous *DSM-IV* associated ADHD with disruptive behavior disorders. APA (2013) notes several important distinctions for ADHD in the *DSM-5*:

- Multiple examples are provided to the criterion items to assist in the diagnosis of ADHD throughout the life span, with examples of symptoms expressed in adults now provided for 15 of the 18 possible symptoms compared to three of the 18 possible symptoms.
- The latest age of onset for ADHD noted in the *DSM-5* is symptoms being present prior to the age of 12, instead of age 7 in the *DSM-IV*.
- There are no longer subtypes of ADHD; instead there are presentation specifics that map to the prior subtypes. These specifics then designate combined, predominately inattentive, and predominately hyperactive/impulsive presentations. The content of the diagnosis has not changed from *DSM-IV* to *DSM-5*; this was a semantic change.
- The comorbid diagnosis of Autism Spectrum Disorder is now permitted.
- The symptoms required for diagnosis in persons 17 and older is at least five symptoms, instead of the six symptoms required for persons under the age of 17.

There continues to be the major symptom domains for ADHD: inattention and hyperactivity impulsivity and combined inattention and hyperactivity impulsivity. Similarly, there remain 18 primary symptoms that are possible for ADHD in the *DSM-5* as there were in the *DSM-IV*.

RELATIONAL AND CULTURAL FEATURES

Neurodevelopmental disorders exist in society through the cultural lens, which, in turn, encompasses the relational customs that could play a role on a neurodevelopmental disorder setting. Culture affects how people relate and cope with neurodevelopmental disorders, and defines neurodevelopmental disorders to such an extent that cultural differences among people act as barriers for the proper assessment and treatment of neurodevelopmental disorders throughout the world. Once this is taken into account, it becomes evident that a family systems approach is the most adequate treatment option because, in family systems, the family's views, goals, relationships, and value systems are the main point of interest for therapy.

Culture and Neurodevelopmental Disorders

Culture is an important denominator in the discussion of neurodevelopmental disorders. Often information about disorders is generalized to individuals in the rest of the world with little consideration on the diverse cultural factors. For example, some studies have shown that Eastern cultures manifest autistic behavioral traits to a greater extent than Western cultures; that Eastern cultures score higher (or lower) on some subscales than Western cultures on the Autistic-Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001); and that, furthermore, some Eastern countries differ on scores on

subscales from other Eastern countries (Freeth, Sheppard, Ramachandran, & Milne, 2013). These multicultural studies have inspired thought on whether some of the subscales should be modified or discarded to be able to properly evaluate a more diverse group of people with ASD. Thus, intentional thought and consideration must be paid to culture and family makeup when discussing and treating neurodevelopmental disorders. This is very important for countries with eminent cultural diversity, such as the United States and the United Kingdom (Norbury & Sparks, 2013).

Regarding the diagnosis of LD, there are some important culture-related implications that should be taken in account and that will be discussed further on, such as the nature of the language that a person with LD natively speaks or how a language suffers dialectical modifications in the different communities in which it is spoken. And not only have Western cultures been compared with Eastern cultures, but also Western countries have been compared among themselves, taking in account their culturally diverse population (when applicable). Continuous research with a cultural approach on neurodevelopmental disorders will, as it has already been shown, broaden the understanding on said disorders and will shed greater light on how neurodevelopmental disorders can manifest differently in the innumerable cultural settings throughout the world.

Language Disorder (LD) and Culture

When assessing LD and other neurodevelopmental disorders in developing countries, it is noted that a lack of any formal education or lack of exposure to visual representations of objects (i.e., people who have seen only physically present objects and have never seen a photograph, drawing, or other visual representation of an object) makes applying standardized tests an unreliable way of diagnosing neurodevelopmental disorders (Carter et al., 2005). It is important to explore culture and language of origin when addressing LD. A non-English speaker or English-as-a-second-language speaker may have challenges that can be accounted for by regional, social, and/or cultural variations of language. Considering these factors is important in the diagnosis of LD along with, for example, potential hearing or sensory impairment, intellectual disability, neurological disorders, and language regression associated with ASD.

Most of the LD standardized tests are made by and for White middle-class, English-speaking people (Hirsh-Pasek, Kochanoff, Newcombe, & de Villiers, 2005). It would be understandable that said tests would not correctly evaluate non–English-speaking people. Even if the tests are translated, elemental differences between English and other languages make English-speaking people with LD manifest deficiencies in certain aspects of language where people who speak another language and also have LD do not manifest impediments (Bedore & Leonard, 2005; Leonard, 2009).

Comprehensibly, different ways of diagnosing LD must be developed for people depending on the language they speak—but not only for people who speak different languages but also for people who speak the same language in different countries. The dialectal differences are another border between countries that speak the same language (Norbury & Sparks, 2013). An example of this is British English when compared to American English (e.g., soccer, football; flashlight, torch; French fries, chips).

Language is not only spoken differently in different countries, but it is also spoken differently in different parts of a same country, and, furthermore, by different people in the same place within a country. An example of this can be seen in the differences between "mainstream American English" and native speakers of African American English (Seymour, Roeper, & de Villiers, 2005). The *Diagnostic Evaluation of Language Variation* is an example of an assessment design that works to evaluate LD in native speakers of African American English. It has been designed to evaluate LD based on similar (noncontrasting)

features instead of utilizing different (contrastive) features of African American English when compared to mainstream American English (Seymour et al., 2005). Assessment designs with this same philosophy are being developed for other dialects in the United States, but many dialects still lack standardized assessments (Norbury & Sparks, 2013).

