

Judicial Spectrum Primer: What Judges Need to Know About Children with Autism Spectrum Disorders

By Sheryl Dicker and Robert Marion

Ricky's Story*

In the summer of 2010, a young mother called 911 after finding her 1-year-old daughter blue and not breathing. She was distraught when the police and emergency medical service arrived. After the police discovered that her 2-year-old son, Ricky, had smothered the little girl, Child Protective Services (CPS) was called and Ricky and his brother, Eddie, age 5, were taken into emergency foster care and placed with their grandmother.

The mother and father were arrested for child endangerment. CPS then moved to get a court order keeping both boys in foster care. The motion was granted after the judge found the boys in imminent risk of harm; the judge also ordered an immediate multidisciplinary evaluation (MDE) of both boys by the local early childhood center that has expertise in mental health and developmental disabilities of young children.

Two days later, the boys were evaluated at the early childhood center. Eddie was found to be a normal kindergartener, but counseling was recommended to help him manage the death of his sibling. In the meantime, Ricky was in the waiting room with his grandmother. He was silently walking in circles, and did not respond to his name or anything else his grandmother said, or take any interest in the other children or toys. The evaluators determined that he had autism spectrum disorder (ASD) and immediately referred him for Early Intervention (EI).

Ricky was, however, already receiving EI for speech delay. The evaluator urged the EI service coordinator to get Ricky into a specialized autism program immediately. Ricky was soon admitted to a day autism program and received Applied Behavior Analysis (ABA) therapy along with Occupational and Speech Therapy. His grandmother also received training.

* Names of children in Ricky's Story have been changed.

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Based on the MDE's findings and evaluations, the criminal charges against the parents were dropped. The Family Court reviewed the case and kept the boys with their grandmother in kinship foster care for six months so that Ricky could receive all the services he needed. Ricky and his brother were then sent home to their parents. Ricky continues to receive intensive ASD services, and the family receives counseling.

INTRODUCTION

Ricky's story is a real Family Court case. Although most cases involving ASD may not be as dramatic, the growing prevalence of ASD—1 in 88 children¹—may signify Ricky's case as a harbinger of the future for juvenile and family courts. His case underscores the importance of early identification of ASD, and demonstrates the necessity for judges to understand the disorder as well as seeking and getting expert recommendations to allow for meaningful decision making.

This article aims to provide information to juvenile and family court judges to help them make effective decisions concerning children with ASD. Part I, written by a pediatrician and geneticist, will present an overview of medical knowledge concerning ASD, including its prevalence, how ASD is diagnosed, and its treatment and prognosis. Part II will review the federal cases involving ASD, with an emphasis on those involving the Individuals with Disabilities Education Act (IDEA), because it will help judges craft orders for services. Part III will provide an in-depth look at the few published appellate family law cases involving children with ASD, and will apply the medical and legal information to issues that have or may arise in child protection, custody, visitation, juvenile delinquency, and child support cases. Finally, the Appendix contains resources including a checklist that can help courts gather information to assist in tailoring court orders and rendering decisions on ASD cases.

I. OVERVIEW OF MEDICAL KNOWLEDGE CONCERNING CHILDREN WITH ASD

ASD affects entire families. Ricky's case demonstrates that ASD profoundly affects the individual with the disorder; the lives of his parents, who often find themselves unprepared to care for a child with such complex needs; his siblings, who have to live with their brother's ASD; the extended family, who must support the nuclear family; and the entire community, which has to provide for the special needs of the child with ASD. Although in the past, ASD was considered rare and relatively unimportant, the recent explosive rise in the prevalence of ASD has turned the condition into one of the most common intellectual and behavioral disabilities in the United States.² Thus, anyone

¹ See CTRS. FOR DISEASE CONTROL & PREVENTION, AUTISM SPECTRUM DISORDERS: DATA & STATISTICS, (March 29, 2012), http://www.cdc.gov/ncbddd/autism/data.html#prevalence. ("About 1 in 88 children has been identified with an autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network").

² Catherine Rice et al., Prevalence of Autism Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 58(SS10) MMWR 1-20 (2006).

working with and supporting children must have a solid understanding of ASD. In this section, we will summarize the medical, developmental, and behavioral aspects of this related group of disorders.³

ASD is not a single disorder, but a group of disorders, each of which has a different etiology with overlapping features.⁴ As in other "spectrum disorders" such as fetal alcohol spectrum disorder, individuals affected with ASD vary greatly in their symptoms. At one end of the spectrum, a child with autism may have a severe intellectual disability, unable to speak or communicate in any way with the outside world—essentially locked into a world of his or her own; such a child will likely need life-long care. At the other end of the spectrum, a child may have some unusual behavioral features, such as difficulty relating to those around him, unusual use of language or other communication systems, and the tendency to perform repetitive activities, such as hand flapping. This child will likely be able to live independently, hold a job, and become a functioning member of society. However, most children who are "on the autism spectrum" will fall somewhere between these two extremes.

In addition to the wide range of severity that occurs in the autism spectrum, a number of different conditions, such as Asperger's syndrome and Pervasive Developmental Disorders, are currently included under the ASD banner.⁵ And, to make it even more confusing, the labels frequently change. For instance, the new draft Diagnostic and Statistical Manual of Mental Disorders (DSM), currently being prepared, will place all conditions under the single umbrella diagnosis—ASD.

For reasons that are still unknown, the prevalence of ASD has increased dramatically over the past half century, and seems to be continuing to increase. Occurring in 1 in 2,000 children in the 1960s, the condition was considered rare. By 2012, its prevalence in the U.S. was reportedly averaged to be 1 in 88 children.⁶

3 A note on nomenclature: Because of trends in the field of developmental disabilities, certain terms, once widely used, have been replaced by other, more appropriate ones. First, the term "mental retardation," once a stalwart descriptor in this field, has in recent years been judged to be hurtful to individuals who have low IQs. In its place, the terms "intellectual disability" or "developmental disability" will be used here. In addition, the development of children should not be assessed as "normal" or "abnormal," as these terms imply a negative or positive judgment. Rather, the terms "typical development" or "atypical development" are more appropriate and will be used in this article. Also, although we use the "person-first" model of referring to individuals with an ASD (in other words, referring to a "child with autism," rather than an "autistic child"), it should be noted that this issue has been debated in the autism community.

