



KIT

"Keeping In Touch"

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Resource Article

Respecting that each family copes with having a child with a disability differently, this month's KIT article presents the real life stories of three families that have a child with the diagnosis of an Autism Spectrum Disorder. The authors of the article, Jayne Lytel, Jorge Lopez-Garcia, and Patricia Stacey, are the parents of children with autism. The article is titled Listening to Parents Understanding the Impact of Autism on Families.



As each parent describes their family experiences, the reader gets a vivid sense of the multiple challenges that families of children with autism face and the extraordinary strengths that families exercise. Also highlighted are the important partnership roles that professionals can play in a family's life. However, in reality the role of professionals is minor relative to all that each family has to cope and deal with.

In the first story, Jayne, the mother of Leo and Lucas, describes how attending a birthday party for her older son (Lucas) was a turning point for her. She describes it as an incredibly unpleasant experience. It was when she first experienced feeling like the outsider in the company of her peers. Having told the host of the party that Leo was recently diagnosed with autism, the host actually introduced him to the group as "having autism." To Jayne's surprise, the host identified her younger son by his diagnosis not Leo, Lucas's younger brother. Jayne's telling of this experience reinforces the vital importance of seeing the child first not the disability. Jayne described her feelings as "...from this point forward the world would see me for my wounds not my bravery..." (p. 47). As her story unfolds, she

describes how the bravery and strength of her family were put in action to navigate the maze of services while continuing to face a host of new and dynamic challenges, such as a compromised social network, which Jayne recalled, "some friends deserted me, and others passed judgment and made hurtful comments" (p. 48). The family continued to tap into their strengths and the support of trusted professionals and celebrated Leo's gradual progress and success as he eventually progressed to the point of losing the diagnosis of autism.

Jorge describes the experiences of being a new parent and not being abreast of developmental expectations. It wasn't until the birth of their second child that Jorge and his wife saw that their son Max was not developing like his younger sister. Being from a Hispanic family, Jorge also discusses the challenge they faced with discussing Max's special strengths and needs. Jorge also describes the extra demands they faced how it was like living in a "world nobody wants to enter" (p. 49).

Patricia's story started when her son Walker was very young. She knew something was wrong right away, as Walker showed no interest in making eye contact or even looking at faces. Rather, he was memorized with the light that came in from the windows during the day and from the illumination of the lights in the home when it was dark outside. Fortunately, Walker and his family started receiving early intervention early on. Patricia describes this as both a blessing and a chore. It was a bundle of work trying to get Walker to shift his steadfast interest in lights to connecting with his parents and others. Patricia and her family, with the support of early intervention, spent many exhausting hours trying to build circles of communication with Walker. Gradually the fruits of their labor began to pay off and Walker started to show increasing interest in

others and began to show pleasure instead of pain as he engaged with others.

The stories these three parents share in this month's KIT article reinforce the incredible efforts and trying moments parents of children with autism face.

Lytel, J., Lopez-Garcia, J., & Stacey, P. Listening to parents understand the impact of autism on families. *Zero to Three*, March 2008, 46-52.

On the WWW



Autism Research Institute (ARI) at www.autism.com is this month's web resource. Bernard Rimland, Ph.D., an internationally recognized authority on autism and the father of a son with autism founded this non-profit organization, which has been in operation since 1967. Its mission is conducting and sharing research on the "triggers of autism" and "methods of diagnosing and treating autism." The site is filled with resources for parents, professionals, and individuals with autism.

Available at the site are links to webcasts, articles, and family stories of their celebrations and challenges. As an international organization, some information is translated into the following languages: Arabic, Armenian, Chinese, German, Spanish, French, Italian, Japanese, Korean, Portuguese, Russian and Turkish. Providers working with families that speak a different language may find this quite helpful.

Under the tab "for individuals" are articles written by Stephen Shore and Temple Grandin. Additional articles are organized by the following topics:

- Education
- Self Advocacy
- Social Issues
- Living Arrangements
- Sexuality
- Transition from School to Work
- Sensory Issues
- Health Issues
- Persons with Aspergers

What Do the Data Say?

How has the number of cases of autism changed over time?