Autism Spectrum Disorder (ASD) and Culture

The AQ (Baron-Cohen et al., 2001) is a widely used test to score the degree of autism in people. It is divided into five subscales: imagination, attention to detail, attention switching, social skill, and communication. The AQ was designed from traits that are relevant to and present in Western cultures. This is evident on the imagination subscale, where people from Eastern cultures tend to score higher than people in Western cultures. Imagination is not cultivated in the same way in Western and Eastern cultures (Freeth et al., 2013), being so that in Eastern cultures, a perceived low imagination may not be an autistic trait, but, in fact, be the outcome of the cultural setting in which the individual develops.

People with ASD tend to be highly aware of details and proficient at identifying patterns. Although this trait may prove to be true in people with ASD around the globe, the items used to score this trait may be biased. One item in which Eastern cultures generally score higher than Western cultures is "I usually notice car number plates or similar strings of information" (Freeth et al., 2013, p. 2577). In some Eastern cultures, some numbers convey a significant meaning, such that people would want certain numbers in their car number plates and avoid others (Pandiyan, 2012; Paul, 2011). Easterners are more prone to notice car number plates than Westerners, and it should not be correlated with the degree of autism, but rather with the beliefs inherent in some Eastern cultures.

These and other differences have been noted between Eastern and Western cultures regarding the AQ, but there are some findings that are constant in both cultures. Females have been reported to score lower than males in the AQ. Also, science students score higher than nonscience students (Freeth et al., 2013).

Furthermore, in some Eastern cultures it is deemed rude to look at another's eyes, so it would be normal for them to perpetuate this conduct upon being examined for ASD. It has been shown that people from Asian cultures usually fixate on the nose area of the face (Blais, Jack, Scheepers, Fiset, & Caldara, 2008; Kelly et al., 2011). This cultural difference is evident from 9 months of age (Liu et al., 2011). Hence, false positives would be common in certain cultures when relying on the area of fixation for assessment.

The overarching differences between people from different cultures (even when residing in the same geographical space) cannot be ignored when diagnosing neurodevelopmental disorders that are so heavily influenced by the social and cultural components of specific populations. Failure to consider these factors will undoubtedly result in false data that will deter progress on the understanding of neurodevelopmental disorders and their undeniable cultural aspects.

Family Systems

Systems theories are derived from general systems theory, an interdisciplinary approach that has been conceptualized as a weltanschauung or "unique worldview." General systems theory proposes that events, situations, and people should be interpreted within their environment rather than in isolation (Von Bertalanffy, 1950). Bearing this in mind, when applying general systems theory, a mental health professional, for example, would treat families coping with ASD together with all the systems and subsystems with which they interact and not as ASD individuals in isolation (Cridland, Jones, Magee, &

Caputi, 2013). Family systems approaches consider families as unique interactive and reactive units that possess a basic social system of rules, values, and goals (Edwards, 2011). Some of the main concepts that are relevant to family-focused ASD research are macroscopic approach, microscopic approach, boundaries, ambiguous loss, and traumatic growth (Cridland et al., 2013).

Macroscopic approaches focus on the way families interact with other systems, such as the community, other families, schools, and social groups. Microscopic approaches examine relationships within the family, such as maternal, marital, and/or sibling subsystems. Both approaches should be taken into consideration when researching ASD families, for they address external and internal family interactions that shape the disorder with which the family lives. Similarly, boundaries encompass the limits to which the roles of a family (as a whole) and the roles of each family member (as individuals) can reach (Cridland et al., 2013). It is important for the well-being of families to be flexible about their boundaries when life event changes such as in employment or residence ensue (Seligman & Darling, 2007), and families that are able to do this have high "permeability" of their boundaries (Cridland et al., 2013, p. 215). The most resilient ASD families are able to be flexible in role and responsibility changes as well as communicate with each other about personal needs (Bayat, 2007).

Families coping with ADHD, as expected, present higher levels of stress than families with children who have no neurodevelopmental disorders, but it has also been shown that these families may present higher levels of stress than families with ASD and families with ASD and ADHD comorbidity. Parents of ADHD children presented higher levels of stress than families with ASD and families with ASD and ADHD due to a lack of emotional closeness and affective bonding with their children and a lower capacity to understand their feelings and needs. This can be explained by the parents' belief that the ADHD child's behavioral problems are caused by factors that are modifiable by the child, whereas parents with ASD children tend to more easily accept that children may not control their behavior due to the nature of the disorder itself (Miranda, Tarraga, Fernandez, Colomer, & Pastor, 2015).

Parents with children diagnosed with ADHD also manifested a higher degree of stress related to feelings of sadness, unhappiness with oneself, and discontent with one's life circumstances than parents with ASD. Finally, ADHD parents perceived, to a greater extent than ASD parents, that they were not competent as parents regarding management of the child's behavior and discipline, and felt a lack of skills and knowledge to appropriately parent their ADHD child (Miranda et al., 2015).

Bearing in mind not only the aforementioned aspects but all the ways that neurodevelopmental disorders affect the family as a whole and its systemic and subsystemic interactions, it is clear that a therapy in which the individual with a neurodevelopmental disorder is treated in isolation would not provide the impact that family systems therapy might attain. Failing to consider the ways families impinge on the family member with a neurodevelopmental disorder, and vice versa, would amount to a partial treatment in which its success would be minimal in comparison to that of a therapy that actively works on goals for the whole family.

Value Systems

An intrinsic part of any family is its value system. Value systems affect the way families see their neurodevelopmental disorder and the goals they have, not only regarding their family member with a neurodevelopmental disorder, but also in other aspects of their lives as a family and as individuals. Some value systems trends have been identified among families with neurodevelopmental disorders (Carona, Silva, Crespo, & Canavarro, 2014). Also, there are studies that show how certain aspects of said value systems affect families.