4 Hannah Gardener et al., Perinatal and Neonatal Risk Factors for Autism: A Comprehensive Meta-Analysis, 128 PEDIATRICS 1036 (2011).

5 These disorders, each of which has its own ICD-9 code (for "International Statistical Classification of Diseases and Related Health Problems," a system for classifying diseases for purposes of billing, among other things), include: infantile or primary autism, in which the child fulfills all the criteria described in the section on diagnosis below (ICD-9 299.0); pervasive developmental disorder not otherwise specified (PDD NOS), in which one of the essential criteria for the diagnosis of autism is not met (ICD-9 299.9); and Asperger's syndrome, a term usually reserved for those individuals with higher IQs and typical language development, but who have significant impairments in social interaction and range of interests and activities, (ICD-9 299.8). In addition, individual genetic disorders, such as Rett and fragile X syndromes, are known to have features of autism as part of their symptom complex. As such, these are also included under the heading of ASD, described as "secondary autism."

6 See AUTISM SPECTRUM DISORDERS, *supra* note 1 (ASD has a male : female ratio of approximately 4:1); Rice et al., *supra* note 2; Young Shin Kim, *Prevalence of Autism Spectrum Disorders in a Total Population Sample*, 46 PSYCHIATRY 7 (2011) (A recent study from a district of Goyang City, South Korea between 2005 and 2009 noted that 2.64% of children (or 1 in 38) between the ages of 7 and 12 had ASD).

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What could account for this rapid rise in prevalence? First, the definition of autism has changed over the past 50 years, making more children "eligible" for the diagnosis.⁷ Second, over the past 10 years, efforts have been made to educate not only parents but also professionals who work with young children, particularly pediatricians, about early warning signs of ASD; through this improved education, more children are being evaluated and diagnosed for ASD.⁸ These factors, however, cannot alone account for the striking increase in prevalence of ASD.

Other factors, as yet unidentified, appear to be contributing to this phenomenon.

What Exactly Is Autism?

Autism is a *complex developmental and behavioral disorder* that *begins in early childhood*. In order for a diagnosis of autism to be made, the child must demonstrate, before age three, abnormalities in three core areas:

(1) *Problems with social interactions:* inability to connect with other people. The term "autism" was coined by Leo Kanner, M.D. in 1943 from the Greek *autos*, meaning *self*, owing to the withdrawn and solitary nature of the children he described.⁹ In his seminal article, Kanner provided an outstanding summary of the condition in his description of 5-year-old Donald:

"He wandered about smiling, making stereotyped movements with his fingers, crossing them about in the air. He shook his head from side to side, whispering or humming the same three-note tune constantly. He spun with great pleasure anything he could seize upon to spin. When he was taken into a room he completely disregarded the people and instantly went into objects, preferably those that could spin. He angrily shoved away the hand which was in the way...."¹⁰

- (2) *Impaired verbal and nonverbal communication:* Delays in speech and other forms of communications often keep these children isolated in their own world.
- (3) A pattern of repetitive behavior with narrow, restricted interests: As Dr. Kanner described, children with ASD will perform repetitive activities, such as hand flapping, spinning in circles, etc. These behaviors are called "stereotypies."¹¹

Children with ASD often have other features beyond the three core areas. They often manifest hyper- and hyposensitivity to sound and touch, and respond adversely to

⁷ Catherine Lord & Somer L. Bishop, Autism Spectrum Disorders: Diagnosis, Prevalence, and Services for Children and Families, 24 SOCIAL POLICY REPORT 1, 5 (2010).

⁸ Comm. on Children with Disabilities, The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children, 107 PEDIATRICS 1221 (2001).

⁹ Leo Kanner, Autistic Disturbances of Affective Contact, 2 NERV CHILD 217 (1943).

¹⁰ Id. at 219.

¹¹ Lord & Bishop, *supra* note 7 at 4; Stereotypies are constant repetitive gestures or movements lacking any meaning and are characteristic behaviors of children with ASD.

loud noises and to the touch of their mothers or other family members.¹² They experience disturbances of motor functioning, including tight heel cords in their ankles, which leads to the tendency to toe-walk.¹³ They may manifest odd behaviors around food, involving the need to smell all items, responding adversely to different textures, and vomiting or having diarrhea.¹⁴ More than 50% of children with ASD manifest abnormal sleeping patterns,¹⁵ showing little or no diurnal rhythm, which causes them to sleep odd hours during the day or night, remaining awake for long periods of time. The abnormal sleep pattern, coupled with their disregard for danger and their tendency toward self-injurious behavior, will require a parent or other family member to remain awake with them, supervising the child's activities at all hours of the day and night.

Approximately 25% of children with ASD will experience developmental regression;¹⁶ that is, after having attained a developmental milestone, they will lose their ability to perform that task. This loss is especially striking with speech: children who have gained the ability to say "Mama" and "Dada" and one or two other words will suddenly lose their ability to speak. *The loss of a milestone should always trigger concern that a child is affected with ASD and should lead to a developmental evaluation as soon as possible.*

How Is ASD Diagnosed?

Because ASD is a complex of symptoms resulting from a large number of pathologic processes, there is no one test to determine whether a child has autism. Rather, the diagnosis is based on a review of the child's history, including age at achievement of developmental milestones, observing the child's behavior and functioning, and the child's performance on one or more screening tests. The diagnosis should only be made after an MDE performed by professionals trained to identify the features of ASD.¹⁷

But how does the child get to this battery of professionals? From early in life, children should be routinely screened for developmental milestones by their primary health care providers.¹⁸ For example, the child should:

- Babble by the age of one year;
- Point for items he or she wants by the age of one year;
- Say three or more single words by 15 months;
- Say two word phrases ("Go out!" "Bye-bye") by two years.

Failure to reach these milestones, or regression of any previously gained milestone, should cause the health provider to order a hearing test (since hearing loss is a common and

12 Chris Plauche Johnson, Scott M. Myers, & Council on Children with Disabilities, Identification and Evaluation of Children with Autism Spectrum Disorders, 120 PEDIATRICS 1183, 1194 (2007).
13 Id. at 1193.
14 Id. at 1194.
15 Id.
16 Id. at 1192.
17 Id. at 1202.
18 Id. at 1195.

treatable cause of delayed speech), a blood test for lead (lead poisoning can result in delay in these and other areas), and other developmental screening tests, such as the CHAT (Checklist for Autism in Toddlers).¹⁹ If ASD is suspected on the basis of these screening tests, the child should be referred for an MDE.

