Catching autism earlier

A flood of new research is advancing our understanding of autism and highlighting the need for earlier interventions

By Eve Glicksman

One in 88 children. That was the jarring statistic released in March when the Centers for Disease Control and Prevention reported the number of U.S. children with autism. If that number didn't get your attention, the report also announced a 23 percent jump in autism rates from 2006 to 2008, and a 78 percent increase since 2002.

Some researchers say the dramatic data are due to broader definitions of autism and earlier identification, but CDC's higher-than-expected statistics are a call to action with implications for psychologists.

"Many psychologists have little or no training in working with autistic adults. Twenty years ago, adult psychologists might have gone through an entire career without really needing this information," says Judith Miller, PhD, training director at the Center for Autism Research, Children's Hospital of Philadelphia. "Today, however, it's important for the general psychologist to understand how mental disorders manifest in people with autism spectrum disorders (ASD). There will be opportunities to incorporate clients with ASD into a more general practice and also to develop specialty services for these unique and interesting individuals."

With the increased attention on ASD, federal agencies, advocacy groups and others have raised or targeted millions of dollars for research to tease out the causes of ASD and identify how best to treat it. The flurry of research began around 2006, with the Combating Autism Act. The federal Interagency Autism Coordinating Committee also spearheaded much of the recent activity.

The latest findings are changing what we know about autism and, in particular, stress the need for diagnosis and treatment before age 6 when treatment is known to be the most effective. The newest research suggests it's even possible to reverse autism symptoms in some infants and toddlers or, more commonly, decrease the severity of the symptoms.

"The hope is that if we can improve intervention with infants and toddlers, many of them will be able to leave their disabilities behind by age 5," says Sally J. Rogers, PhD, a professor of psychiatry and behavioral sciences at the M.I.N.D. Institute at University of California Davis Medical Center.

Diagnosis and assessment

Experts are finding they can now reliably diagnose ASD in children from 12 to 18 months old by looking at their social deficits or repetitive actions. But the trajectory of the disorder is
unpredictable, says Catherine Lord, PhD, who has studied high-risk ASD babies from 18 months to 36 months (Journal of Consulting and Clinical Psychology, Lord, et al. 2012).

"In young children—especially under 2-and-a-half years—we shouldn't treat it as a lifetime diagnosis. We can offer parents some hope that a very young child will move out of the autism spectrum or improve," says Lord, who directs the Center for Autism and the Developing Brain at the Weill Cornell Medical College/New York Presbyterian Hospital.

At the same time, she adds, other children with ASD regress—and this can happen whether or not the child receives treatment. The reasons are unknown, but Lord's study highlights the need to frequently monitor and re-evaluate the child throughout the preschool years.

Psychologists need to advise parents that the "wait-and-see" approach is not appropriate when autism is suspected, says Laura Schreibman, PhD, a professor at the University of California, San Diego, who directs the university's Autism Intervention Research Program. Delaying a diagnosis can mean giving up the significant gains of intervention that have been demonstrated before age 6. Early intervention can even prevent regression of communication and social skills in some cases, she says.

Rogers explains that it's easier to develop comprehensive treatment approaches for infants and toddlers than for older children. "This is because they are not as diverse a group as 10-year-olds," she says. "We haven't yet isolated the key ingredients and variables affecting treatment outcome in older children who need a more individual approach," she says.

**Intervention for young children**

One research-proven intervention for very young children with ASD is the Early Start Denver Model (ESDM), a structured teaching and relationship-based approach in the child's home that uses play as a learning tool. A randomized, controlled trial over two years found that children age 18 to 30 months participating in ESDM significantly improved their IQs, social interaction and language abilities (Pediatrics, Dawson, et al. 2010). The children received 20 hours per week of ESDM intervention plus five or more hours of guided care from parents.

Rogers, who co-authored the study and developed the ESDM approach with Geraldine Dawson, PhD, chief science officer for Autism Speaks and professor of psychiatry at University of North Carolina, Chapel Hill, notes that not all children will respond to the same treatment, though. Additional studies have underscored that it's the earliness of the intervention—not the method itself—that leads to the positive outcomes. "There is more than one way to get good outcomes, and different therapists will gravitate to different methods," she stresses.

LEAP (Learning Experiences and Alternative Program for Preschoolers and Their Parents) is another successful intervention for young children. This treatment model mixes children with ASD with typically developing preschool kids in the classroom. In this way, the ASD child has the opportunity to learn appropriate language and behavior from other kids who are taught how to interact with them. The learning program is designed so kids become engaged with activities "organically"—not through the direction of a teacher.
One study found that the best LEAP outcomes were linked to how well the teacher complied with the protocol (Topics in Early Childhood Special Education, Strain, et al. 2011). Teachers who received intensive training and coaching over the two-year study adhered to the LEAP practices 90 percent of the time. Their students with ASD showed significantly greater improvements on behavioral measures and symptoms than the ASD students whose teachers were simply given the LEAP manual to follow.

Properly trained parents can also help infants and toddlers with autism make gains in areas such as "joint attention," says Dawson. Joint attention skills involve sharing through pointing or coordinating looks, for instance, or sustaining attention with a parent or an activity. In one study (Journal of Autism Development Disorder, Kasari, et al. 2010), parents were trained from once a month to several times a week on how to expand their children's interest in play. The quality of the parents' participation—not the number of training sessions—was linked to how much progress was made.

