CHAPTER 4

AUTISM SPECTRUM DISORDERS:

Information for Pediatricians Supporting Families of Young Children on the Spectrum

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Abstract: Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder affecting in US 1 in 110 individuals.[1] As increasingly younger children are receiving ASD diagnoses, many pediatricians are now faced with the unique needs of parents and other caregivers of newly diagnosed toddlers and young children. This chapter provides an overview of ASD designed to offer information and resources to pediatricians that could, in turn, be provided to families of children newly diagnosed with ASD.

INTRODUCTION

Ellen and Reid have one son named Mason. Mason is 26 months old, delayed in learning to talk and has just been diagnosed with autism. Ellen and Reid have heard of autism but don't feel that they understand what it is. What does this mean for Mason? What will he be like when he's five, ten, twenty years old? These uncertainties scare Ellen and Reid. They have heard that some children with ASD never learn to talk and can have difficulties in school. However, they have also heard that there are programs designed to help children with autism to learn and they want to enroll Mason in one of these programs as soon as they can. The team who diagnosed Mason gave Ellen and Reid a few brochures but they don't feel it's enough information. They decide to visit Mason's pediatrician to see if he can help them better understand ASD and take the necessary steps to enter intervention programming.

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Ellen and Reid are one example of a family who need more information about ASD. Pediatricians, nurse practitioners and other health care staff are often the front line medical staff available to parents for consultation when they either have concerns about their child's development or when they have questions about a new diagnosis. Families may inquire about a number of different topics related to ASD including prevalence, etiology, core symptom domains, the diagnosis process and intervention programming. Medical practitioners would benefit from knowing how a diagnosis of autism impacts a family and how to provide parents with guidance to better understand ASD so that they can take steps to reduce with the symptoms and promote their child's development.

PREVALENCE OF AUTISM SPECTRUM DISORDERS

In the current Diagnostic and Statistical Manual (DSM-IV-TR),[2] five different diagnoses are included under pervasive developmental disorders or as they shall be referred to in this chapter, autism spectrum disorders. These include: (1) autistic disorder, (2) Asperger's syndrome, (3) Pervasive Developmental Disorder Not Otherwise Specified (PDD- NOS), (4) Rett's syndrome and (5) Childhood Disintegrative Disorder (CDD). Although the DSM-IV-TR describes a prevalence rate for autism, the most common pervasive developmental disorder, of 1 in 15000 several recent research reports find the prevalence much higher, occurring at a rate of 1 in 110 live births[1] or 1 in 165.[3] The other ASDs occur at lesser rates than autism. Asperger's syndrome, which includes children who do not demonstrate the language and cognitive delays found in children with autism,[2] is noted to occur at a quarter of the rate of autism.[3] Both Rett's syndrome and CDD are considerably rare and children with these diagnoses demonstrate different trajectories of development than children with autism[4,5] where children demonstrate marked regression in development culminating in severe mental retardation and autism symptoms.[4,5] Rett's syndrome is the only diagnosis under the ASD umbrella that has an identified genetic etiology.[4] Rett's syndrome is rare, occurring in 1 in 10,000-20,000 females[4] while CDD is estimated to occur in 1 or 2 children in 100,000.[3]

ETIOLOGY

Although the specific mechanisms and etiology of autism are unknown, researchers have accumulated evidence for both biological and environmental considerations. Over the past 50 years, notions regarding the etiology of ASD have changed drastically. During the height of the psychoanalytic movement, ASD was thought to be the product of detached or cold parenting, associated with the notion of the "refrigerator mother", a notion that has long since been disregarded.[6] Throughout the 1960's ASD was identified with schizophrenia and psychosis, however comparative studies have demonstrated this too is not the case.[6] Once considered a condition found only in children, researchers have demonstrated that ASD is a lifelong neurodevelopmental disorder.[6] Through early twin studies and later, the examination of the infant siblings and close relations of individuals diagnosed with autism, researchers found that ASD is highly heritable (90%) with a recurrence risk of 5-6% when one child in the family has been diagnosed with ASD.[7] Although some genetic markers associated for increased risk of ASD are being examined (for more information on genetics and ASD see Abrahams and Geschwind[8]), less than 10% of ASD diagnoses may be associated with a known medical condition.[9] Clear links between one or several biological or environmental mechanisms across the population of individuals with ASDs have yet to be identified. The notion of a single gene being responsible for ASD in individuals across the spectrum has been more or less abandoned by the research community.[7] Rather, it is suggested that a combination of biological factors and environmental triggers leads to the expression of the behavioural profile associated with ASD, which is referred to as the gene dosage model.[7] This model suggests that the impact of these factors is cumulative where once a certain threshold has been reached, behavioural symptoms can arise—a notion currently being explored by researchers.[7]