It is important, as part of an integral treatment for families with a neurodevelopmental disorder, to assess their value systems and to work on them to better improve the family's quality of life.

It has been shown that parents of children with neurodevelopmental disorders are more likely than parents of children without such disorders to adopt coping strategies that reduce the family's quality of life (Raina et al., 2005). One of these deleterious coping strategies is *disengagement behavior*. Disengagement behavior consists of renouncing life goals and other aspects that gave meaning to life (Carona et al., 2014). In this scenario, the caregiving burden experienced by parents was overencumbering (Garner et al., 2011) and led them to feelings of helplessness (Taft, Resick, Panuzio, Vogt, & Mechanic, 2007). Disengagement behavior makes the family's value system change into an unhealthy state, which makes caregiving not only the number one priority, but also makes any other activity, project, or goal something not worth considering anymore (Carona et al., 2014). Although it may appear congruent that setting everything aside to take care of a child with a neurodevelopmental disorder would render better results, it actually impacts on the child in a negative way (Duffy, 2011). A possible explanation is that, because disengagement behavior diminishes the parents' quality of life (Guðmundsdóttir, Guðmundsdóttir, & Elklit, 2006), the stress experienced by parents directly impinges in a deleterious manner on the child's quality of life (Carona et al., 2014). This is an example of why the family's value systems need to be considered when treating families with a neurodevelopmental disorder. In this case, parents should be refocused on their goals and valued directions in life, by encouraging them to pursue meaningful activities that they have been avoiding or abandoning, while assessing the underlying processes that have led to a maladaptive coping behavior (Veale, 2008). Leaving this aspect of the family untouched could prove to be an impasse in the process of a family successfully coping with a neurodevelopmental disorder.

FAMILY SYSTEMS ASSESSMENTS

When it is suggested that an individual has a neurodevelopmental disorder, it is essential to obtain an accurate diagnosis. Many times, the children, teens, and adults dealing with a suspected diagnosis are confused and find themselves confronting time-consuming and costly processes. It is important that family members, especially parents and guardians of children and teens thought to have a neurodevelopmental disorder, locate qualified personnel who are able to determine if their children or teens meet the criteria for a disorder.

Counselors and/or a medical doctor with training and expertise in neurodevelopmental disorders may do an initial assessment for a neurodevelopmental disorder. In many cases, an initial or preliminary diagnosis will require further and more involved assessment and observation. An accurate diagnosis by a clinician is based on specific observable behaviors and characteristics across a variety of environments and situations, in addition to a comprehensive history of early development. Because neurodevelopmental disorders are complex and multifaceted, it is recommended that family members of the person experiencing symptoms be involved in the diagnostic process. Oftentimes, the family must coordinate numerous care providers and clinicians to achieve an accurate diagnosis and/or treatment approach. Specifically, family members of persons with a neurodevelopmental disorder often engage in the assessment process to obtain a diagnosis from not only a mental health professional and a medical doctor, but also assessments from physical and occupational therapists, neurologists, psychiatrists, and speech and language pathologists (SLPs). Similarly, if the individual suspected of having a neurodevelopmental disorder is in a school program, an educator with knowledge of the individual's academic performance should be involved in the assessment process to determine if educational support is warranted.

Parents of a child with a suspected neurodevelopmental disorder should be encouraged to discuss concerns with their child's pediatrician and contact individual providers/centers to identify their assessment options. In addition, for infants or toddlers prior to their third birthday, parents can investigate early intervention programs in their locale or a First Steps program via their local health department for early intervention services. If children are ages 3 (children approaching the age of prekindergarten) through 5 (children of kindergarten age) or even up to 21, and in need of assessment, parents can contact their local school district for information. School districts employ psychologists and other trained professionals to assess school-aged children. In order to be eligible for special education and related services, typically a team of qualified professionals must complete an educational assessment to determine suitability. The educational assessments done via the school system are typically at no cost to the family. Parents, guardians, or advocates have a legal right to request that the assigned public school evaluate a child for special education. Federal law, the Individuals with Disabilities Education Act (IDEA) as amended in 2004, gives parents, guardians, and advocates this legal right. States, through local school districts, must "identify, locate, and evaluate every child who may have a disability requiring special education services." This is called "Child Find." When there is suspicion that a child has a disability, parents and educators have a responsibility and a right to request a full, individual, comprehensive, multidisciplinary evaluation. However, some families may want a second opinion or second evaluation. In this scenario of second opinion or second evaluation, parents can contact their insurance company to determine how much and what portions of the assessment will be covered by insurance or whether or not they accept Medicaid. Also, if the school district refuses to evaluate the child, the parents may be able to have an evaluation still done at the school's expense. IDEA requires schools to have procedures in place to ensure evaluation of children in need and resolution of disputed cases.

Because neurodevelopmental disorders appear in the developmental period, associated assessment typically occurs in childhood. For example, in the majority of ASD cases, a diagnosis is possible before or around a child's second birthday (Chawarska, Klin, Paul, Macari, & Volkmar, 2009). Early and accurate diagnosis of a neurodevelopmental disorder can help families access appropriate services, provide a common treatment objective for professionals working with the client and family, and establish a context for families and caregivers to understand the client's challenges. Any diagnosis of a neurodevelopmental disorder should be periodically reviewed for changes in the child's development or revisions to diagnostic categories. Collaboration across an interdisciplinary team of professionals with training and expertise specific to the neurodevelopmental disorder in question and family involvement are essential in assessment and diagnosis of specific neurodevelopmental disorders. More so, it is important that clinicians agree with the assessment results and believe assessment results are consistent with respective diagnostic characteristics of a given disorder.

