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Autism Spectrum Disorder

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Abstract

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder that is characterized by deficits in communication and social interaction and the presence of restricted and repetitive behavior. This chapter will provide an overview of ASD including screening and evaluation process, physical health implications, and current knowledge of interventions. The chapter will also focus on interprofessional issues associated with providing treatment to individuals with ASD including increased presence of behavioral and medical disorders, number of practitioners providing service across different settings, and the importance of and methods to facilitate coordination of services.

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Definition

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction and is accompanied by restricted, repetitive patterns of behavior, interests, or activities. The signs of ASD are usually evident in early childhood prior to age 3. Some studies have shown that it is possible to diagnose ASD in toddlers as young as 12–24 months (Kim & Lord, 2012).

Prevalence and Etiology

In 2014, the Centers for Disease Control and Prevention reported that the prevalence of ASD had risen to 1 in every 68 births in the United States (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). ASD is four to five times more likely to affect boys than girls and can be found in all racial, ethnic, and social groups. The surveillance study found that the incidence of ASD was 1 in 42 in males and 1 in 189 in females. There is no known single cause for ASD. However, the research literature suggests that there is a large genetic component to the disorder. Strong evidence for the genetic etiology can be found in twin studies (e.g., Frazier et al., 2014). For example, Frazier and colleagues found that in monozygotic twin pairs, if one twin is diagnosed

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with ASD, the other twin has a 76% chance of also being diagnosed. In fraternal twin pairs, if one twin has a diagnosis of ASD, the other twin has a 34% likelihood of being diagnosed with ASD.

Diagnosis of Autism Spectrum Disorder

The diagnostic criteria for ASD encompass two broad areas. The extent to which these deficits are present may vary significantly (mild to severe), allowing for a wide spectrum of symptom presentation.

Persistent deficits in social communication and social interaction across multiple contexts. These deficits can be characterized by a lack of social-emotional reciprocity (e.g., failure of normal back-and-forth social exchange), a lack of nonverbal communicative behavior during social interaction (e.g., a lack of eye contact or facial expressions), and deficits in developing, maintaining, and understanding social relationships.

Restricted, repetitive patterns of behavior, interests, or activities. The repetitive patterns of behavior may manifest in several ways. They may include stereotyped or repetitive motor movements or speech (e.g., repeated motor movements, echolalia). There may also be an insistence on sameness and/or inflexible adherence to specific routines or rituals. Individuals with ASD will also often present with highly restricted, fixated interests that are abnormal in intensity or focus. People with ASD may also present with hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.

Screening and assessment/evaluation. The identification of a child with ASD may first begin with parents who notice differences in the way their child learns or behaves as compared to other children, or with a friend or relative who expresses concerns about the child's development to the parent. As the child enters school settings with peers, teachers may share ways in which the child differs from other children his or her age, such as tending to play by him or herself, expressing frustration with changes in the environment, or limits in communication skills. The concerns of the parent, family member, friend, or teacher may eventually spur the parent to seek out a professional opinion.

Often, parents may first turn to their child's pediatrician. As per the American Academy of Pediatrics (AAP), pediatricians should conduct a developmental screening at preventative care visits for children aged 9, 18, and 24 months. Early signs of ASD, such as lack of eye contact, may appear in a 9-month screening. The AAP recommends an autism-specific screening in addition to the developmental screening at the ages of 18 and 24 months (AAP, 2006). To accomplish this screening, pediatricians who follow the recommendations often make use of a screening questionnaire such as the Modified Checklist for Autism in Toddlers - Revised (M-CHAT-R; Robins, Fein, & Barton, 2009). The M-CHAT-R is a 23-item questionnaire comprising questions regarding symptoms of ASD that may be noticed by parents, such as the child's infrequent use of eye contact or lack of responsiveness to his or her name. If a pediatrician finds that a child screens positive for ASD using the M-CHAT-R, he or she should complete the M-CHAT-R follow-up, which guides the practitioner through a structured interview regarding the child's symptoms. If the child again screens positive on the follow-up interview, the pediatricians should provide a referral to a diagnostician and early intervention.