Resources on ASD Prevalence and Etiology

There are several resources that medical personnel can use to keep up to date on the changing prevalence rates of autism.For example, the **National Centers for Disease Control and Prevention (CDC)** is an American organization with a large database of online resource available, specific to the prevalence and etiology of autism: http://www.cdc.gov/ncbddd/autism/addm.html. Further, an information booklet suitable for parents can be found at the **National Institute for Mental Health (NIMH)**. It includes brief research summaries and information regarding the prevalence and etiology of ASD in the United States. Hard copies of the booklet can be ordered from NIMH. Online it can be viewed at: http://www.nimh.nih.gov/health/publications/autism/complete-index.shtml

EARLY DIAGNOSIS: SCREENING OF 'RED FLAGS'

One of the most intriguing features of autism is the range of ways it can present initially and across the lifespan. Despite this variability there are several key 'red flags' that have commonly been observed during the screening process.

Red Flags Noted by Parents

Retrospective report using home video tapes and now prospective systematic study of infant siblings of children with ASD, have revealed that autism symptoms in the three core domains can typically be recognized in children between the first and second years of life.[10] The presence of autism symptomatology can emerge in different patterns with some children demonstrating delays in early life in domains such as language, communication, social, cognitive and motor skills while others may demonstrate a marked regression in their skills.[7] Delayed development and achievement of early milestones (e.g., early language including verbal, nonverbal communication and early social skills including joint engagement and imitation) is the more common presentation. A lesser reported 20-30% of children demonstrate patterns of regression or skill loss.[10]

Delays or marked losses in early expressive language are usually what brings parents into their pediatrician's office. Most families voice concerns about language development by the time the child is 18 months old.[11] Children are now being reliably diagnosed with austism as young as 24 months of age.[12] Diagnoses at age 2 and 3 have been demonstrated to be stable over time, especially if clinicians are using standardized tools[13] including the Autism Diagnostic Observation Scale Generic (ADOS-G)[14] and the Autism Diagnostic Interview Revised (ADI-R).[15] However, some diagnostic changes may still occur up to seven years of age.[16]

Autism Screening Resources

Several reliable screening tools have been developed to assist physicians and clinicians in assessing risk for autism. The Modified—Checklist for Autism in Toddlers (M-CHAT) is available for free download for medical, clinical and educational purposes (checklist and scoring available at: www2.gsu.edu/~wwwpsy/faculty/robins.htm). This screener has been validated for toddlers 16- 30 months of age and can be administered and scored in less than two minutes during a medical appointment. Further understanding of the 'red flags' for autism can be obtained by examining a set of instructive videos contrasting typical and atypical development that have been posted online by **First Signs**, a nonprofit organization in the United States under the direction of a Scientific Advisory Board including prominent autism researchers. The site provides resources and information for both parents and clinicians regarding the behaviours of autism and their presentation in very young children with autism: http://www.firstsigns.org/

DIAGNOSIS: GETTING IT RIGHT

There are three core behavioural domains that are examined when a diagnosis of autism is being considered. In accordance with the current Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), in order to receive the diagnosis, a child must demonstrate: (a) impairments in social skills; (b) deficits in the domain of communication and (c) the presence of stereotypic and repetitive behaviours.[2] However, it should be noted that the criteria for an ASD diagnosis is under review and revisions will be published in the upcoming DSM-V.[17] Although the diagnosis is now often made in children prior to school entry, in each of the three domains the challenges and atypical behaviours can present differently across the lifespan and across each individual diagnosed. In order to address the immediate needs of most families with a new diagnosis, the information provided here is relevant to the behavioural presentation of these domains in toddlerhood.