### Causes: prenatal development factors

Researchers have not yet been able to pinpoint the exact causes of ASD, but they are closer. They do know that autism results from a genetic mutation in 15 percent to 20 percent of cases. But environmental factors can combine with and increase a genetic susceptibility, says Dawson. Risk factors identified to date include:

- Mother's exposure to pesticide (Environmental Health Perspective, Shelton, et al. 2012).
- Mother's exposure to air pollution (Environmental Health Perspective, Volk, et al. 2011).

Another risk is having a sibling with the condition. Scientists have long documented that autism can run in families: estimates are that a sibling of an ASD child has an increased risk of 3 percent to 10 percent of having the disorder. But last year, a larger sample and more thorough study in Pediatrics (Ozonoff, et al.) determined that the sibling recurrence rate is much higher, with nearly one in five siblings likely to develop autism.

This finding again underscores the need for increased vigilance in monitoring and screening at-risk infants as early as possible, when their brains are more malleable, says study co-author Wendy Stone, PhD, professor of psychology who directs the University of Washington Autism Center. "If we can begin intervention for high-risk children in the first or second years of life, we may find the effects are much more powerful," Stone says.

Another study (Molecular Psychiatry, Constantino, et al. 2012) showed that half-siblings are also at risk. By examining half-siblings, researchers were able to show that mothers and fathers appear to transmit genetic risk equally in families where autism recurs. Researchers compared
the genetic structure of the maternal half-siblings with autism with that of the full siblings with autism. The risk was about half of what they saw in full siblings.

Psychologists can help parents identify ASD early on by teaching them how to observe and look for behavioral signs of the condition, says Rogers, who also co-authored the *Pediatrics* study. These signs typically involve lack of interaction—not initiating or responding to cuddling, for instance, or not responding to his or her name or not smiling by 9 months of age.

Knowing about the elevated risk for siblings of children with ASD also raises the issue of genetic counseling, she adds. Psychologists may want to suggest this option to families who are concerned.

**Early brain development**

Could ASD be diagnosed even earlier? The answer appears to be yes. More sophisticated brain imaging technology such as functional MRI has enabled scientists to trace infants' neurodevelopment. In one study (*American Journal of Psychiatry*, Wolff, et al. 2012), also co-authored by Dawson and Joseph Piven, research professor of psychiatry at University of North Carolina at Chapel Hill, researchers compared the brains of infants who had siblings with autism with those of infants who did not have that high-risk factor. The study, employing diffusion tensor imaging, identified marked differences in the white matter (fibers that surround neurons and support transmission of neural signals) among high-risk six-month-olds who would later develop ASD. These changes were seen six months to a year before affected children typically show the full range of outward signs of autism.

Stone hopes such findings will herald a new ASD risk-prevention model. "By developing new ways of working with very young children, we hope to change their brain architecture and improve their developmental course," she says.

In other work, researchers are learning more about interactive strategies parents can use to help at-risk infants in the first year of life. "A child of 11 months is too young to participate in structured behavioral therapy, but parents are in a position to help in other ways to improve emotional engagement and promote eye contact or language development through play with toys, early babbling and nonverbal gestures," says Dawson.

**Interventions for older children**

When ASD is diagnosed in school-age children or teens, it is a lifelong condition. At this stage, the brain is more developed and intervention becomes more complex. There are far fewer studies of ASD in school-age children and teens, but a roundup of the latest findings showed that intervention could improve an older child's social competence and peer relationships, too. (*Current Opinion in Pediatrics*, Dawson, et al. 2011). In particular, "friendship training" enhanced the emotional development of children age 7 to 12 and their ability to have empathy. Older children with ASD also can make strides in communication, adaptive behavior and
cognitive abilities, although the improvements have not been as dramatic as in preschoolers with ASD who received interventions.

Cognitive behavioral therapy combined with social skills instruction has proven successful in reducing anxiety (a common co-morbidity in ASD) and aggression in some high-functioning teens and adults with autism. For autistic children with intellectual disabilities, systematic desensitization was the more effective therapy for anxiety (*Developmental Neurorehabilitation*, Lang, et al. 2010). For treating aggressive behavior, one study (*Journal of Child and Adolescent Psychopharmacology*, Frazier, et al. 2010) found that combining behavioral interventions with antipsychotic medication is more effective than using medication alone.

Future research needs to compare a variety of treatments for older children with ASD, Dawson says. In addition, there needs to be long-term follow-up to determine what may be needed to sustain any gains throughout the person's life.

Perhaps the largest gap in autism research, programs and services pertains to adults with the condition. The National Institute for Health and Clinical Excellence, in association with The National Health Service in England and Wales, took the step of issuing clinical guidelines this year on the referral, diagnosis and management of autism in adults. The document for physicians and other health-care professionals provides a clinical pathway of care for adults with ASD, including when a diagnostic assessment is warranted.

Many more new studies on autism are likely as funding for ASD research increases. The Interactive Autism Network (IAN) created by the Kennedy Krieger Institute is facilitating the collection of autism data with an online registry that includes information from 43,000 people with ASD or their family members.

Earlier this year, a study in the *Journal of Autism and Developmental Disorders* (Daniels) authenticated the IAN database participants and validated their responses on questionnaires. This means researchers can use the network with confidence, says Ericka Wodka, PhD, a pediatric neuropsychologist at the Kennedy Krieger Institute's Center for Autism and Related Disorders. She believes the data can accelerate autism breakthroughs and make research more cost-effective and efficient. More than 500 studies have already drawn data from the network or used it to recruit families for their own studies. "Online-based research is good for families, too, because they can participate in their own homes and on their own time," says Wodka.

Meanwhile, other psychologists are excited by research focused on determining which treatments are best for children at different developmental stages. "Brain research will help us learn how to individualize treatment so we can tailor it to each child," UCSD's Schreibman says.

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