Commonly, diagnoses of ASD are provided by a developmental pediatrician, pediatric neurologist, or psychiatrist. Parents of children under the age of 3 may also seek assessment through their state's early intervention program, while parents of those over the age of 3 years may also seek an evaluation from their school district's evaluation team. This team must be multidisciplinary and include a teacher or specialist with expertise in the area of ASD evaluation and treatment. The team must also use multiple methods of assessment, such as those described below.

Parents who seek out a diagnosis for their child can expect a two-component evaluation process. First, the professional will conduct an interview with the parent regarding the symptoms of ASD to identify whether the child demonstrates common markers of the disorder, such as difficulties with social-communication skills or the presence of repetitive or restricted interests. While pediatric experts may employ their own interview techniques, structured interview tools are available for diagnostic purposes. As an example, the Autism Diagnostic Interview - Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) is an evaluation tool that may be used to conduct this interview. The ADI-R protocol guides the professional through a set of 93 interview items that focus specifically on the presence of abnormalities in social reciprocal interaction, communication, and restricted and repetitive interests or behaviors. Parent responses to these interview questions, scored using an algorithm to generate a summary score, help inform the diagnosis of ASD.

While structured interviews are a valuable tool in evaluating a child for the possibility of an ASD diagnosis, the professional cannot rely solely on the report of the caregiver for diagnosis. Parents may under-report or over-report their child's symptoms, or justify them in ways that may challenge the diagnostician. A comprehensive evaluation of the child must also rely on observation and interaction with the child with ASD so that the diagnostician can determine whether and how the symptoms of autism manifest. The use of a semi-structured observation provides the clinician with a standard method of assessment that will highlight specific symptoms of ASD if they are present.

The gold standard for observational assessment is the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2; Lord et al., 2012), which is supported by substantial research.

In the ADOS-2, a series of activities is presented that pull for communication and social interaction and that may also set the occasion for any rigid or repetitive behavior. The examiner does not prompt communication or social interaction during the activities, but merely sets the occasion for them to occur and observes to see how the child responds. Following the ADOS-2 observation, the examiner provides ratings for the individual with ASD in the areas of communication, reciprocal social interaction, imagination and creativity, and stereotyped behavior and restricted interests. A summary score that provides a classification of ASD based on the findings of the ADOS-2 is provided, which can subsequently be used to inform a clinical diagnosis. As with the interview process, the ADOS-2 is not meant to stand alone in the evaluation, but should be used in tandem with other components of diagnostic evaluations, such as the interview, to provide a full picture of the child and his or her symptoms.

Some clinicians may also make use of questionnaires, such as the Social Communication Questionnaire (Rutter, Bailey, & Lord, 2003), to assess overall symptomatology and to help differentially diagnose children with ASD from other developmental disabilities, such as a language delay. These measures can also be administered to other individuals who know the child well, such as a teacher, to provide another source of information regarding the child's behavior in settings other than home. While these measures can be informative, they should not be used in isolation as a method of diagnosis.

Although some of the assessment tools described here can be used with children as young as 12 months, the median age of diagnosis for children with ASD is between the ages of 4 and 5 years of age (Christensen et al., 2016). Notably, the age of diagnosis for children of color, including African-American, Hispanic, and Asian children is later than that of White children. As an example, Black children are diagnosed, on average, 1.5 years later than White children and are more likely to receive another diagnosis such as attention-deficit-hyperactivity disorder or conduct disorder prior to a diagnosis of ASD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Given the significant benefit of early intervention for children with ASD, the delay in diagnosis is highly contraindicated and continued outreach efforts to provide early and accurate diagnosis for all children, and especially so for children of color, is warranted.

Outcomes

ASD is a lifelong condition. Research suggests that individuals who are diagnosed in childhood retain the diagnosis in adolescence and adulthood (e.g., Billstedt, Gillberg, & Gillberg, 2005). Due to the heterogeneity of the condition, outcomes can vary significantly across individuals. Individuals who present with less severe symptoms in early childhood are more likely to improve rapidly over time (Fountain, Winter, & Bearman, 2012). Early identification and subsequent intervention are also thought to improve long-term outcomes for this population (e.g., Sallows & Graupner, 2005). However, individuals with ASD and intellectual disabilities require continued support into adulthood and very few are able to live independently (Billstedt et al., 2005).