Core Symptom Domains: Expression in Toddlers

Below is a description of the diagnostic criteria associated with each of the three behavioural domains in accordance with criteria set out in the DSM-IV-TR[2] as well as a description of their expression in young children with ASD.

Social Skills and Communication

For an autism diagnosis, children must demonstrate at least two of: (1) difficulties in social interaction including challenges with nonverbal social behaviours (e.g., gestures, eye contact), (2) lack of age appropriate relationships with peers, (3) lack of sharing of social experiences with another (e.g., sharing, showing behaviours) and/or (4) a lack of social reciprocity in an interaction.[2] In terms of the domain of communication and language, children must demonstrate challenges through either delayed verbal language, lack of ability to start or maintain a conversation, the presence of repetitive language (e.g., echolalia, stereotyped language) or a lack of symbolic play.[2]

A notable deficit in joint engagement occurs in many young children with ASD and is considered an early warning sign.[18] Joint attention or engagement, involves the coordination of one's attention between another individual and an object or activity and have been found to be foundational for not only language skills but also skills in the social and academic domains.[18] Early joint attention behaviours can include sharing and directing attention as well as following another person's eye gaze.[19] A lack of imitation skills is also seen as an early sign of autism.[19] Immediate imitation, copying what others sounds or actions, is another preverbal skill that is foundational to later language development.[19] These early social communicative skills have been identified as predictors of early language development.[18,20]

The American Academy of Neurology and Child Neurology Society practice recommendations, for autism assessment four different diversions in communication development that indicate assessment taking place with a young child should include: (1) a lack of babbling or gestures in the first year, (2) lack of single words by 16 months, (3) lack of generative two word phrases by two years of age and, (4) any loss of language.[21] In terms of a lack of babbling or gestures, early symbolic gestures are also often either delayed in children with ASD.[22] Alternatively, when children with ASD do demonstrate gestures, they are less often coordinated with vocalizations than those of typically developing children.[23] Criteria 2 through 4 relate to verbal language. Children with ASD often develop verbal language at a different rate and later in life than typically developing children.[24] Delays in verbal language or less frequent and varied use of language than typically developing children often encourages assessment.

Stereotypic and Repetitive Behaviours

The domain of stereotypic and repetitive behaviours (SRBs) and restricted or circumscribed interests includes a wide range and topography of behaviours (for an examination of the forms and functions of SRBs see Turner, 1999[25]). In accordance with DSM-IV-TR criteria, children must demonstrate one or more of an intense preoccupation with a particular interest, an intense lack of flexibility (e.g., scheduling, routines, rituals), repetitive motor movements (e.g., hand flapping, spinning) or intense focus on components of an object (e.g., the wheels of a toy car).[2]

In some ways SRBs are not unique to children with autism or other developmental delays. Very young typically developing children can demonstrate in the first 12 months of life including repetitive motor behaviours such as waving and rocking which can serve to reduce anxiety and create repetition in learning.[26] However, for typically developing children these behaviours, most often, fade after the first year while in the population of children with ASD, the frequency and intensity of the behaviours tends to increase. Mixed results have provoked discussion in the literature as to whether or not in very young children, there are consistently observable differences in SRBs between ASD population compared to typically developing children and children with developmental delays.[26,27] Watt et al[27] explored differences between these populations and found that the sample of children with ASD demonstrated repetitive object exploration (e.g., banging, tapping, spinning or rolling of objects), repetitive motor movements (e.g., hand movements, body rigidity/stiffening) and repetitive sensory behaviours with significantly greater frequency and for significantly longer period than children who were typically developing and those with developmental delays.