A professional experienced in diagnosing ASD should always be involved in making the diagnosis. The professional could be a developmental-behavioral pediatrician, a child neurologist, a child psychiatrist, or a neuropsychologist. After the child's medical and family histories are obtained and a physical exam is performed, a professional who suspects ASD can direct one or more autism-specific screening tests, which include:

- The Childhood Autism Rating Scale (CARS),²⁰ which rates children on a scale of 1 to 4 for 15 criteria, yielding a composite score that places the child in one of four categories: non-autistic; mildly autistic; moderately autistic; or severely autistic. The CARS is accurate, quick, and easy to perform.
- The Autism Diagnostic Interview—Revised (ADI-R),²¹ which is a structured interview performed with parents of a child in whom the diagnosis of autism is being considered. It consists of 93 questions in three major domains. Although highly accurate, the test is long and somewhat laborious to perform.
- The Autism Diagnostic Observation Schedule (ADOS)²² is the "gold standard" test for confirming the diagnosis of ASD. It consists of a series of tasks that involve social interaction between the examiner and the subject. The interactions are observed by the examiner, who assigns a score to each; research-determined cut-offs identify the potential diagnosis of ASD. The ADOS is accurate, but time consuming.

If a child is diagnosed with ASD, he or she may undergo genetic testing to identify an etiology for the disorder. Such testing would be performed by a medical geneticist, one of the many members who compose the multidisciplinary team that cares for children with ASD.

What Causes Autism?

There is no single answer to the question "What causes autism?" Because ASD is a group of conditions whose features overlap and whose etiologies differ for each child, the etiologies also represent a spectrum, ranging from those that are purely genetic to those

22 Catherine Lord et al., The Autism Diagnostic Observation Schedule-Generic: A Standard Measure of Social and Communication Deficits Associated with the Spectrum of Autism, 30 JOURNAL OF AUTISM AND DEVEL-OPMENTAL DISORDERS 205 (2000).

¹⁹ Id. at 1202-03.

²⁰ David L. DiLalla & Sally J. Rogers, *Domains of the Childbood Autism Rating Scale: Relevance for Diagnosis and Treatment*, 24 JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS 115 (1994).

²¹ Catherine Lord et al., The Autism Diagnostic Interview-Revised: A Revised Version of a Diagnostic Interview for Caregivers of Individuals with Possible Pervasive Developmental Disorders, 24 JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS 659 (1994).

that are largely environmental. Generally, ASD is caused by an interplay between genetic factors and environmental factors.²³

For example, recent studies have demonstrated that genetic factors, not bad parenting, play an important role in the etiology of ASD.²⁴ In some cases, the cause is purely genetic: this is the case with a number of relatively rare genetic syndromes in which autism is one of the features.

At the other end of the spectrum are children whose ASD is caused largely by exposure to environmental pathogens, drugs, chemicals, or biological agents that in some way damage the central nervous system before birth or very early in life. Examples include viruses such as Rubella ("German measles") which can infect the fetus during intrauterine life, leading to a series of adverse effects, including ASD. Other teratogenic ("birth defects-causing") agents that can lead to ASD in exposed fetuses include certain medications, such as Valproic Acid (an anticonvulsant).²⁵ Prenatal environmental agents, however, only account for a small number of the total ASD cases.²⁶

It is believed that post-natal exposure to environmental pathogens plays an important role in the etiology of ASD, but there is less certainty which agents may be responsible. One thing is certain, however: childhood immunizations, which may include thimerosal or methyl mercury, have *not* been shown to play a role in causing ASD, despite the media attention.

The "myth" that childhood immunizations are responsible for autism can be traced to an article written by Andrew Wakefield and published in the journal *The Lancet* in 1998.²⁷ Wakefield and his colleagues established an association between autism and the measles, mumps, and rubella vaccine, which at that time was given to all 15-month-olds. The article received a tremendous amount of media attention and resulted in parents refusing to allow their children to be immunized.

Other researchers tried but failed to duplicate Wakefield's findings, and in January 2010, the five-member statutory tribunal of the British General Medical Council concluded that Wakefield and his colleagues had committed four counts of dishonesty and 12 counts involving the abuse of developmentally challenged children.²⁸ As a result, the article was retracted by *Lancet*, and Dr. Wakefield lost his license to practice medicine.²⁹

23 Gardener et al., supra note 4.

24 Lord & Bishop, supra note 7.

25 Jennifer L. Ingram et al., Prenatal Exposure of Rats to Valproic Acid Reproduces the Cerebellar Anomalies Associated With Autism, 22 NEUROTOXICOLOGY AND TERATOLOGY 319 (2000).

26 Deborah Bilder et al., Prenatal, Perinatal, and Neonatal Factors Associated with Autism Spectrum Disorders, 123 PEDIATRICS 1293 (2009).

27 Andrew Wakefield et al., Ileal-lymphoid-nodular Hyperplasia, Non-specific Colitis, and Pervasive Developmental Disorder in Children, 352 LANCET 234 (1998).

28 General Medical Council, Fitness to Practice Panel Hearing (Jan. 28, 2010), available at http://briandeer.com/solved/gmc-charge-sheet.pdf.

29 Retraction—Ileal-Lymphoid-Nodular Hyperplasia, Non-specific Colitis, and Pervasive Developmental Disorder in Children, THE LANCET (Feb. 2, 2010), http://download.thelancet.com/ flatcontentassets/pdfs/S0140673610601754.pdf; *see also* Scott Hensley, Lancet Renounces Study Linking Autism and Vaccines, Nat'l Pub. Radio (Feb. 2, 2010, 12:25 PM), http://www.npr.org/blogs/health/2010/ 02/lancet_wakefield_autism_mmr_au.html.