Physical Health Implications

The diagnosis of ASD interacts with a number of physical health issues that have a significant impact on the long-term quality of life. In fact, the mortality rate for individuals with ASD is estimated to be three to ten times higher than that of the general population (e.g., Hirvikoski et al., 2016). This disparity in the mortality rate is largely the result of medical comorbidities that interact with the diagnosis of ASD and contribute to poor health outcomes. As an example of how the diagnosis of ASD can complicate and exacerbate a medical diagnosis, many individuals with ASD are unable to effectively convey the nature of the physical symptoms they experience (e.g., telling someone they have a headache or pain in their chest) and may exhibit a variety of different behaviors while in pain that are erroneously attributed to the ASD diagnosis itself (e.g., aggression, self-injury, irritability, impulsivity, sleep disturbances). Thus, the inability to report physical discomfort has the potential to lead to larger, more costly health issues in the future. Similarly, the restricted, repetitive patterns of behavior associated with ASD can also interact with these health comorbidities. Certain types of repetitive behavior, for example, can produce tissue damage (e.g., hand wringing), and food selectivity, a type of restricted behavior, has the potential to produce gastrointestinal problems or cause significant weight gain. Medical conditions commonly associated with ASD follow.

Intellectual disabilities (ID). ASD is commonly associated with intellectual disabilities. Given the difficulties in measuring intelligence in people with ASD, the ranges of ID vary widely across studies. It has been reported that the incidence of ID in individuals with ASD ranges from 25% to 70% (Chakrabarti & Fombonne, 2001; Mash & Barkley, 2014). While the presence of intellectual disabilities does not necessarily *directly* contribute to poor health outcomes, they represent a contributing factor that may exacerbate health issues. For instance, individuals presenting with ID may make more impulsive, less health-conscious decisions regarding healthy life choices.

Severe maladaptive behavior. Individuals with ASD often present with behavioral challenges which have a negative impact on their quality of life. These behaviors include, but are not limited to, self-injurious behavior, aggression, pica, property destruction/disruption, socially offensive behavior, and noncompliance. While estimates of the prevalence of maladaptive behavior in individuals with ASD tend to vary widely depending on how they are defined, more than half of the population is reported to exhibit abnormal levels of challenging behavior (e.g., Woodman, Smith, Greenberg, & Mailick, 2015). Studies have found that the prevalence of maladaptive behavior is higher in individuals diagnosed with ASD relative to neurotypical peers or people with intellectual disability alone (e.g., Matson & Rivet, 2008). The presence of maladaptive behavior can be particularly problematic as the damage produced by the behavior itself can lead to health complications (e.g., injuries sustained from aggressive or self-injurious episodes).

Epilepsy. Epilepsy is another commonly diagnosed comorbid health issue for individuals with ASD. It is estimated that approximately one in four individuals diagnosed with ASD develops epilepsy in early childhood or adolescence (Canitano, 2007). Epileptic episodes are caused by abnormal electrical activity in the brain and can produce a temporary loss of consciousness, body convulsions, unusual movements, or staring spells. The comorbid diagnosis of epilepsy can have both direct (e.g., injury from falls, neurological problems) and indirect (e.g., disruptions to social/community integration) negative outcomes for people on the autism spectrum.

Sleep disorders. Sleep disorders are another common health issue for individuals diagnosed with ASD. Sleep disturbances are reported in approximately 53–78% of individuals diagnosed with ASD (Malow et al., 2012), and they may be characterized by late sleep onset, early morning awakening, and poor sleep maintenance (Reynolds & Malow, 2011).

Gastrointestinal difficulties. Gastrointestinal (GI) difficulties are among the most common medical conditions associated with ASD. The prevalence of reported GI symptoms in this population ranges anywhere from 23% to 70% (Gorrindo et al., 2012; Molloy & Manning-Countney, 2003). Among the most commonly reported GI problems are chronic constipation, frequent diarrhea, irritable and inflammatory bowel conditions, and gastroesophageal reflux. Several studies have shown that children with ASD are much more likely than age-matched typically developing peers to suffer GI discomfort, chronic diarrhea, or constipation (Chaidez, Hansen, & Hertz-Picciotto, 2014).