Resources for Parents: ASD Core Symptom Domains

Although parents of newly diagnosed children with autism may have some understanding of what a diagnosis of autism means, it is common for them to feel confused about the core symptoms domains and how autism may impact not only their child's development but also their family functioning. **Autism Speaks,** an American autism science and advocacy group, has created a package called the "*100 Day Kit*" designed to support families through the first 100 days after the diagnosis. The kit contains basic information regarding ASD, information regarding many different kinds of intervention programming and steps to help parents take the necessary steps forward to obtain support: http://www.autismspeaks.org/community/family_services/100_day_kit.php.

FIRST STEPS INTO EARLY INTERVENTION

Research is accumulating to indicate that early intervention provided before the age of three and a half years may be of greater impact than intervention provided after five years of age.[11] A variety of intervention programs are available for children with ASD and recently, a number of programs have been developed specifically for very young children with ASD such as Mason who was introduced in the beginning of this chapter. However, research examining the efficacy of individual programs and the details of the programs' impact on children's developmental trajectories over time varies by intervention and in some cases, is just beginning to emerge. Available services and funding policies will differ based on a family's geographic location, however, for many families with a newly diagnosed young child such as Mason's family, a number of intervention programs may be available and there are several considerations to be made when choosing and implementing an intervention.

Intervention Components

In 2001, the National Research Council[28] published recommendations for evidence based intervention practices for individuals with ASD. Based upon these recommendations, the intervention needs to be individualized to the child's needs and using positive and empirically supported methods, address the development of the child's functional communication, facilitate the teaching of social skills in natural situations with peers, address the child's cognitive development (including functional academic skills) and strategically address challenging behaviours that can negatively impact the child and his or her family. Ongoing evaluation of the child's progress is necessary to re-assess the goals targeted within the intervention and the appropriateness of the intervention program.

Intensity

Research examining intervention 'dosage' is emerging. Precedent for intensity was set in early studies using applied behaviour analytic interventions conducted by Ivar Lovaas in the 1980s and 1990s. These studies recommend at least 40 hours of week of this behavioural mass trialed intervention approach in order to obtain optimal child outcomes.[29] More recently, recommendations from the NRC[28] indicated that children should receive at least 25 hours a week of intervention. Yet, these levels of intervention intensity delivered by highly trained clinicians can be difficult to manage in terms of the financial costs, the human resources involved and the time required from the family. Dawson and colleagues[30] recently reported in a 2010 randomized control trial that families of young children enrolled in their examination of the Early Start Denver Model were not choosing to utilize all 20 hours of "clinician implemented intervention" offered to them with the mean accepting just over 15 hours a week. Families may vary in their willingness and their ability to accept high level of intrusion into their homes amidst the many other demands inherent in these parents' lives. This should be a consideration when contemplating the implementation of parent mediated vs clinician directed intervention services.

Parent vs Clinician Implemented Intervention

The active inclusion of parents in intervention is a recommended practice.[28] Several interventions that target the communication and language development of toddlers utilize a parent-mediated method of "intervention delivery" including the Early Start Denver Model,[30] Hanen More Than Words Program,[31] Joint Attention Based Intervention[32] and Pivotal Response Training.[33] Although the content and delivery of the programs vary, each of these programs engages in parent training or education, which Mahoney et al[34] call the "process of providing parents and other primary caregivers with specific knowledge and childrearing skills with the goal of promoting the development and competence of their children". Evidence is now accumulating which supports the use of parent implemented interventions with young children with ASD including positive effects for children (e.g., increased communication skills,[35] social initiations,[36] joint attention[32]) and positive effects for parents (e.g., increased positive affect[37] and mastery of intervention content.[33] However, this body of research is relatively young and it is unclear what level and forms of supports are required to assist parents in implementing high quality intervention over time as their children grow and develop.