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The Wakefield debacle created huge problems. Not only did parents react to it and refuse to inoculate their children, leaving them vulnerable to the adverse effects of infectious diseases that had nearly been eliminated, it set back autism research because professionals conducting research had to backtrack to prove that immunizations did not cause harm. Moreover, lawsuits proliferated claiming that pediatricians and the companies that made and marketed immunizations were responsible for individual ASD cases. These lawsuits led to the creation of the "Vaccine Court," within the federal Court of Claims by Congress. In every case except one, which is still on appeal, the court determined that there was not proof that the childhood immunization caused the autism.³⁰ Instead of working toward identifying causes and treatments, researchers lost valuable time and expended valuable resources to disprove a fraudulent finding. The damage continues to this day: fueled by media reports, some families continue to believe that immunizations cause damage and refuse to permit their children to be immunized against serious childhood diseases.³¹

In addition, other controversial post-natal environmental agents have been implicated as causes of these disorders. During the past 10 years, large-screen televisions and TV watching in general, cell phones, and even sunlight have been implicated. No large-scale epidemiologic studies have yet borne out an association between any of these agents and autism.³²

It has become clear in recent years that one's genetic background plays a major role in the etiology of most ASD cases. Genome-wide association studies have identified numerous sites throughout the human genome at which variations confer an increased susceptibility to the development of autism. Studies involving twins have shown that identical twins, who have identical DNA, are more likely to be concordant for autism than are fraternal twins, who, like other siblings, share only 50% of their genetic material. And epidemiologic studies reveal that in families where one child has ASD, the second child has an increased risk 4 to 8 times greater than the general population.³³ Consequently, it is generally believed that autism is caused by one or more environmental influences at work in an individual who possesses a genetic predisposition to developing autism. It is hoped that future research will better identify the specific genetic and environmental causes in order to develop personalized treatments.

What Are the Possible Treatments for ASD?

There is no cure for ASD. Some treatments, however, have been shown to be effective in lessening ASD's symptoms and improving the long-term prognosis in indi-

32 Michael Waldman et al., *Does Television Cause Autism?*, NATIONAL BUREAU OF ECONOMIC RESEARCH (2006), *available at* http://www.nber.org/papers/w12632.

³⁰ Snyder ex rel. Snyder v. Sec'y of Health & Human Servs., 88 Fed. Cl. 706, 741 (Aug. 11, 2009); *see also* Thomas H. Maugh II & Andrew Zajac, "Vaccines Court" Rejects Mercury-Autism Link in 3 Test Cases, L.A. TIMES, March 13, 2010, *available at* http://articles.latimes.com/2010/mar/13/science/la-sci-autism13-2010mar13.

³¹ Interagency Autism Coordinating Comm., Dep't of Health & Human Servs., 2010 Strategic Plan for Autism Spectrum Disorder Research 1 (Jan. 2010) [hereinafter IACC Strategic Plan], *available at* http://www.iacc.hhs.gov/strategic-plan/2010/IACC_2010_Strategic_Plan.pdf.

³³ Johnson et al., supra note 12 at 1187.

vidual children. In medicine, we speak of evidence-based treatments, therapies that in controlled studies have shown efficacy in improving outcomes. Because the number of evidence-based therapies is small and ASD manifestations are often so disabling, many families turn to treatments touted to be effective, even though no evidence of efficacy exists. The evidence is clear that early diagnosis and referral to an appropriate early intervention (EI) treatment program is the most effective way to lessen ASD's severity, providing the best chance of improving long-term prognosis.³⁴

The goal of an EI program is to provide the child with services appropriate to that child's needs. Most EI programs provide physical (PT), occupational (OT), and speech and language therapy (SLT), in addition to special instruction and other services and build on the child's interests to provide a highly structured program of activities. EI programs can be home-based (usually for younger children) or center-based (for those older than two years). The center-based programs are helpful because children get to interact with others, offering them an opportunity to improve their social skills.

In addition to OT, PT, SLT, and special instruction, Applied Behavioral Analysis (ABA) has been found to be an effective therapy.³⁵ ABA uses an intense, one-on-one teaching approach to reinforce the child's ability to perform various skills improving his or her functioning in these areas. Usually performed by a behavioral psychologist in the home, ABA requires long hours and is currently very expensive. ABA, however, has been found to be effective in controlled studies, and the benefit to the child's long-term functioning justifies the expense and hard work.

To manage behavioral disturbances, many children with ASD are treated with medication. Specifically, the children frequently manifest aggression, anxiety, extreme compulsions, hyperactivity with attention problems, tantrums, and other behavioral problems that often prevent them from being able to join in activities. Risperidone³⁶ is currently the only medication approved for use in treatment of aggression and irritability in children with ASD between the ages of 5 and 16, but other medications, such as methylphenidate (Ritalin) and mood stabilizers, have been effective in treating hyperactivity and other behavioral problems.³⁷

Aside from these treatments, no other therapies have been shown to be effective in improving functioning or long-term outcome in children with ASD. For example, there is no evidence that sensory integration, vision therapy, diet modification, secret in therapy (an enzyme used for chronic diarrhea), chelation (treatment to remove toxic heavy metals

³⁴ Zachary Warren et al., A Systematic Review of Early Intensive Intervention for Autism Spectrum Disorders, 127 PEDIATRICS 1303 (2011).

³⁵ Geraldine Dawson et al., *Randomized, Controlled Trial of an Intervention for Toddlers with Autism: The Early Start Denver Model*, 125 PEDIATRICS e17, e18, e22 (January 2010) (reporting that the Early Start Denver Model was more effective with toddlers than other interventions available in the community).

³⁶ Christopher J. McDougle et al., Risperidone for the Core Symptom Domains of Autism: Results from the Study by the Autism Network of Research Units on Pediatric Psychopharmacology, 162 PSYCHIATRY 1142 (2005).

³⁷ Research Units on Pediatric Psychopharmacology Autism Network, *Randomized, Controlled, Crossover Trial of Methylphenidate in Pervasive Developmental Disorders With Hyperactivity*, 62 GENERAL PSY-CHIATRY 1266 (2005).

such as lead from the body), hyperbaric oxygen, vitamin supplementation, and antifungal medications are useful.³⁸ It is important to stress that treatments must be tailored to the needs of the individual child.