Obesity. Another commonly reported health issue in individuals diagnosed with ASD is obesity. Estimates suggest that 30.4% of people with ASD are obese as compared to 23.6% for their neurotypical counterparts (Curtin, Anderson, Must, & Bandini, 2010). Obesity is a pervasive problem in this population and has been linked to a number of serious health problems, such as heart disease, type 2 diabetes, orthopedic problems, sleep apnea, and certain cancers (He & Baker*, 2004).*

While several studies have documented the high rate of comorbid health issues in individuals with ASD, relatively few viable solutions address these concerns. This is problematic on at least two fronts. Although the human cost of these poor outcomes is readily apparent, there are significant financial costs to both the individual family and society as well (Cidav, Marcus, & Mandell, 2012; Knapp, Romeo, & Beecham, 2009). These comorbid health issues are all problematic in their own right; however, their interaction with the symptoms of ASD creates a significant barrier to the identification and treatment of health problems in this at-risk population.

Intervention

Although there are more studies aimed at investigating treatments for ASD than ever before, what constitutes effective intervention continues to be disputed (McGrew, Ruble, & Smith, 2016). Much of the intervention research has relied on single subject experimental designs. These designs allow for the demonstration of effectiveness of strategies for specific target behaviors on an individual level but do not allow for the demonstration of efficacy for the larger clinical population. Randomized control trials (RCTs) are considered the gold standard to determine intervention efficacy and evaluate potential treatment moderators but relatively few have been conducted. In addition, inclusion and exclusion criteria for research studies limit the focus on intervention effectiveness to a specific portion of the ASD population in highly controlled settings. Thus, the extent to which effects generalize to the wide variety of individuals with ASD and across contexts is unknown.

Behavioral intervention. Despite the limitations in current empirical knowledge, a number of behavioral and educational treatment strategies have been shown to be effective at alleviating symptoms of ASD. Treatment location may vary based upon the age of the individual but it is not uncommon for school-aged children with ASD to receive behavioral and education treatment services at home, school, and/or in specialty clinics. The most well-established interventions for ASD are based upon the principles of behavior analysis and are known as applied behavior analysis (ABA; Smith & Iadarola, 2015; Wong et al., 2015). Behavior analytic interventions incorporate measurement of behavior targets to evaluate the effectiveness of treatment procedures. Individualized assessments are conducted to identify specific skill deficits and effective teaching strategies. Additionally, variables responsible for behavioral excesses are evaluated so that the environment can be arranged to promote appropriate communication and reduce problem behavior.

Treatments using ABA strategies typically involve highly structured, one-to-one instruction to promote pre-academic, academic, communication, and social skills. Each skill is broken down into basic components and is taught through systematic prompting and reinforcement. Teaching strategies may include adult-led discrete trial teaching (DTT) or child-led naturalistic teaching strategies. For example, using DTT, a therapist may target the skill of responding to one's name by simultaneously providing the instruction (i.e., stating the learner's name while he is distracted) and a prompt (e.g., gesture to look at the therapist) before providing reinforcement for compliance. This process would be repeated across numerous learning trials. Using naturalistic teaching strategies, the teaching may take place in the context of turn-taking during a preferred board game. Before the learner takes a turn, the therapist could state the child's name and provide a prompt to respond. The student's appropriate response would result in natural reinforcement of resuming the game and taking a turn. In both cases, additional prompts could be systematically faded over trials until the learner is independently responding to his or her name.