Assessments Tools or Techniques Commonly Used for Neurodevelopmental Disorders

There are numerous assessments to diagnose a neurodevelopmental disorder. In general, historical information is initially reviewed with the parent(s) and the clinician. There are typically subsequent visits to assess medical, developmental, behavioral, or neurological factors impacting functioning. All of the following might be included in the assessment process:

- Child and parent interviews
- Biopsychosocial assessment with a complete family history

- Genogram
- Parent and teacher self-completed rating scales of child behavior
- Self-reported information from parent or caregivers
- Observation of child behavior at home, school, and in the office
- Psychological tests
- Medical record review
- School record review
- Intelligence testing and achievement testing
- Pediatric examination for medical conditions
- Neurodevelopmental screening
- Vision, hearing, and speech and language assessments

Given the multitude of potential assessments, exams, and tests, the most commonly used measures that are administered by a clinician trained and expert in neurodevelopment are summarized in Table 1.3.

TABLE 1.3 Neurodevelopmental Disorders and Associated Assessments

Category/ Disorder	Assessment
Intellectual Disability	The Wechsler Preschool and Primary Scale of Intelligence—Revised Edition (WPPSI-R; Wechsler, 1989)
	Wechsler Intelligence Scale for Children—Fifth Edition (WISC-V; Wechsler, 2014)
	Differential Ability Scales (DAS; Elliott, 1990)
	Stanford–Binet Intelligence Scale—Fourth Edition (SBIS-IV; Thorndike, Hagen, & Sattler, 1986)
	Wide Range Achievement Test 3 (WRAT3)
	Test of Nonverbal Intelligence—Third Edition (TONI-3; Brown, Sherbenou, & Johnsen, 1997)
Communication Disorders	Sequenced Inventory of Communication Development—Revised Edition (SICD-R; Hedrick, Prather, & Tobin, 1984)
	Nonspeech Test (Huer, 1988)
	Assessing Semantic Skills Through Everyday Themes (ASSET; Barrett, Zachman, & Huisingh, 1988)
	Expressive One-Word Picture Vocabulary Test—Revised Edition (Gardner, 1990)
	Receptive One-Word Picture Vocabulary Test—Revised Edition (Gardner, 1990)
	Clinical Evaluation of Language Fundamentals—Preschool (CELF-P; Wiig, Secord, & Semel, 1992)
	ECOScales Manual (MacDonald, Gillette, & Hutchinson, 1989)
	Peabody Picture Vocabulary Test—III (PPVT-III; Dunn & Dunn, 1997)
	Reynell Developmental Language Scales (Reynell, 1977)

(*continued*)

TABLE 1.3 Neurodevelopmental Disorders and Associated Assessments (continued)

Category/ Disorder	Assessment
	Preschool Language Scale—Third Edition (PLS-III; Zimmerman, Steiner, & Pond, 1992)
Autism Spectrum Disorder	Ages and Stages Questionnaire—Third Edition (ASQ-3; Squires & Bricker, 2009)
	Modified-Checklist for Autism in Toddlers—Revised With Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009)
	Autism Diagnostic Interview—Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994)
	Gilliam Autism Rating Scale (GARS; Gilliam, 1995)
	Childhood Autism Rating Scale, Second Edition (CARS2; Schopler, Van Bourgondien, Wellman, & Love, 2010)
	Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999)
Attention-Deficit/ Hyperactivity Disorder	Vanderbilt ADHD Teacher Rating Scale (VADTRS) and Vanderbilt ADHD Parent Rating Scale (Wolraich, Feurer, Hannah, Baumgaertel, & Pinnock, 1998)
	Behavior Assessment System for Children—Second Edition (BASC-2; Reynolds & Kamphaus, 2005)
	Child Behavior Checklist/Teach Report Form (CBCL; Achenbach, 1991)
	Conners' Parent and Teacher Rating Scales
Specific Learning Disorders	Reading
	Scholastic Reading Inventory (SRI)
	Woodcock Reading Mastery Test—Third Edition (WRMT-III)
	Gray Oral Reading Test—Fifth Edition (GORT-5)
	Test of Word Reading Efficiency—Second Edition (TOWRE-2)
	Test of Early Reading Ability—Third Edition (TERA-3)
	Math
	KeyMath-3 Diagnostic Assessment
	Test of Mathematical Abilities—Third Edition (TOMA-3)
Motor Disorders	Beery–Buktenica Developmental Test of Visual Motor Integration
	Peabody Developmental Motor Scales——Seond Edition (PDMS-2)
	Pediatric Evaluation of Disability Inventory (PEDI)
	Functional Independence Measure for Children (WeeFIM)
	Vineland Adaptive Behavior Scales (VABS)
	Bayley Scales of Infant Development II (BSID-II)
	Movement Assessment of Infants (MAI)

FAMILY SYSTEMS INTERVENTIONS

There is a plethora of intervention approaches for individuals and families coping with neurodevelopmental disorders. Ultimately, the intervention approaches differ in the method used to address goals. Interventions can range from behavioral therapies to social–emotional strategies to developmental techniques. Also, the goals of the intervention program can differ from individual treatment of the person with a neurodevelopmental disorder to comprehensive interventions involving parents and caregivers with an interdisciplinary team to address a wide range of skills or behaviors. Since neurodevelopmental disorders are multifaceted and the needs of persons with neurodevelopmental disorders are complex, families often become educators, advocates, and interventionists themselves.

Comprehensive intervention programs work with parents and caregivers to develop effective strategies for the given client and provide feedback for the growth and development of treatment goals and objectives. Clinicians should be aware of the social contexts of home, school, vocation, and community when choosing interventions. In addition, clinicians should incorporate culture, gender, and language when deciding on specific treatment activities. Finally, clinicians should be aware that over time family interactions and relationships will change, and thus the needs of the family for specific interventions will change over time. Ultimately, when planning interventions, careful attention must be paid to family priorities and concerns (Marshall & Mirenda, 2002).