Resources for Parents and Caregivers: Intervention

Knowing where to begin accessing services for a child with autism can be a complicated road to navigate. Understanding the range of services available for comprehensive early intervention programs is necessary before parents make important decisions regarding their child's plan of intervention. Physicians should feel confident in directing parents to reputable sources and organizations as a good place to begin looking for intervention services in their area. **Autism Speaks** provides a comprehensive overview of the different treatment options that are available in the United States, many of which are also available in Canada: http://www.autismspeaks.org/treatment/index.php. **The Association for Science in Autism Treatment** is a nonprofit organization which aims to provide a range of evidence-based resources for caregivers and professionals seeking information regarding autism: http://www.asatonline.org/. More information regarding interventions that have an evidence base can be found on the **National Autism Center (NAC)** website (www.nationalautismcenter.org). The NAC is a nonprofit organization that recently published a comprehensive report, the National Standards Report, that summarizes effective research validated educational and behavioural interventions for children with autism. This report can serve as good guide for clinicians to guide parents in selecting appropriate interventions.

THE IMPACT OF ASD ON THE FAMILY

Parental Stress and Functioning

Research has demonstrated that parents of young children with autism such as Ellen and Reid undergo an enormous amount of stress during the diagnostic process[38] and in particular, during the six-month period following diagnosis.[39] Further research has demonstrated that overall, parents of children with ASD report higher levels of stress than parents of children with other developmental disabilities[40] and that the process of developing care and education plans for children with ASD is also uniquely stressful.[38]

Importance of Reliable Sources

Several examinations of the information sources that parents use to obtain information about ASD have been published recently. Surveys exploring the choice parents make in regard to treatment[41,42] are beginning to emerge however, how parents make sense of the conflicting reports found online from professionals and those familiar with autism, or reported in the popular media to make decisions regarding their children's health, education and supports is not well understood. These surveys demonstrate that the information sources most often used by parents are other parents of children with ASD[43] while information and support were also frequently sought out from books, web pages and newsletters than medical and educational professionals.[43] Similarly, when a small sample of parents of young toddlers were asked directly, what information supports they found useful, they reported that information gleaned from other parents is most useful but desired to have more information provided by medical and clinical staff in the time immediately after the child's diagnosis and the transition into early intervention.[44] The importance of social supports have been documented within the autism literature[45,46] where social support may be a predictor of successful adaptation and a coping mechanism for the increased stress that accompanies having a child with exceptional needs. However, with the sheer number of behavioural, educational, biomedical and alternative treatments available to families of individuals with ASD and their toll on resources including human, family and financial, it is important that families receive up to date, relevant and accurate information about the evidence around these interventions. It is difficult to examine the quality of information received by parents from nonprofessional sources. Medical and clinical front line professionals have the potential to provide and direct parents to reliable sources of information. These efforts will ensure that vulnerable and stressed parents of young children with ASD do not fall prey to inaccurate information that may prevent optimal care for their youngster.

Resources for Parents and Caregivers: Supports

A wide range of support groups are available for caregivers of individuals with ASD. These are accessible through countrywide societies that can be accessed online. Caregivers and practitioners worldwide can seek out local groups through autism societies and advocacy organizations at regional and national levels.

- *The United Kingdom*
  The National Autistic Society is a broad resource which links caregivers with local support groups and provides resources to a range of professionals working with children with autism. It has a comprehensive directory for local organizations

and services throughout the UK: http://www.autism.org.uk/en-gb/our-services/get-help-in-your-area.aspx

- *The United States of America and Canada*

  The Autism Society of America (ASA) is a general ASD information resource suitable for both caregivers and professionals. Local organizations throughout the country, affiliated with the ASA, can be accessed at the national website: http://www.autismsource.org/

  The Autism Society of Canada (ASC) is a nationwide organization providing general ASD information and facilitates connections with local organizations within Canada: http://www.autismsocietycanada.ca/provincial_territorial_societies/overview/index_e.html

CONCLUSION

Families who are in the process of obtaining or have just received a diagnosis of autism for their young child such as Ellen and Reid, can feel enormous amounts of stress and anxiety. Obtaining a diagnosis for a child can be both relieving and frightening for parents. In any case, families are forced to navigate a wide array and large volume of information in order to effectively navigate this new terrain for their child. The internet is a common place to search for autism information but it can be difficult to identify good sources of information. Pediatricians can assist families by first identifying evidence based accurate sources of information and then helping families parcel through and unpack the dense information in order to support parents in their learning and to facilitate families' uptake of appropriate services and supports.

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