Early intensive behavioral intervention (EIBI) is type of ABA treatment that aims to provide as many learning opportunities as possible throughout a young child's day and includes instruction in naturalistic settings and high levels of parent involvement (Lovaas & Smith, 2003). Research has shown some positive gains for most children who receive EIBI with greater treatment gains correlated with a younger age (prior to the age of 5 years) of treatment onset, greater intensity and duration of treatment, and higher developmental level of the individual (Harris & Handleman, 2000; Makrygianni & Reed, 2010). The most well-established model of EIBI was described by Lovaas and colleagues in their work with young children with autism at UCLA. In the seminal experiment, Lovaas (1987) compared an experimental group of young children with autism who received 40 h per week of intensive behavioral treatment for up to 3 years to a control group. This study found that children in the experimental group showed gains in educational and intellectual functioning, with 47% achieving normal-range IQ scores. This finding stood in contrast to 2% of the control group who achieved normal functioning levels. Numerous replications of the Lovaas model have been conducted and have shown similar treatment gains with a slightly lower dose of treatment and in community settings (e.g., Eldevik, Hastings, Jahr, & Hughes, 2012).

Additional comprehensive intensive behavioral and educational treatment models utilizing behavioral principles have been developed and shown to be effective including Pivotal Response Training (Koegel, O'Dell, & Koegel, 1987), the Early Start Denver Model (Dawson et al., 2010), Learning Experiences and Alternative Program for Preschoolers (LEAP; Strain & Bovey, 2011), and Treatment and Education of Autism and

Related Communication-Handicapped Children (TEACCH; Marcus, Schopler, & Lord, 2001).

Behavioral treatment of core ASD symptoms and challenging behavior. Many behavioral treatments target specific symptoms of ASD including communication and social skills deficits. Although approximately a third of individuals with ASD do not develop fluent vocal language (Norrelgen et al., 2015), a number of alternative and augmentative communication strategies including Picture Exchange Communication System (Bondy & Frost, 1994), sign language, and speech generating devices may be used to repair language deficits as well as increase social skills and reduce challenging behavior. Once basic forms of communication are established, treatments may focus on increasing the frequency and quality of social interactions as well as help the individual navigate various social situations. Established strategies to increase social skills include prompting, video modeling, self-monitoring, and social scripts (Bellini & Peters, 2008).

Numerous studies on the assessment and treatment of restricted and repetitive behavior exist in the behavioral literature and primarily focus on the assessment and treatment of stereotypy. Behavior analytic approaches to decreasing stereotypy assume that stereotypic behavior is maintained by environmental variables. Stereotypy often persists in the absence of social consequences and is thought to be maintained by the sensory consequences the behavior itself produces (Rapp & Vollmer, 2005). Several strategies that have been shown to be effective include providing the individual with leisure items with which to engage, interrupting stereotypy and redirecting the individual to engage in a more socially appropriate activity, and teaching the individual appropriate times or places to engage in stereotypy.

While behavioral treatment has been effective at addressing core symptoms of ASD, it can also be helpful for decreasing other prevalent challenging behavior and behavioral issues. A behavioral approach to treatment of challenging behavior presumes that each behavior serves a purpose for the individual and may be used as a form of communication. For example, an individual may engage in aggressive and self-injurious behavior to escape demands because he or she has no means to appropriately ask for a break. Best practices include conducting a functional analysis (Iwata, Dorsey, Slifer, Bauman, and Richman, 1982/1994) to identify maintaining environmental variables. Once variables are identified, function-based treatments such as functional communication training can be implemented to teach the individual appropriate ways of requesting wants and needs. In addition, caregiver training can be conducted to teach caregivers to minimize access to reinforcers (i.e., stimuli whose contingent delivery or removal increases behavior) when problem behavior occurs.

Psychopharmacological interventions. It is estimated that over half of children with ASD are prescribed at least one psychotropic medication (Mandell et al., 2008). A number of psychotropic medications have been prescribed including antipsychotics, ADHD medications, and antidepressants. However, evidence for effectiveness of these medications is extremely limited. Siegel and Beaulieu (2012) conducted a review of psychotropic medication use for children and categorized the level of evidence for each pharmacological agent. Only three antipsychotic drugs showed established evidence (highest level) in the treatment of some target symptoms. Aripiprazole was found to be effective in treatment of irritability, hyperactivity, and stereotypy, haloperidol was found to be effective for treating behavioral symptoms and risperidone was found to be effective for irritability and hyperactivity. In addition, methylphenidate, naltrexone, and atomoxetine showed preliminary evidence of effectiveness in the treatment of hyperactivity. Even less is known about the effectiveness of psychotropic medications for adolescents and young adults with ASD. For example, Dove et al. (2012) found insufficient evidence for all medications for this population.