There are a number of different treatment interventions for neurodevelopmental disorders that are systemic in nature. When a clinician is selecting an intervention, the clinician can match the intervention with the treatment goals and objectives for the family and their current functioning around the disorder. The developmental stage and diagnosis of the individual with the neurodevelopmental disorder is always considered. For instance, an intervention that is evidence based for families coping with ASD may not be evidence based for families coping with ADHD. The following is a summary list of family-oriented interventions used for neurodevelopmental disorders.

Intellectual Disability

Intellectual Disability is characteristically a deficit in general mental abilities (APA, 2013). Specifically, families may notice minimal-to-slow-motor skills, language skill, and self-help skill development in comparison to peers. Similarly, there may be failure to develop intellectually or problems maintaining expectations in school. Some parents may also notice social challenges, such as difficulty adapting to new situations and difficulty understanding and following common rules. Individuals with an intellectual disability are most commonly served via the educational system via an Individualized Education Plan (IEP). However, prior to school age, family interventions or services for the family and individual may be the best ones. Familial interventions include but are not limited to the following types.

Individualized Family Service Plan

An individualized family service plan details the child's specific needs and the services that will help the child thrive. Early interventions may be numerous and could include speech therapy, occupational therapy, physical therapy, family counseling, or nutritional services. Counselors can assist in the development and coordination of such plans.

Stress Intervention

Services associated with intellectual disabilities are often associated with educating parents on how to best promote child development and assist parents in their well-being

(Blacher, Neece, & Paczkowski, 2005). Because parents of children with intellectual disabilities are at increased risk for stress and other mental health issues, a stress intervention for parents is suggested. Specifically, cognitive behavioral group interventions designed to reduce the stress of mothers show the strongest research evidence for success (Hastings & Beck, 2004).

Communication Disorders

A communication disorder is a deficit in receiving, sending, processing, and/or comprehending concepts or verbal, nonverbal, and graphic symbols. The specific disorders within the communication disorder domain include LD, speech sound disorder, childhood-onset fluency disorder (stuttering), social (pragmatic) communication disorder, and unspecified communication disorder. Common family interventions may include the following, but are not limited to these interventions.

Parent-Mediated Interventions

Parents are encouraged to use individualized intervention approaches at home with their child. Using the learned interventions from a session(s) with an SLP or other trained professional such as teachers, special educators, and/or counselors can increase learning outcomes for the child. Parents can also assist in the coordination of various professionals.

Speech Therapy

There are many options for speech therapy. An SLP is able to work with the child and parents to formulate the best treatment approach. Under the umbrella of speech therapy, an SLP may use various modalities or treatment options.

Autism Spectrum Disorder (ASD)—Family-Oriented Interventions

There are multiple other interventions for ASD and emerging interventions for ASD. Interventions range from traditional behavioral interventions to social communication interventions. Clinicians are encouraged to do additional research on techniques and treatment approaches that might support the child and family with whom they are working. This is not an exhaustive list.

Pivotal Response Treatment (PRT)

Derived from applied behavioral analysis, PRT is play based and child initiated. PRT addresses what are called "pivotal" areas in development, such as motivation, response to various cues, self-management, and social interaction initiation. The result is improvements across a variety of areas and skills (Koegel & Koegel, 2006). Parents and caregivers and everyone involved in the child's life are encouraged to adopt the skills and techniques used in PRT; more specifically, parents can lead PRT (Minjarez, Williams, Mercier, & Hardan, 2010). PRT is considered one of the most heavily researched and efficacious treatments for ASD (Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014).

SCERTS© Model

The Social Communication, Emotional Regulation, and Transactional Support (SCERTS) Model involves using various interventions to achieve child-initiated communication and

authentic progress, that is, the ability to learn and apply skills in a spontaneous functional way in a variety of settings (SCERTS, 2016). The SCERTS Model (2016) was derived from empirical and clinical work, and as such is noted to be consistent with evidence-based practice in ASD and other neurodevelopmental disorders commonly related to or diagnosed with ASD (National Research Council, 2001; Prizant & Rubin, 1999).

Early Start Denver Model

The Early Start Denver Model (ESDM) is designed to address ASD through child-led, play-based treatment that zones in on the development of social communication skills via individual counseling, peer interactions in a school or care setting, and home-based psychoeducation (Dawson et al., 2010). ESDM is rooted in deep parental involvement and shared engagement in activities. Children engaged in ESDM for a 2-year span showed improvement in cognitive and language abilities and adaptive behavior, in addition to few autism symptoms (Dawson et al., 2010). Clinicians can become certified in ESDM.

Attention-Deficit/Hyperactivity Disorder—Family-Oriented Interventions

There are numerous interventions for ADHD. Interventions range from psychopharmacological interventions to school-based interventions. Often parents feel pulled to seek the assistance of medication and can neglect the efficacy of other interventions. Clinicians are encouraged to seek interventions that work with the family and create wellness for the child in all areas of his or her life.

Parent Behavior Training

Parent behavior training for ADHD primarily includes four manualized programs of behavior training interventions for parents (of preschoolers). These manualized programs involve assisting parents in managing problem behaviors and developing effective parenting strategies. The programs include the Triple P (Positive Parenting of Preschoolers program), Incredible Years Parenting Program, Parent–Child Interaction Therapy, and the New Forest Parenting Program. All four programs are considered efficacious for treating ADHD (Charach et al., 2011). These programs are also evidence based for disruptive behaviors in general (Charach et al., 2011) and may be beneficial for other neurodevelopmental disorders that present with disruptive behaviors (i.e., intellectual disability and ASD).