II. REVIEW OF MAJORITY OF ASD CASE LAW

Federal courts have been impacted by the high prevalence of ASD. Parents have filed thousands of cases alleging that immunizations caused a child's ASD under the National Childhood Vaccine Injury Act (NCVIA).³⁹ The Special Masters assigned to the "Vaccine Court" have found no scientific or legal causal link between the immunization and the injury of ASD. State courts have also seen the cases and had to transfer them to the Vaccine Court. State courts have also had to deal with the anger triggered by the controversy in divorce or custody proceedings, especially since immunizations are required by law,⁴⁰ where a juvenile or family court orders the child to be vaccinated or appoints one parent as the medical decision maker.⁴¹

In addition to the Vaccine Court cases, there are the cases filed under the Individuals with Disabilities Education Act (IDEA) which address issues such as a child's eligibility for services, the nature and location of services, and funding. Juvenile and family court judges must understand these precedents to shape decisions that may arise concerning services for children with ASD in a range of family law cases as well as the need for insurance considerations in divorce proceedings.

Children With ASD Under IDEA

The words autism or ASD do not appear in the 1975 Education for All Handicapped Children's Act (EHA)⁴² or in its 1986 amendments that established the Early Intervention Program for infants and toddlers and the pre-school special education program for children ages 3-5.⁴³ It was not until 1990 that the word "autism" first appeared in the federal law that guarantees all children with a handicapping condition a "free appropriate

38 Susan Levy & Susan Hyman, Complementary and Alternative Medicine Treatments for Children with Autism Spectrum Disorders, 17 CHILD ADOLESCENT PSYCHIATRIC CLINICS OF NORTH AMERICA 803 (2008); Manya Angley et al., Children and Autism—Part 2—Management With Complementary Medicines and Dietary Interventions, 36 AUSTRALIAN FAMILY PHYSICIAN 827 (2007); Patricia Rao et al., Social Skills Intervention for Children with Asperger's Syndrome or Higb-Functioning Autism: A Review of Recommendations, 38 JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS 353 (2008); Meryl Schechtman, Scientifically Unsupported Therapies in the Treatment of Young Children with Autism Spectrum Disorders, 36 PEDIATRIC ANNALS 497 (2007).

39 Pub. L. No. 99-660, 100 Stat. 3755 (codified as amended at 42 U.S.C. § 300aa).

40 Angie A. Welborn et al., Mandatory Vaccinations: Precedent and Current Laws (2005), http://www.fas.org/sgp/crs/RS21414.pdf.

41 Martocchio v. Savior, No. TTDFA064006261, 2008 WL 3853514, at *5 (Conn. Super. Ct. July 28, 2008).

42 Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 (codified as amended in scattered sections of 20 U.S.C.).

43 Education of the Handicapped Act Amendments of 1986, Pub. L. No. 99-457, 11 Stat. 1145 (1986).

public education (FAPE)."⁴⁴ To qualify for IDEA services prior to 1990, children with ASD were given other labels such as "severely emotionally disturbed" or "otherwise health impaired."⁴⁵ In recognition of its increasing prevalence, autism was listed as one of the disorders categorized under the term "children with disabilities" in the 1990 EHA reauthorization⁴⁶ (renamed the Individuals with Disabilities Education Act, or IDEA).⁴⁷ The subsequent regulations define autism as a developmental disability significantly affecting verbal and nonverbal communication and social interaction, often characterized by repetitive and stereotyped activities, resistance to change, and unusual responses to sensory experience that adversely affects a child's educational performance.⁴⁸ The regulations clearly provide that autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance.⁴⁹

The 1994 DSM-IV definition, by contrast, provided a more in-depth description of the various behaviors a child with autism must exhibit by age three and does not focus on educational deficits, nor does it exclude children with primary emotional disturbance.⁵⁰ The court decisions, however, unanimously hold that the statutory IDEA definition, not the DSM-IV definition, must be used to obtain an autism classification in order to receive necessary services. Thus, when faced with the issue, juvenile and family court judges must order that the professionals evaluating children between 3-21 have familiarity with the IDEA definition, as well as ASD expertise, to ensure that the children will receive the services they are entitled to under the law.

Services Required Under IDEA

The Supreme Court, in *Board of Education v. Rowley*, determined that, in accordance with the IDEA, a child's required Individualized Educational Plan (IEP) needs to be reasonably calculated to provide only some educational benefits to the child.⁵¹ The decision, consequently, is the basis that most courts use to reject parents' proposals for their child with ASD to get the "best" program or the program that will "maximize their child's potential.⁵²

The *Rowley* definition limits the services that the IDEA guarantees children with ASD. Most controversy in the courts has involved a child's entitlement to Applied Behavioral Analysis (ABA), one of the few evidence-based treatments. Many courts have held that a child is not necessarily entitled to an ABA program even when parents can

44 Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476, § 101(a)(1), 104 Stat. 1103, 1103.

45 Edith Fairman Cooper, Cong. Research Serv., 77-227 SP, Autistic Children: Background Information and Legislative Concern 3, 19 (1977).

46 Education of the Handicapped Act Amendments of 1990, supra note 44.

47 Id. § 901(a)(1), 104 Stat. at 1142.

48 Assistance to States for the Education of Children with Disabilities, 34, C.F.R. § 300.8(c)(1)(i)

49 Id. § 300.8(c)(1)(ii).

(2006).

 $50\,$ Am. Psychiatric Ass'n, Diagnostic and Statistical Manual of Mental Disorders 75 (4th ed. 2000).

51 Bd. of Educ. v. Rowley, 458 U.S. 176, 207 (1982). 52 Id. at 198.

prove the effectiveness of this program for their child if the school provides an alternative that gives the child some meaningful benefit.⁵³ For example, in J.P. ex rel. Popson v. West Clark Community Schools, the parents and the school district strongly disagreed about the importance of ABA therapy to J.P.'s specific needs.⁵⁴ J.P. had a severe case of ASD and at age two was not using any words, did not exhibit any non-verbal communication, and did not engage in any appropriate play for a child his age.⁵⁵ Even though the district offered ABA, district officials believed a combination of various services would better suit the child's needs, while the family saw ABA as their child's only hope.⁵⁶ The court found for the school district and held that since the provided services were approved by experts and school staff the district was not required to implement the parents' desired program.⁵⁷ Courts, however, have reminded the parties that decisions must be based on the individual child's needs⁵⁸ and school districts cannot have a policy that refuses to provide ABA, ABA-type programs, or any other program to children with ASD.⁵⁹ Typically, children with ASD will receive ABA therapy, speech, and occupational therapies.⁶⁰ They may also receive special instruction, counseling, and social skills training by a variety of professionals.⁶¹ Indeed, their families may also receive training under the IDEA.⁶²