Sensory integration therapy. Sensory integration therapy (SIT) involves presenting items and activities that offer different sensory inputs to individuals to address underlining "sensory processing" issues (Ayres, 1979). The American Academy of Pediatrics policy statement on sensory integration therapy (2012) raises several concerns with the practice including no standard diagnostic criteria for sensory processing disorder. In addition, there is a lack of empirical evidence for the clinical usefulness of SIT.

Complementary and alternative medicine. Although there is little to no evidence of their effectiveness, complementary and alternative medicine (CAM) interventions are frequently used for individuals with ASD (Höfer, Hoffmann, & Bachmann, 2017). The most frequently used CAM interventions are special diets or various dietary supplements, which may be viewed as relatively innocuous. However, therapies such as chelation have also been used in treatment, and deaths from inappropriate administration of chelation therapy have been reported (Brown, Willis, Omalu, & Leiker, 2006).

Implications for Interprofessional Care

Due to the complexity of symptoms that often accompany an ASD diagnosis, individuals with ASD and their families rely on a network of professionals for care. These professionals may span educational and medical settings, and include public or private school teachers and personnel, psychologists, behavior analysts, speech therapists, occupational and physical therapists, primary care physicians, neurologists, and other medical specialists such as gastroenterologists. While each professional may work to address the same symptoms of ASD, these professionals often operate independently with little collaboration or coordination with one another. To best provide comprehensive services to individuals with ASD, communication between these professionals and the family of the individual with ASD is monumentally important.

One reason why coordination care is critical among individuals with ASD is that individual treatment approaches may affect a child's health or behavior in a way that other professionals should be aware. For example, the administration of some medications may have side effects that significantly alter the individual's behavior; he or she may become more agitated, or lethargic, or hungry, or exhibit unexpected behaviors such as tics or seizures. Awareness of these possible side effects will help other professionals be prepared for and account for these changes.

Additionally, the efforts of each professional to improve the health and progress of the individual with ASD may also impact the treatment provided by other providers, or the ability to accurately evaluate the outcome of such treatment. For instance, if a child with ASD exhibits significant aggression at home and at school, one might expect that it would be a primary focus of treatment for a number of professionals. A psychiatrist might address the problem by providing medication, such as risperidone, to reduce agitation. Simultaneously, a behavior analyst may suggest that the child's special education teacher address aggression by teaching the individual to request for preferred activities while simultaneously reducing access to those activities when the problem behavior occurs. However, if changes are made in both educational and medical settings at the same time, neither of the professionals will be able to clearly attribute the changes to the treatment they have provided. Ideally, one change will be made at a time and the changes on behavior will be assessed separately. A process such as this will allow for a careful analysis of the effects of each treatment on behavior and reduces the likelihood that progress will be misattributed to an ineffective treatment.

Additionally, professionals can often work together to provide the best opportunities for evaluation of treatment by pooling the data they have available for the expected outcome of the treatment. For example, occupational therapists may make recommendations to incorporate sensory activities into the school day of a child with

ASD. The child's teachers and behavior analysts can help evaluate a treatment such as this by taking data on the child's behavior both before and after the implementation of the treatment. If an effect is observed, brief removal of the treatment is conducted to assess if behavior returns to pretreatment levels. The treatment can then be reimplemented to confirm its effectiveness.

The use of data and the coordination between professionals is especially important when the treatment is medical in nature; while the implementation and removal of sensory activities have no expected impact on the child's health, the manipulation of medication regimens is not so straightforward. Medication can have tremendous impact—both therapeutic and detrimental—on the child's behavior and progress in home and school settings. However, only the prescribing doctor can determine how medication changes should be made to evaluate their impact on behavior, and so coordination between the doctor and educational staff is necessary. By working directly with private or public schools, a medical doctor can clearly convey the changes that are made and teachers or other professionals within the school system can carefully monitor, using data, the behaviors of interest.