Teacher-Training Programs

Teacher programs offer teachers the opportunity to learn behavioral strategies to better the classroom environment. Children and Adults With Attention-Deficit/Hyperactivity Disorder is an organization that conducts numerous trainings for teachers interested in improving their interaction with children who have ADHD. Also, the American Academy of Pediatrics offers multiple suggestions of what teachers can do to help students with ADHD.

Specific Learning Disorder

In the *DSM-5*, a specific learning disorder is a single overarching diagnosis with specifiers for deficits in reading, mathematics, and written expression. Characteristics of a specific learning disorder are noted based on a client's medical, developmental, educational, and

familial history. The broad approach to specific learning disorder diagnosis is an effort to ensure that persons with deficits in learning are provided appropriate services.

Family Support

Treatment for learning disorders tends to focus on assisting the child or adolescent in classroom performance, teaching the child how to advocate for him- or herself at school, identifying the learning strengths of the child or adolescent, enhancing self-esteem and general confidence, and finally improving the child's social and behavioral skill set. There are many mediating factors that can impact the success of a person with learning disorders. Self-esteem may be influenced by what a person with a learning disorder perceives is family support (Nalavany & Carawan, 2011). A supportive parent or family member can make a difference by supporting a child to identify his or her strengths and improve his or her classroom performance. In addition, a supportive parent or family member can help advocate for the child at school, thus modeling appropriate self-advocacy for educational needs.

School Resource Room

A child may qualify for part-time or full-time assistance at school depending on what is recommended by his or her IEP. Specialized services can be provided in a resource room for specific academic subjects. Typically, students maintain a "mainstream" schedule for some subjects and activities depending on the specific learning disorder specifier(s).

Motor Disorders

Motor disorders are associated with developmental coordination impairment, repetitive movement, or the various tic disorders. With motor disorders, an individual can feel embarrassed. Support groups and psychoeducation around these disorders are often a positive addition to any familial intervention.

Early Intervention

Identifying and treating motor developmental concerns early in a child's life is associated with facilitating developmental gain in motor development (Blauw-Hospers, de Graaf-Peters, Dirks, Bos, & Hadders-Algra, 2007; Blauw-Hospers & Hadders-Algra, 2005). The type of intervention that might be beneficial for a preterm child should be differentiated from a child who was born full term (Blauw-Hospers & Hadders-Algra, 2005). Although the outcomes for early intervention on motor development may not exceed what can be accounted for by maturation, early intervention does assist with cognitive development in at-risk groups (Orton, Spittle, Doyle, Anderson, & Boyd, 2009). In addition, an early enriching environment that stimulates and facilitates cognition, motor, and sensory development is key for successful motor abilities (Morgan, Novak, Dale, Guzzetta, & Badawi, 2014) to develop.

Occupational Therapy

Expanding on the idea and importance of early intervention, occupational therapy can be beneficial for children with motor disorders. Occupational therapy is not just for adults with occupations. Children with motor disorders can work with occupational therapists to improve fine-motor and gross-motor development, along with addressing the various social, environmental, and psychological factors that might impact physical functioning and well-being.

ETHICAL AND LEGAL IMPLICATIONS

The legal and ethical issues associated with neurodevelopmental disorders range from informed consent of parents and minors to the legal implications of disorders in childhood. Counselors are called on to service and advocate for children and families in multiple systems from home environments to school classrooms. Thus, it is essential to be aware of the legal and ethical implications of neurodevelopmental disorder diagnosis.

Ethical

In order to receive services, as is often the case with neurodevelopmental disorders, a diagnosis is required. The ethical consideration of treatment needs and current disability may or may not be considered until a diagnosis is reached. This lag in time between assessment and qualifying for services can be critical given the developmental level and need for early intervention as it relates to neurodevelopmental disorders. More specifically, certain programs or services may have restrictive diagnostic criteria for admission or age limitations or geographic catchment areas. Clinicians can assist with the need for service by providing opportunities for intake, referrals for services that are available while waiting for assessment, and advocating for services that are "needs driven." The aforementioned should be discussed in the informed consent process. The American Counseling Association (ACA) outlines informed consent in the *Code of Ethics* (2014; Section A.2.a: Informed Consent). Similarly, Section B.2.a of the ACA *Code of Ethics* outlines the counselor's responsibility to minors or adults who lack the capacity to give voluntary, informed consent. Also, informed consent, according to the ACA and the American Association for Marriage and Family Therapy (AAMFT) *Code of Ethics*, is an ongoing process, and as treatment, services, or diagnosis is deemed appropriate, so should the informed consent be reviewed.

Given that neurodevelopmental disorders typically continue throughout the life span, it is important to consider "quality of life" care and services versus curative treatments. Clinicians, parents, family members, and clients can benefit from understanding the lifetime experience of a disorder and what services will look like over time. Similarly, parents and the identified person with a neurodevelopmental disorder can work to share responsibilities of care with various care providers and family members instead of a single parent or the person with the disorder assuming all care responsibilities for a lifetime. Clinicians can assist greatly with diagnosis acceptance and long-term treatment planning.

Clinicians and parents may feel challenged by the overwhelming amount of information about neurodevelopment and what does or does not impact development. Sorting through what is evidence based and is causative for neurodevelopmental disorders may also be a dilemma. Given easy access to the Internet and alternative therapies for neurodevelopmental disorders, parents, caregivers, and clinicians alike may be tempted to pursue untested and biased approaches or even consider explaining disorders via untried causes. However, parents and caregivers should not ignore warnings about the risk factors, precipitating behaviors, and known causes of neurodevelopmental disorders when conceiving and caring for children.