A recent U.S. Supreme Court decision holding that parents have the burden of proof in appeals only adds to the hurdles parents face when trying to get services for their children.⁶³ Since there is a paucity of ASD treatment research and little research on intensity (the number of days and hours required for effective ABA), parents are in a limited position to advocate for intensive services.⁶⁴ For example, several courts have rejected the desire of parents wanting to get 40 hours a week of ABA where less intensive services will provide the child with an "educational benefit."⁶⁵

Placement for a Child with ASD

The IDEA requires that students with disabilities between ages 3 to 21 be educated in the least restrictive environment (LRE). 66 Many courts have held that a school district

53 E.g., J.P. ex rel. Popson v. W. Clark Cmty. Sch., 230 F. Supp. 2d 910, 945-46 (S.D. Ind. 2002). 54 Id.

55 *Id.* at 921.
56 *Id.* at 939.
57 *Id.* at 917.

58 *See, e.g.*, Deal *ex rel.* Deal v. Hamilton Cnty. Bd. of Educ., 392 F.3d 840, 845-47 (6th Cir. 2004). 59 *Id.* at 858.

60 See IACC STRATEGIC PLAN, supra note 31 at 37.

61 Id.

62 20 U.S.C. § 1431(b)(1) (2005).

63 See Schaffer v. Weast, 546 U.S. 49, 62 (2005) ("The burden of proof in an administrative hearing challenging an IEP is properly placed upon the party seeking relief. In this case, that party is . . . represented by his parents.").

64 See IACC STRATEGIC PLAN, supra note 31 at 37.

65 A.G. ex rel. N.G. v. Frieden, No. 08 Civ. 1576 (LAK), 2009 U.S. Dist. LEXIS 24887, at *18 (S.D.N.Y. Mar. 25, 2009).

66 20 U.S.C. § 1412(a)(5) (2006).

can place children outside the regular classroom only if the child cannot be educated satisfactorily with the use of supplemental aids and supports.⁶⁷ Yet, it seems clear that the more IEP services that are provided for children with ASD, the more restrictive the setting. Some courts, as a result, have decided that the needed services could only be provided in a separate school placement.⁶⁸ These rulings could result in children being placed in more restrictive settings and limiting the opportunities for children with ASD to interact with their non-disabled peers. Juvenile and family courts can monitor these placements to ensure that children receive the services they are entitled to under the IDEA. Judges must also ensure that any placement outside of the home—whether in a residential school or other restrictive program—be IDEA compliant and subject to its requirements and funding mechanisms.

Payment for Services

Children with ASD do not have to pay for IDEA services.⁶⁹ Ironically, most decisions in the last decade concerning services and placement for children with ASD have occurred in the context of a reimbursement claim. In *School Committee of Burlington v. Department of Education*, the U.S. Supreme Court held that parents can get reimbursement for private placement pursuant to the IDEA if the court determines that the private placement, rather than the proposed IEP placement, is appropriate.⁷⁰ Juvenile and family court judges must be aware that federal courts have held that reimbursement can be appropriate even when parents move a child to a private placement without school district consent but they do so at their own risk.⁷¹

These decisions give an advantage to wealthy families who can afford to take the risk of paying for private programs without a guarantee of reimbursement. Therefore, these issues will probably be raised only in divorce proceedings. But, regardless of how an issue presents, the courts should remember that the IDEA provides for a free education and the courts should ensure that the IDEA and other special education funds—not child protective or other resources—be used for special education placements.

Many parents have sought to use insurance to pay for services not covered by the IDEA. Insurance companies have often denied benefits because of pre-existing conditions or because the services requested are deemed experimental, not restorative, or are special education-related. The 2010 federal Health Care Reform law will alleviate some of these problems.⁷² Insurance companies are required immediately to cover all children with pre-existing conditions such as ASD and to cover adults by 2014.⁷³ The new law also will

⁶⁷ Daniel R.R. v. State Bd. of Educ., 874 F.2d 1036, 1048 (5th Cir. 1989).

⁶⁸ Roncker ex. rel. Roncker v. Walter, 700 F.2d 1058, 1063 (6th Cir. 1983).

^{69 20} U.S.C. § 613(a)(2), 89 Stat. at 782.

⁷⁰ Sch. Comm. of Burlington v. Dep't of Educ., 471 U.S. 359, 370 (1985).

⁷¹ Winkelman v. Parma City Sch. Dist., 550 U.S. 516, 531-32; see also Burlington, 471 U.S. 359.

⁷² Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010). 73 Id.

cover "behavioral health treatments" that are medically necessary and evidence based, such as ABA, as part of the essential benefits package.⁷⁴ Even if the policy does not have the language, it is statutory and the carrier has to provide the coverage.

The Importance of Early Intervention

Early identification is critical to optimal outcomes and the most effective management of ASD. The program known as Part C of the IDEA is the richest entitlement program available to children under age 3 and their families.⁷⁵ It is also the nation's only two-generational entitlement, providing a wide array of services to infants and toddlers with developmental delays or disabilities (such as special instruction, physical, occupational and speech therapies, psychological, nursing, nutrition, audiological, transportation, and other services) and their parents (foster, kin, or biological parents can be eligible for counseling, training, respite, or other services).⁷⁶ All children under EI must have a service coordinator or case manager to assist the parents in accessing the EI system and to secure all services enumerated in the Individualized Family Services Plan (IFSP) in natural environments, such as at home or in a day care center where young children typically spend their days.⁷⁷ Judges can ensure that young children with developmental delays who are involved in child protection, custody, visitation, divorce or even child support cases be referred to EI to receive a wealth of important services. Federal law requires that all children with substantiated cases of abuse and neglect under age 3 be referred to EI.78 Thus, in child protection proceedings, judges should inquire as to that referral and may order child protection to make these vital referrals, if needed.

III. ANALYSIS OF JUVENILE AND FAMILY LAW CASES INVOLVING CHILDREN WITH ASD

Few published family law cases involve children with ASD. No cases have been decided by a state's highest court, so the few published cases are predominately intermediate appellate court decisions. Most cases, like Ricky's, started as child protection matters, including termination of parental rights proceedings (TPR) or custody disputes. The issues, however, may arise in a child support dispute or delinquency case where services are needed.