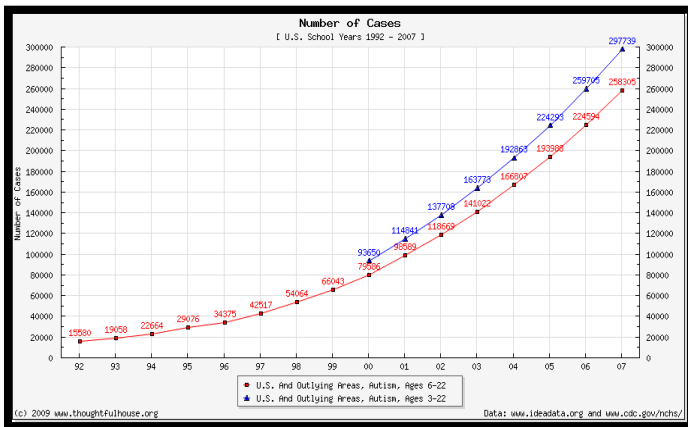
To answer this question data from the U.S. Department of Education, Office of Special Education Programs (OSEP) were analyzed and reported in the following tables by Thoughtful House, whose mission is "fighting for the recovery of children with developmental disorders through the unique combination of medical care, education, and research."

States are required to collect child count data for the 13 different special education eligibility categories, defined by the Individuals with Disabilities Education Act (IDEA). Included in the categories is autism. Each state collects its own data and submits it to OSEP. These data are in turn aggregated by OSEP and used for reports for the US Congress. OSEP data tables are available at www.ideadata.org

When reviewing the data it is important to note that the child count data are point in time and not a cumulative count of students served during a school year. Therefore, it is likely that states serve more students during the school year. State policy changes over the years may also influence the data reported. The data tables presented below are available at www.fightingautism.org

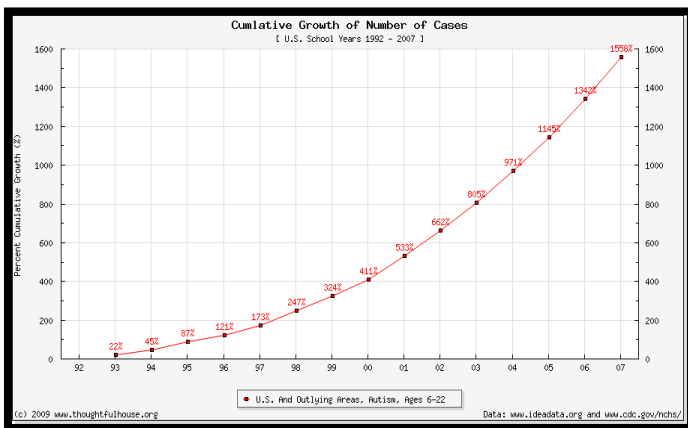
Table one illustrates the number of reported cases of autism during school years 1992 through 2007. The red line represents students 6-22 years of age while the blue line includes students 3-22 years of age. From this table alone it is evident that the number of cases of autism has been progressively on the rise since 1992 when autism was added as a separate eligibility category.

Table 1



Looking at these data in a different way, table 2 below illustrates the cumulative percentage growth of cases of autism that states report.

Table 2



These data and other data sets on the prevalence of autism provide alarming evidence of the increase of autism spectrum disorders. The widespread incidence of ASD across the country also shows that the conditions can affect anyone. The increase in the number of cases reinforces the urgent need for more research.

Consultation Corner

From September 2009 through January 2010 the consultation corner topic is:



ASD and the Role of Early Interventionists

Celine Saulnier, Ph.D., the Training Director for the Autism Program at the Yale Child Study Center and

Karyn Bailey, the Social Work Director for the Yale Child Study Center's Post-graduate Social Work Training Program are the KIT Consultation Corner experts sharing their knowledge and experience.