Legal

Children and adolescents with a neurodevelopmental disorder such as intellectual disability or ASD are covered under the IDEA. IDEA is a law-ensuring service to children with disabilities throughout the nation, including infants, toddlers, children, and youth with disabilities. Infants and toddlers with disabilities (birth to 2 years) and their families receive

early intervention services under IDEA Part C. Children and youth (ages 3–21) receive special education and related services under IDEA Part B (www2.ed.gov/about/offices/list/osers/osep/osep-idea.html, n.d.). There are six pillars under IDEA to which children with disabilities are entitled: an individualized plan, free appropriate public education, least restrictive environment, appropriate evaluation, parent and teacher participation, and procedural safeguards (www2.ed.gov/about/offices/list/osers/osep/osep-idea.html, n.d.). These six pillars are extremely important during the assessment and intervention processes. Parents and families should work closely with schools and care providers around the services provided under IDEA.

Confidentiality and educational records as they relate to the IEP can be confusing for parents and some school personnel. The IEP is considered part of the educational record. The Family Educational Rights and Privacy Act (FERPA; 1974) is a federal law that protects the privacy of student educational records. It is important to note that schools must have written permission from the parent or eligible student to release any information from the student's educational record. However, FERPA allows schools to disclose those records, without consent, under several different conditions (34 CFR § 99.31); specifically school officials with legitimate educational interest can access the school record. Thus, a teacher working with a child who has an IEP can have access to this record (www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html, n.d.). Understanding the legal limits of confidentiality under FERPA is especially important as parents work to coordinate with school personnel, teachers, and care providers the most effective treatment plan for their child.

CASE CONCEPTUALIZATION

In order to further conceptualize working with families impacted by neurodevelopmental disorders, a case example is provided. The following case example discusses Ren and his family as they navigate the various systems associated with the diagnosis and treatment of ASD.

Presenting Concerns

Ren is a biracial (Mexican American) child and his age is 5 years and 3 months. His parents, Anna (26) and Sam (31), report a family history of a learning disorder for the father, Sam. The parents are concerned because Ren is mostly fussy and the mom, Anna, continues to "baby" Ren who does not like the texture of most baby food. He refuses to eat crunchy foods such as pretzels or carrots. Ren is large for his age (reportedly in the 98th percentile for height and weight per his pediatrician). He was slow to walk, starting at 20 months old, but even now he is clumsy and frequently has difficulty running without falling, or manipulating smaller objects with his hands. Ren was also slow to talk, starting at age 18 months, and even now he communicates in simple sentences. Ren does make verbal sounds and will regularly grunt repeatedly when he is frustrated. Ren also is very focused on his large Lego set and does not like other toys. Similarly, Ren will fixate on the ceiling fans in the family home and is soothed to sleep by a spinning night light near his bed.

More specifically, Ren regularly grabs his mom's hand to do things for him or uses her hand to point at what he wants. Yet, Ren also does initiate conversation and responds to his own name. During time with other children, Ren is reluctant to share and becomes emotional if his preferred toys are not in his possession. Ren's mom notes that she feels Ren can be "distant" but that he does respond to her kisses and hugs for soothing, even noting that Ren will initiate physical touch from her.

The family lives paycheck to paycheck. Sam, the father, works in construction and regularly gets work. However, his job does not allow for regular time at home. Anna, the mother, is the primary caregiver to Ren and she is now pregnant with her second child. Anna feels strained to care for Ren sometimes due to his size and difficulty communicating. Despite Anna being bilingual (Spanish and English), only English is spoken in the home.

Concurrent Problems (Treatments and Services Received)

Ren regularly sees his pediatrician. Ren is up-to-date on all of his vaccinations. Ren is rarely if ever sick per the mother. The pediatrician referred the family for a developmental assessment due to the lack of emotional reciprocity, deficits in verbal and nonverbal communication, repetitive interest in objects, and sensory hyperactivity to food textures and potentially touches. The pediatrician also referred Ren to a physical therapist for his gross- and fine-motor development to assist him in meeting his milestone of walking.

The parents were aware of this referral after Ren's 18-month-old developmental screening and routine well-child visit. However, they delayed seeing a counselor because they believed he would grow out of motor challenges and difficulty communicating. But now at his 5-year-old well-child care visit with the pediatrician, he is still experiencing challenges with his development. The pediatrician recommended that the mother and father take the child to a clinician who specializes in child development and consider also following up with an SLP depending on what the clinician recommended.

Background History and Stressors

The mother, Anna, reports that she had a normal pregnancy with Ren and that he was a full-term baby delivered vaginally. The mother reports that there were no complications at birth and that she started taking her prenatal vitamins as soon as she knew she was pregnant around month 2 of the pregnancy. Both mother and father report that they live in a suburban area not far from a large farming community. Anna, who was born in Mexico, grew up on a farm in the United States and regularly helped her parents who were migrant workers. Anna worries that she was exposed to large amounts of pesticides, but is unsure and tries to not think about this impacting her children. Sam grew up in an urban area and reports that he was also slow to walk and had difficulty in school, saying that he has dyslexia.

Sam believes nothing is wrong with his son and he believes that Anna worries too much and "babies" Ren due to her Mexican heritage. Anna identifies strongly with her Mexican heritage and regularly involves her family in the care of Ren. The family reports that they eat an "all-American" diet and love pizza and pasta and anything that is quick and easy. Anna reports that she knows she should eat healthy for herself and her children but doesn't know how and feels strained for time to prepare food. Anna feels very concerned about Ren's development and worries that he might be autistic after looking at the behaviors Ren exhibits online.

