Importance of Trauma-Informed Practice in Evaluation of Children Diagnosed with Autism Spectrum Disorder

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CASE: **As part of a multidisciplinary adoption support clinic, Erin, a 5-year-old girl, adopted approximately 6 months before the clinic visit, presents for postadoption evaluation. Erin was born at full term. Her birth history was significant for reported maternal treatment for liver failure during pregnancy. Her previous medical history included hospitalization for a viral illness at age 2 months, recurrent ear infections, and a fractured forearm. Family history was significant for a maternal history of bipolar disorder, depression, anxiety, borderline personality disorder, and concern for substance abuse; a paternal history of attention-deficit/hyperactivity disorder (ADHD) and depression; and full biological brother with a history of ADHD and oppositional defiant disorder. Erin and her brother lived with their parents until she was approximately 3 years old. At that time, there were concerns for poor hygiene, inconsistent medical care, poor school attendance for her brother, financial instability, and significant neglect. Erin was reportedly confined to her crib for hours at a time. She and her older brother were removed from the home because of concerns for significant neglect and placed into foster care. Approximately 3 months after foster placement, Erin underwent testing because of concerns for abnormal behaviors and possible developmental delays. Symptoms included poor sleep, repetitive behaviors such as head banging, delayed speech that primarily involved grunting, and lack of toilet training. She was hyperactive and aggressive and had poor caregiver attachment. On evaluation, she was small for age, poorly groomed, and easily distracted with poor eye contact and did not tolerate interactions with examiners. Neuropsychological testing consisted of symptom checklists and caregiver interview only because she did not tolerate diagnostic testing. She was diagnosed with autism spectrum disorder and global developmental delay with intellectual and language impairments. Over the following year, Erin was transitioned to a second foster family and was subsequently adopted. She received speech, occupational, and physical therapy, along with trauma-informed therapy. She made significant gains in multiple domains and was able to graduate from trauma-informed therapy after 1 year. On examination, Erin greets you with appropriate eye contact and reports that she is feeling "good." She is verbal and interactive with her brother and parents. She looks to parents for support when asked to participate in the physical examination. She does not display any significant repetitive behaviors. Erin's parents are concerned that her initial diagnoses of autism spectrum disorder and global developmental delay do not accurately reflect her current level of functioning and are afraid she may have been misdiagnosed. How would you proceed with next steps to address these diagnoses?**

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Autism spectrum disorder (ASD) is a developmental disorder characterized by impairments in social communication and the presence of restricted and repetitive behaviors and interests. Recent data suggest that the current prevalence in the United States is 1 in 54.[1] Accurate diagnosis of ASD is critical for families to gaining access to effective and timely interventions. Diagnosis of ASD involves multiple steps, including parent interview, standardized behavior rating scales, and diagnostic testing. However, obtaining an accurate diagnosis in the presence of comorbid psychiatric disorders can be challenging. Children with ASD are likely to have psychiatric comorbidities, including attention-deficit/hyperactivity disorder (ADHD), anxiety disorders, and depression.[2]

In addition to comorbid psychiatric disorders, children with ASD and other neurodevelopmental disorders may be at an increased risk of experiencing adverse or traumatic events, leading to diagnoses including reactive attachment disorder (RAD) and posttraumatic stress disorder (PTSD).[3] RAD is a trauma-related and stressor-related condition of early childhood caused by social

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neglect and maltreatment by a primary caregiver. It is characterized by reduced social engagement, comfort seeking, atypical response to comfort, and reduced social reciprocity with adult caregivers; reduced or absent positive effect; and unexplained fearfulness or irritability with caregivers. These symptoms result from experiences of social or emotional neglect or repeated caregiver transitions. Children with RAD have difficulty forming close emotional relationships with parents/caregivers.

Posttraumatic stress disorder is characterized by avoidance, negative alterations in cognition and mood, reactivity, and intrusion symptoms, which occur in response to traumatic experiences. Children with a history of early neglect and deprivation may display disturbances in social communication and other autism-like symptoms.[4] Behaviors displayed by children with a history of trauma and diagnosis of RAD or PTSD often overlap significantly with behaviors associated with ASD, making it challenging to obtain an accurate diagnosis.

A limited number of studies suggest an overlap between ASD and RAD/PTSD.[5] Some children with ASD who have experienced trauma may not display significant changes in mood or reactivity, whereas others may display significant differences in behavior after relatively minor changes in routine, making it difficult to identify unreported trauma in these children. Some have hypothesized that the diagnosis of ASD may increase the risk of trauma,[5] because children with ASD are often more vulnerable to changes in environment and routine, and parents of children with ASD report higher levels of stress.

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Annually, over 400,000 children in the United States experience out-of-home care placement or foster care.[1] Most children come into the foster care system after enduring trauma in the form of abuse or neglect. Based on research from Adverse Childhood Experiences studies, we know that experiences of childhood trauma, such as abuse and neglect, can be directly linked to future health conditions, such as depression, anxiety, heart disease, and cancer.[2] The American Academy of Pediatrics Task Force on Foster Care identified that children in foster care can have a higher prevalence of physical, developmental, dental, and behavioral health conditions. Specifically, more than 80% of children in foster care are diagnosed with developmental, educational, and emotional problems.[3]

Foster care is meant to be only a temporary living situation, with the goal for permanent placement for a child through parent reunification, adoption, legal guardianship, or kinship placement. Although foster care is meant to be only temporary, the average length of placement is nearly 20 months. If we look just at children who are waiting to be adopted from foster care, 54% of children are in foster care for over 2 years before being adopted.[4] In addition, over one-third of children in foster care will find themselves in 2 to 3 foster care placements, so the 2 to 3 years that they are in the foster care system are likely to be continually disrupted with transitions of care.