74 *Id.*75 Education of the Handicapped Act Amendments of 1986, Pub. L. No. 99-457, 11 Stat. 1145
(1986).
76 20 U.S.C. § 1434.
77 *Id.* § 1436(d).
78 42 U.S.C. § 5106a.

The Family Law Issues in ASD Cases

ASD case law builds on the foundation of family law concerning children with special needs.⁷⁹ As in other cases involving children with disabilities, parental capacity to care for a child's special needs is a paramount issue.⁸⁰ The other key factor in ASD cases is the child's need for consistency and routine.

Custody

One of the most illustrative cases concerning parental capacity is a custody case, *Martocchio v. Savoir*.⁸¹ In *Martocchio*, the father, who did not know he was a parent for two and a half years, fought for custody of his son, Nathan, who had been diagnosed with a severe form of ASD.⁸² The maternal grandparents had temporary custody of Nathan due to the mother's alcohol and substance abuse and multiple prison sentences.⁸³ The trial court granted the father sole physical custody of Nathan, plus sole legal custody to choose the boy's physicians, medical regimen, and educational and social activities.⁸⁴

Martocchio focused on the father's capacity to provide and care for his son. The court stressed that the father was the more fit and informed parent because he voluntarily immersed himself in "the study of autism and the proper treatment and care of his son," networked with experts in the field, participated in support groups for individuals with children on the autism spectrum, and became a "relentless advocate" for his child.⁸⁵ The court found immersion into the field of ASD so important that it ordered the mother and the grandparents to learn all they could about children with ASD.⁸⁶ *Martocchio* emphasizes the importance that a prospective caregiver of a child with ASD be willing and able to learn about ASD and apply that knowledge to meet the child's special needs.⁸⁷

Child Protection Cases

Child protection cases have also focused on parental capacity.⁸⁸ In *In re Juan R.*, the court affirmed that the Connecticut Department of Children and Families (DCF) made reasonable efforts to prevent removal of Juan, a child with ASD, from his home due to his

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82 *Id. Id.* at *1. *Id.* at *5; *see also In re* D.W., No. A11A1465, 2011 WL 4089949 (Ga. Ct. App. Sept. 15, 2011). *Id.* at *2. *Id.* at *5. *In re* D.W., *supra* note 84, at *7. *In re* Juan R., No. W10CP06015101A, 2007 WL 4801440 (Conn. Super. Ct. Dec. 28, 2007).

⁷⁹ In re L.J., 436 N.W.2d 558 (N.D. 1989); In re R.L.H., 755 N.W.2d 145 (Iowa Ct. App. 2008); In re Elijah F., 56 A.D.3d 260 (N.Y. 1st Dep't 2008).

⁸⁰ Sheryl Dicker & Elysa Gordon, Ensuring the Healthy Development of Infants in Foster Care: A Guide for Judges, Advocates and Child Welfare Professionals (Zero to Three Policy Center, Jan. 2004); Jack P. Shonkoff & Deborah Phillips, From Neurons to Neighborhoods: The Science of Early Childhood Development (National Academies Presses, 2000).

⁸¹ Martocchio v. Savior, No. TTDFA064006261, 2008 WL 3853514 (Conn. Super. Ct. July 28, 2008).

mother's neglect.⁸⁹ His mother argued that DCF had not made reasonable efforts and requested substitute parenting by a team of professionals 24 hours a day. Juan, who was seven when he was adjudicated as a neglected child, had been diagnosed with ASD, chromosomal abnormalities, and severe intellectual disabilities with an IQ between 20 and 30.⁹⁰ He was, as multiple experts testified, one of the most severe cases of autism they had ever seen.⁹¹

Juan received EI as a young child, special education pursuant to an IEP at school, cash assistance from his church, and respite care for his family.⁹² DCF also funded two ABA mentorship programs for him.⁹³ Additionally, DCF had provided a wealth of services to his mother including respite care, counseling services, in-home parenting assistance, and instruction from the Department of Mental Retardation.⁹⁴ Despite all of this effort, the court found that Juan's mother lacked the ability to benefit from these services and care for Juan's special needs.⁹⁵

Visitation

The need for consistency in the life of a child with ASD is most evident in visitation cases. In *LaGuardia v. LaGuardia*, the Court of Appeals of Tennessee reviewed the trial court's order awarding visitation by the father every other weekend and alternating Wednesdays.⁹⁶ The children were both diagnosed with a mild form of ASD by an autism specialist who was optimistic about their futures.⁹⁷ The specialist testified that children with autism require "sameness and consistency" and that when they are subjected to change they are known to regress.⁹⁸ He also testified, however, that while children with autism experience setbacks because of changes in their schedule, the regression will not be permanent with proper planning.⁹⁹ In affirming the visitation order, the appellate court relied heavily on the specialist's testimony emphasizing that the goal is to be consistent.¹⁰⁰

Termination of Parental Rights

The dual issues of parental capacity and need for routine have been raised in TPR proceedings. In a New Jersey case decided in June 2011, the Superior Court applied both

89 Id. at *1.
90 Id.
91 Id.
92 Id.
93 Id. at *4.
94 Id. at *3.
95 Id. at *4.; See also In re M.B., No. 96724, 2011 WL 4090352 (Ohio Ct. App. Sept. 15, 2011).
96 LaGuardia v. LaGuardia, No. E2004-00822-COA-R3-CV, 2005 WL 1566592, at *1 (Tenn. Ct. App. July 6, 2005).
97 Id. at *4.

98 Id.

99 Id.

100 See also In re Marriage of George-Easterson, No. A128963, 2011 WL 5023954, at *5 (Cal Ct. App. 1d Oct. 21, 2011).

the parental capacity and consistency analysis to a TPR case involving a child protection matter.¹⁰¹ The court affirmed termination of parental rights based on the expert's testimony that the parent's lack of "psychological capacity" to understand and address the child's needs only served to magnify those needs.¹⁰² Additionally, the court held that, based on expert testimony, the child's need for stability and consistency is multiplied by his ASD, only underscoring the importance of parental capacity.¹⁰³ Thus, these two legal requirements can be intertwined.