Strengths

Both Anna and Sam love their son Ren. They are eager to assist Ren and determine what is "going on" with him. Anna is open to improving her parenting and willing to do things to assist Ren. Both Anna and Sam are self-sufficient and report strong family support from grandparents and siblings. Sam shows resilience from his identified learning disorder and shows empathy for his son not yet walking.

DSM-5 Impressions and Implications

Autism Spectrum Disorder—requiring substantial support for restricted repetitive behavior, interests, and activities (level 2-moderate); requiring support for social communication and social interaction (level 1-mild); without accompanying intellectual impairment; with accompanying language impairment, speaks in simple sentences and regularly uses nonverbal sounds to communicate; associated with Developmental Coordination Disorder; without catatonia.

Relational Problems

The amount of care that Ren requires and Anna's pregnancy have resulted in increased verbal arguments between Anna and Sam. Anna feels overwhelmed and stressed. Sam is working extra to pay for recommended physical therapy and assessments with various clinicians, such as a counselor specializing in development and an SLP. It is noted that the family is eating a high gluten and casein diet. And the family may be exposing themselves to unknown environmental toxins.

Assessments

The recommended assessments for Ren and his parents could be numerous. Initially, a neurodevelopmental assessment should be completed involving an interview of the parents to gather detailed information about Ren and the family along with an observation of Ren. An Ages and Stages Questionnaire—Third Edition (ASQ-3; Squires & Bricker, 2009) and a Childhood Austim Rating Scale—Second Edition (CARS2; Schopler et al., 2010) are also recommended. Given that Ren is school aged, an assessment from a school psychologist would be requested based on the aforementioned assessments and findings. Depending on the outcome of the assessment from the school psychologist, an IEP would be initiated and followed by school personnel in contact with Ren.

Interventions

The suggested intervention would be PRT. Additional interventions are recommended by the physical therapist and SLP to be coordinated by parents via a parent-mediated intervention approach. The adjunctive services of nutrition and environmental wellness counseling are recommended as needed. The parents would also collaborate on the completion of the IEP and follow-up meetings with school personnel to ensure that school interventions are working well for Ren.

Ethical and Legal Implications

The required parental informed consent as outlined in Sections A.2.a and A.2.d of the ACA *Code of Ethics* and Standard 1.2 of the AAMFT *Code of Ethics* is to be discussed with the parents and child prior to the start of assessment and intervention. Also the counselor should review the limits of confidentiality per Sections B.1.d and B.5.c of the ACA *Code of Ethics* and Standard 2.1 of the AAMFT *Code of Ethics*. Given the likely collaboration between multiple clinicians and caregivers, releases of information should be completed to

coordinate services. How to disclose information to third parties is outlined in Section B.6.g of the ACA *Code of Ethics* and Standard 2.3 of the AAMFT *Code of Ethics*. It is also important to explain how IDEA and FERPA relate to Ren.

DISCUSSION

As you continue to reflect on the case study and the overall approach, contemplate these questions:

- How might you coordinate with the various service providers in this case, such as the pediatrician, physical therapist, SLP, and potential nutritionist?
- What recommendations would you make for the family as a sibling is born and becomes part of the family system?
- How would you build on the strength of Mexican family heritage in this family?
- What are the identified gender roles of this family and how do they impact the success of interventions chosen? How will you assist in reducing the stress of the parents and building parental wellness?
- What might be some values of this family and how might their value system impact treatment outcomes?

Ren is a 5-year-old male child with ASD. He also has the comorbid diagnosis of a Developmental Coordination Disorder given that he is slow to walk, struggles to run more than a few steps, and he is large with somewhat awkward gross motor movements. At this juncture, it is not believed that Ren has any intellectual deficits to constitute an intellectual disability. Ren's parents are actively involved in his life. Anna, his mother, is currently pregnant with her second child and still provides constant care and attention for Ren. Sam, his father, is understanding his delay in walking and is working extra to pay for the services Ren is currently in need of. The family is eager to understand what is going on with Ren and how to best assist him.

The family is open and honest in the sharing of all developmental and historical information as it relates to Ren. They are also willing participants in the observation of Ren in the home. Observed behaviors are repetitive vocalization, that is, grunting and fixation on certain toys and home objects. Ren also demonstrates minimal to no flexibility with food and textures of food. He is similarly sensitive to the textures of toys, preferring smooth to rough. Yet, Ren does provide eye contact with his parents and regularly seeks emotional comfort from the mom. His parents are attentive, but noticeably anxious and stressed in their desire to help.

After the completion of assessment, the family is eager to begin interventions to assist Ren and improve the wellness of the family. All persons involved is in agreement that PRT is the intervention to proceed with at this time. The family also agrees to pursue the pediatric recommendations of physical therapy (PT) and speech and language pathology (SLP) as well. The prognosis for this family is overall good, given the early diagnosis, willingness of the parents to participate in treatment, and the additional clinical services being provided.

SUMMARY

Neurodevelopmental disorders can appear throughout the life span, but they are characteristically associated with the developmental period or childhood. The onset of neurodevelopmental disorders is most commonly seen in childhood. Individuals with

neurodevelopmental disorders do not typically experience a remission or relapse, and the disorders are considered to be stable over the course of a lifetime. Given the onset of symptoms occurring in childhood, parents and families are also impacted and involved in the diagnostic and treatment process. Similarly, the value systems and culture of an individual can greatly impact the therapeutic course of neurodevelopmental disorders. Systemic clinicians must be aware of the legal and ethical implications of working with said families while also using evidence-based interventions that are relational in nature. The case illustration of Ren and his family highlights the importance of early intervention and family inclusion in treatment interventions and assessment.

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