Children in foster care have higher rates of various health issues (physical, developmental, or behavioral) and are more likely to not have a well-established health care home or primary care clinician. Without good continuity of care, they are at higher risk for delayed diagnosis or misdiagnosis of ongoing health issues. Although some medical conditions can be diagnosed through more objective means, such as a blood test or imaging study, developmental disorders such as autism spectrum disorder rely on a compilation of information—parent/caregiver interview, standardized behavior rating scales, and diagnostic testing. In the context of foster care, which often lacks caregiver continuity, this leads to a situation in which a diagnostic professional must rely on limited or lacking information. On the other hand, we do know that early diagnosis and intervention can increase potential positive outcomes for a child with a developmental disorder and, in the context of a child in foster care, will likely improve their chances at a successful permanent placement, either through reunification or through adoption/guardianship. This can leave the diagnostic professional in a tricky situation, weighing incomplete information that may render a diagnosis less definitive versus withholding a diagnosis that may help the child gain access to the needed services and resources that could improve success with caregiver permanency.

This case helps highlight that it is important to see a diagnosis in the context of the larger picture. For the initial diagnostic professional, the behaviors and symptoms exhibited must be considered in the context of the child's environment and lived experiences. Then, for subsequent professionals, there should be ongoing critical evaluation of whether the diagnosis continues to meet criteria or whether, with changed circumstances,

previous behaviors can be better explained by severe neglect and trauma.

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This case demonstrates the complexity of accurately differentiating between symptoms of trauma and symptoms of autism spectrum disorder (ASD) in young children. Young children with psychological disorders are difficult to accurately diagnose because they are unable to describe their own thoughts, feelings, and behaviors. When evaluating a child to determine whether behaviors are due to ASD or some other cause, establishing a timeline of current behaviors through a parent interview and chart review is essential. Clinicians should assess for changes in functioning rather than the presence or absence of symptoms at the current evaluation. Children with ASD most likely have not met developmental milestones related to appropriate social initiation throughout life and are often observed either to be disinterested in social interactions or to have marked difficulty with age-appropriate social behavior. Children with reactive attachment disorder (RAD) or post-traumatic stress disorder (PTSD) display reductions in social-emotional skills at the onset of trauma exposure and increases in those skills after placement into supportive environments. However, this sort of interviewing may be particularly difficult to do in cases of adoption or multiple caregiver transitions. For example, in the current case, it was challenging to establish a timeline because of lack of a consistent caregiver history and her insufficient medical care. The child was previously diagnosed with ASD based on an interview with the current foster parent and a symptom checklist. She was also unable to tolerate evaluation using standardized tests to evaluate current functioning. Although there were no documented behavioral changes, the child's long-standing history of neglect and trauma, along with a limited history before foster care placement, made it particularly difficult to differentiate symptoms of trauma and attachment difficulties from symptoms of ASD.

Despite the overlap in symptoms between RAD, PTSD, and ASD, the recommended treatments for each diagnosis are very different. For ASD, interventions often focus on increasing social communication skills and decreasing problematic behaviors through behavioral-oriented parenting strategies such as those taught through applied behavior analysis programs.[1] For PTSD, treatments include trauma-focused cognitive behavioral therapy for children that focuses on psychoeducation around trauma reactions, relaxation, improving the attachment relationships, and desensitization strategies.[2] For RAD, treatments that focus on developing parent sensitivity to a child's signals and needs include programs such as Child-Parent Psychotherapy[3] and parent educational programs such as Circle of Security.[4]

Children with co-occurring trauma and ASD should participate in trauma-informed therapies adapted for those with ASD.[5] Furthermore, until traumatic circumstances are resolved and children undergo trauma-informed services that focus on establishing warm, supportive, and responsive relationships, clinicians should hesitate to provide ASD diagnoses for young children. Continued evaluation of the patient after undergoing treatment can help track whether children in supportive caregiving environments and receiving targeted therapies are seeing rapid reductions in socioemotional difficulties. If children do meet the criteria for both diagnoses, they will likely have a significantly more difficult time following parent directives and learning more nuanced social communication skills that are targeted in ASD therapies without first addressing trauma responses. In the current case, it was only after receiving significant support, living in a nurturing home environment, and getting trauma-informed therapies that the child was able to show marked improvements in growth and socioemotional development, indicating that her initial diagnosis may have been due to neglect and trauma rather than due to ASD.

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The phenomenon of "moving off the spectrum" is one often asked about by families sometimes on the day a diagnosis is made. In the past 2 decades, as the prevalence of autism spectrum disorder (ASD) has increased, this phenomenon has also increased. Research focused on the stability of the clinical ASD diagnosis has suggested that moving off the spectrum may be the product of maturation, intervention, or overdiagnosis at an early age.[1] A recent study used a probability-based national survey to compare currently diagnosed and previously diagnosed children (1420 vs 187) examining several factors. Approximately 13% of the children ever diagnosed with ASD were estimated to have lost the diagnosis, and parents of 74% of them believe it was changed because of new information.[2] This patient reminds us of the critical importance of always looking at the patient, not the diagnosis in front of us when determining the next step in care.

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