These cases illuminate the importance of parental capacity to care for a child with ASD as a core component of a determination of the best interests of the child. Additionally, courts have focused on the particular needs of a child with ASD for consistency in every aspect of life. All of these cases have relied on expert testimony to provide insight into each child's specific diagnosis and particular needs.

Child Support

Only one published decision concerns a child with ASD in a child support case. The child support case affirms existing law holding that a parent is responsible for child support for a child with a disability, including ASD, beyond his or her 18th birthday.¹⁰⁴ In determining the support order for a child over age 18 with ASD or another disability, the court will analyze the actual expenses of caring for the child minus any benefits received such as SSI. In the instant case, the court held each parent equally responsible for any uncovered needs.¹⁰⁵ Courts can also order continuation of health insurance as part of a support order.¹⁰⁶

Juvenile Delinquency

The three published juvenile delinquency decisions involving children with ASD are from a New York family court and Indiana and New Jersey appellate courts. Both the New Jersey and New York decisions raise the threshold issue of whether the juvenile has the capacity to participate in the hearing.¹⁰⁷ In the New York case, in response to a defense motion to determine whether the 16-year-old was an incapacitated person, the judge secured several reports from experts.¹⁰⁸ All agreed that the teen had ASD, and some pointed to other infirmities including a low-IQ and psychological problems.¹⁰⁹ The court, as a result, found that the teen was an incapacitated person unable to understand the

101 N.J. Div. of Youth & Family Servs. v. G.S., No. FG-07-218-09, 2011 WL 2566160 (N.J. Super. Ct. App. Div., June 30, 2011). 102 Id. at *10; In re D.W., supra note 84, at *4.

103 Id. at *9.

104 State ex rel. Moore v. McCampbell, 786 N.W.2d 519 (Iowa Ct. App. 2010).

105 Id. at *3-4.

106 Id.

107 In re Erick B., 777 N.Y.2d 253 (Family Ct. Kings County 2004); State ex rel. J.P., No. FJ-09-2577-10, 2011 WL 4916939 (N.J. Super. Ct. App. Div. Oct. 18, 2011).

108 In re Erick B. at 255. 109 Id. at 256. proceedings against him or to assist in his own defense.¹¹⁰ If the threshold issue of capacity is resolved and the child with ASD is found to be able to understand the proceedings and participate in his own defense, the issue of ASD still remains critical.

In *Marlett v. State*, a 17-year-old diagnosed with ASD¹¹¹ was charged with attempted murder, criminal confinement, and battery.¹¹² The juvenile pleaded guilty to the criminal confinement charge and was sentenced to 20 years in adult prison.¹¹³ The key issue before the appellate court was the appropriateness of his sentence. The court found the evidence of his ASD insufficient to overturn the trial court decision.¹¹⁴ The court, however, noted that the critical issue is the nexus between the crime and the ASD, and it found none.¹¹⁵ The court's dicta about a possible nexus between the crime and the ASD, and it found none.¹¹⁶ raises questions that may have to be litigated in the future, including how a child with ASD reacts and what those reactions mean. What does it mean if the child does not make eye contact, runs away under stress, refuses to answer, or responds to questions in a confusing way.¹¹⁷ Clearly, lawyers and judges will have to educate themselves, as well as juries, about the characteristics of ASD.

CONCLUSION

The court's understanding of ASD can make an enormous difference in a variety of juvenile and family law cases. Judges and other court professionals need to be educated about ASD, and it is also critical for the court to use experts with knowledge and experience in all facets—diagnosis and services—of ASD. These experts may be different than those traditionally used in juvenile and family courts. A psychologist, for example, who may routinely perform custody evaluations or recommendations on capacity to stand trial, may have little knowledge of ASD. ASD is a new and growing field requiring up-to-date expertise. It will be important for the court to find new experts to tap for future cases. Ricky's case illustrates the importance of a judge's understanding of ASD and the importance of using experts steeped in the latest developments in this emerging field.

The appendix to this article contains an ASD checklist that all court participants judges, advocates, and other professionals—can use to gather information, identify needs and services, and fashion court orders. This checklist attempts to utilize the medical and legal information contained in this primer and turn that knowledge into a workable tool for the court. The appendix provides a starting point for judges to acquire this information. The appendix includes a Web site that can be used to identify ASD experts through

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110 Id. at 258.
111 Marlett was actually diagnosed with Asperger's, a condition of ASD.
112 Marlett v. State, 878 N.E.2d 860 (Ind. Ct. App. 2008).
113 Id. at 863.
114 Id. at 866.
115 Id.
116 Id. n.2.
117 See IACC STRATEGIC PLAN, supra note 31, at 1.
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the network of University Centers for Excellence in Developmental Disabilities (UCEDD). Every state has at least one UCEDD which either has ASD experts on staff or can make referrals to such experts.

APPENDIX

Putting the Medical and Legal Knowledge Together: An ASD Checklist for Judges, Advocates, and Other Professionals

- 1. Does the child exhibit any red flags for ASD? (See infra pp. 4-5)
- 2. Has the child had a screening for ASD by a professional knowledgeable about ASD? (*See infra* pp. 5-6)
- 3. Has the child had an MDE by professionals with knowledge and experience concerning ASD? (*See infra* pp. 5-6)
- 4. Has the child had a complete medical work-up for ASD? (See infra pp. 5-6)
- 5. Has the young child been referred to EI and is he or she receiving EI services pursuant to an IFSP? (*See infra* pp. 8-9)
- 6. Does the older child receive Special Education and related services? (*See infra* pp. 9-10 and 13-14)
- 7. Has the child's caregiver demonstrated parental capacity to care for the special needs of this child with ASD? (*See infra* pp. 15-18)
- 8. Have visitation orders been tailored to address the child's need for routine and consistency? (*See infra* p. 16)
- 9. Has the juvenile with ASD been found competent to stand trial? (*See infra* pp. 17-18)
- 10. Has the court reviewed the nexus between the juvenile's alleged act and his or her ASD? (*See infra* p. 18)

Directory of University Centers for Excellence in Developmental Disabilities can be found at: http://www.aucd.org/directory/displayall.cfm?program=UCEDD&CFID=742916&CFTOKEN=88006642.