Currently, the coordination of child care commonly falls to the parents of the child with ASD. However, this burden of acting as liaison may be alleviated by the efforts of care providers to coordinate their services. A "medical home" can be rooted in virtually any setting, including hospitals, pediatrician's offices, and school clinics, but in all cases the setting is a regular source of care and the treatment of the child is managed by well-trained physicians (Medical Home Initiatives for Children with Special Needs Project Advisory Committee & AAP, 2002). The guidelines provided by the AAP recommend that medical treatment of children within a medical home be accessible, continuous, comprehensive, family-centered, compassionate, culturally effective, and, of importance here, coordinated. To coordinate care, the AAP recommends that primary and pediatric medical subspecialties collaborate as a team by taking steps such as sharing treatment plans across professionals and with the family and clearly delineating the roles each will play in the child's treatment. Further, the AAP recommends that medical homes communicate with educational programs or other care providers to ensure that the needs of the child with ASD are met. Finally, a central record should be maintained that can be accessed by all clinicians in the medical home (AAP, 2002).

Research indicates that children with ASD who receive services through a medical home are four times more likely to have no unmet medical needs than children who do not, with the effects of the model driven largely by the positive impact of family-centered care and coordination of services provided (Cheak-Zamora & Farmer, 2015). However, the receipt of services consistent with a medical home model for children with ASD lags behind that of other childhood medical conditions, with less than 25% of children with ASD receiving services through a medical home (Farmer et al., 2013). Parents specifically cite lack of comprehensive services, family-centered care, and coordination in their child's medical care. Physicians point to a lack of resources, time, and training as primary barriers for the development of medical homes for children with ASD (Carbone, Behl, Azor, & Murphy, 2010), while the insurance coverage and family income can also impact the extent to which a family's needs are met. These findings indicate that physician training on the healthcare needs specific to individuals with ASD, beyond just diagnosis, is greatly needed. Further, medical systems that support coordinated care through the use of technology and other communication systems, and that provide the necessary insurance coverage for the care provided are necessary for the coordination of effective treatment of individuals with ASD.

Case Study

Harold is a 12-year-old Hispanic male with ASD. Harold has an IQ of 42 as measured by the Stanford-Binet and limited vocal language. He was diagnosed with ASD at age 2 after failure to meet expected milestones in language and social development. Because Harold has significant intellectual impairments and engages in severe problem behavior, he was placed at an out-of-school district placement at a university-based school specializing in applied behavior analysis. In addition to his school placement, Harold also receives in-home services to address behavioral issues and deficits in daily living skills and is under the care of a neurologist who prescribes medication for severe problem behavior. Harold's case will be used to illustrate the importance of treatment coordination across care providers.

Medication evaluation. Harold engages in severe aggression (hitting, kicking, scratching, biting others) and self-injurious behavior (head banging and hitting, hand biting) at home and school. Harold received clearance from medical professionals that his behavior was not caused by medical issues. After obtaining consent to assess, the board certified behavior analyst (BCBA) who oversees Harold's classroom began the assessment process, including operationally defining and collecting data on target behaviors. A functional analysis (Iwata et al., 1982/1994) was conducted and showed that Harold engaged in high rates of target problem behavior when he was asked to complete tasks and would stop engaging in target problem behavior when contingent breaks were provided. A treatment was implemented which included teaching Harold to appropriately ask for breaks from demands and granting those requests frequently, providing motivation for compliance, and redirecting Harold to complete tasks when he engaged in challenging behavior (i.e., escape extinction). The treatment resulted in substantial decreases in problem behavior at school. However, although these decreases in challenging behavior were an improvement from the level measured prior to the start of treatment, Harold continued to engage in severe episodes of behavior that occurred every 2–3 weeks. Escalations were observed at both home and school and Harold's behavior was often so dangerous that crisis management strategies (e.g., physical restraint) were implemented as a safety precaution.

Due to the severity and cyclical nature of Harold's behavior, his parents brought him to see a neurologist for medical treatment. Harold's parents informed the school program staff when medications were begun so that they could note the change on his behavior graphs. School staff also ensured that behavioral treatment procedures were kept constant across the school day so the particular effects of the medications could be isolated and evaluated. Behavioral data collected at school were shared with Harold's doctor to assist in the medication evaluation.