1. If an early intervention provider suspects ASD should he/she tell the family? If so how and when? How might it be different if the family suspects ASD or if the family has never heard of ASD? (Karyn Bailey)

A suspicion of ASD suggests that a given child is evidencing areas of need in the communication, social, and behavioral domains. Generally, there is consensus that intervention should begin as soon as needs are identified. Thus, one could argue that an early intervention provider has an ethical duty to inform parents of suspicion of ASD without delay. This, of course, should be done with care and consideration. When the family suspects ASD, this provides a natural entrée into a discussion of how diagnostic considerations relate to their child's presentation. When working with a family that is unfamiliar with ASD and/or is not raising concerns, it is sometimes helpful to focus on the specific areas of development that are worrisome. For example, "Mrs. Smith, have you noticed how Jack prefers to line up all of his cars rather than pretend to go for a ride?" "Have you noticed how Jack takes you by the hand and leads you to the refrigerator when he wants juice without ever looking at you or saying anything?" If the parent confirms these behaviors, a service provider can move the conversation to a recommendation for an evaluation of social development. If the parent is not able to confirm these behaviors, it may be helpful to encourage the parent to monitor and possibly log these behaviors as a means to raise awareness. This can then be followed by a conversation to confirm the existence of the behaviors and the subsequent recommendation for an evaluation of social development. Words do make a difference. An evaluation of "social development" is typically easier for families to consider rather than an assessment for "Autism." However, using the term autism or ASD should not be avoided if the team believes an assessment for autism is warranted.

2. When should the diagnosis be made? (Celine Saulnier, Ph.D.)

Current research on children with autism spectrum disorders (ASD) shows that about 50% of parents are typically concerned about their child's development in the first year of life, and that almost all (90%) are concerned by age two (e.g., Zwaigenbaum et al., 2009). The most common symptoms of autism in very young children including the following: no development of babbling/cooing by 12 months; no single words by 16 months; no spontaneous phrase speech by 24 months; limited responsivity to name; limited joint attention skills; limited use of communicative gestures; poor eye contact; and delays in the development of functional and symbolic play (e.g., Chawarska et al., 2009; American Academy of Pediatrics). Although each of these symptoms, in and of themselves, may not be indicative of autism, they are cause for concern and merit further evaluation. The American Academy of Pediatrics currently recommends that pediatricians screen for autism in all children, regardless of concern, at least twice prior to the age of 24 months (e.g., during the 9, 12, 18 and 24-month well visits). Screeners can be used to detect at risk behaviors, although they should never be used to actually diagnosis a child. One of the most widely used screeners is the *Modified Checklist for Autism in Toddlers* (MCHAT; Robins et al., 2001), which can identify the red flags listed above in children ages 15 to 30 months.

Research also shows that when diagnoses are made just after the second birthday they tend to be stable over time. In an early detection study conducted by Chawarska et al. (2009), 80-90% stability of ASD diagnoses was determined between the ages of 2 and 4. Upon diagnosis, 70% of 2 year-olds exhibited significantly delayed verbal skills compared to only 25% with significantly delayed nonverbal skills. By age 4, less than 50% continued to present with delays in development. Thus, early detection and subsequent intervention proves beneficial.

Despite the wealth of research showing that diagnoses can be made in the first two years of life and advocating for early detection, the average age of ASD diagnoses is well over the age of 3, denoting at least a year's gap between when parents are raising concerns and when action is actually set into place (Zwaigenbaum, 2009). This gap is highly concerning, especially considering the well documented fact that early intensive intervention is imperative for all

children with ASD (e.g., National Research Council, 2001). Therefore, the diagnosis of ASD should be made as early as possible, with early intervention services set into place to address any and all areas of concern immediately upon detection.

References

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- Zwaigenbaum, L., Bryson, S., Lord, C., et al. (2009). Clinical Assessment and management of toddlers with suspected Autism Spectrum Disorder: Insights from studies of high-risk infants. *Pediatrics*, 123: 1383-1391.

Continuing Education for KIT Readers

The Comprehensive System of Personnel Development (CSPD) is offering a continuing education opportunity for EDIS KIT readers.



In line with the focus on ASD and the Role of the Early Interventionist, readers are invited to receive continuing education contact hours for reading the monthly KIT publications (September 2009 through January 2010) and completing a multiple choice exam about the content covered in these KITs.

If you are interested, complete the exam online at www.edis.army.mil and upon successful completion, you will receive a certificate of non-discipline specific continuing education contact hours.

Please send your Consultation Corner questions and KIT ideas via email to ediscspd@amedd.army.mil