Figure 14.1 presents summary data from the medication evaluation and includes levels of problem behavior (aggression and self-injury) and compliance with instructions (percentage of time that Harold initiated a task within 5 s of an instruction). Data from 10 days prior to medication implementation were summarized as a baseline measure. During baseline, Harold engaged in problem behavior in 25% of 1-min intervals. Compliance with demands occurred during 80% of opportunities. Harold was initially prescribed Clonidine for hyperactivity. However, following increases in frequency and intensity of problem behavior (to 50% of 1-min intervals on average) as well as increases in other disruptive behavior and decreased compliance, clonidine was discontinued and Harold was prescribed risperidone. An initial dose (risperidone A) was administered for 2 weeks before being increased. An immediate decrease in target behavior was observed during the initial dose (problem behavior decreased to 15% of 1-min intervals). Problem behavior was further reduced to zero levels during when the medication dosage was doubled (risperidone B). However, additional side effects were observed. Harold became lethargic and showed decreased responsiveness to instructional demands and bids for communication. These side effects are evident in the low levels of compliance observed during risperidone B. When medication dosage was reduced slightly (risperidone C), problem behavior increased slightly but was still greatly reduced in frequency and intensity. In addition, compliance returned to baseline levels.

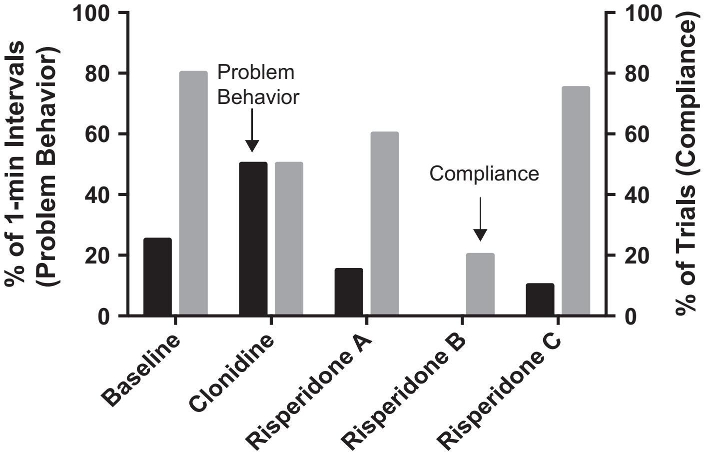

Fig. 14.1 The graph displays the results for the medication evaluation for Harold. Conditions are plotted on the x-axis. Percentage of 1-min intervals with severe problem behavior are represented by the black bars and are plotted on the left y-axis. Percentage of learning trials with compliance are represented by the gray bars and are plotted on the right y-axis

Harold's parents and physician are pleased with his progress and have no plans to make modifications to his medication regimen. The school program will continue to collect and evaluate behavior data as well as share information on any perceived side effects. The coordination between Harold's parents, neurologist, and school program staff ensured that the medication evaluation was conducted in a timely matter and that Harold was not placed on a medication dose that prevented him from engaging in habilitative and preferred activities.

Summary

ASD is a neurological disorder characterized by deficits in social communication and interaction and restricted and repetitive behavior. It is considered to be a lifelong disorder and most individuals with ASD will require continued support throughout their lifetime. Individuals with ASD are at a greater risk of having intellectual disabilities, severe behavior disorders, seizures, sleep and feeding disorders, and obesity than their neurotypical peers. Interventions based on the principles of applied behavior analysis are one of the only established treatments for ASD. Additional research is needed to compare behavioral treatments to identify effective components as well as individual factors that may predict treatment effectiveness. Because of the complexity of ASD, individuals may seek out and receive treatment from a variety of treatment providers and across different contexts. Coordination between providers is paramount because implementation of one treatment may inadvertently affect treatment in another context. The medical home model provides a method to coordinate services across professionals and alleviate the need for family members having to fill a coordinator role. However, this approach is currently lacking for families of individuals with ASD. Therefore, additional research on overcoming barriers to implementing a medical model as well as training for physicians is necessary.

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