RAISING THE BAR ON AUTISM
Key Programs Lower the Age for Detection and Intervention

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Raising the Bar on Autism

New programs help lower the age for detection and effective intervention

BY CHERYL ENGLAND

As anyone who is familiar with autism spectrum disorders knows, this is not atypical behavior. But numerous studies have shown that early detection and intervention—before the age of four at the latest—are generally the most effective in providing the best long-term prognosis. "Certainly, some interventions such as social skills training or occupational therapy are only appropriate at older ages," says Alycia Halladay, PhD, Director of Research for Environmental Sciences with Autism Speaks’ Move the Needle Initiative. "But early interventions give the child the greatest likelihood of being mainstreamed into regular school and not showing some of more disabling symptoms of autism"—symptoms such as behavioral, intellectual, social or communication problems. That's why a number of new programs, initiatives and even new laws—many of which have been initiated in L.A. County—aim to lower the age at which children are diagnosed, educate parents, and make resources easier to find and use.

The Importance of Screening

In March, the U.S. Centers for Disease Control and Prevention greatly raised its estimate of the number of 8-year-olds with some form of autism from 1 in 150 in 2000 to 1 in 88 in 2008. The report sparked debate over whether a growing environmental threat could be at work. But autism researchers around the country said the CDC data—including striking geographic and racial variations in the rates and how they have changed—suggest that rising awareness of the disorder, better detection and improved access to services can explain much of the surge, and perhaps all of it.

In L.A. County, the statistics are even more shocking. “We have more cases of autism in this County than there are throughout the rest of the state,” says Caroline Sandberg Wilson, RN, the Executive Director of the Autism Society of Los Angeles and the parent of two adults with autism. “There are an inordinate number of cases due to our dense population. One-third of all people with ASD in California live in Los Angeles.”

Yet, despite the explosion of autism cases in Los Angeles, it is still a challenge for parents to have their child diagnosed much less how they plan their way through state and national programs, insurance company denials and the school system for treatment. “Autism is a disability that is frequently overlooked in young children,” says Patricia Herrera, MS, Project Director of Developmental Screening for 211 LA County. “Physicians rely on clinical observation and some disabilities such as autism need more than that because they are difficult to identify.”

There are a variety of reasons that autism is difficult to diagnose and can include inadequate screening practices, slow response to parental concerns, or a lack of awareness of symptoms that manifest early in life. Similarly, misdiagnosis is likely because of the similarity of some features of ASD with other conditions that: show up in childhood, such as hyperactivity or repetitive behaviors. Early diagnosis of ASD also is further complicated by intellectual disability, which occurs in about half of children who have more severe symptoms and can, therefore, result in a primary diagnosis of delayed development.

The American Academy of Pediatrics recommend that physicians use...
Evidence-based screening tools at both 18 and 24 months of age to cast the broadest net for identification of children who possibly have or are at risk for autism. Many of these screening tools such as the Ages and Stages Questionnaire, the Ages and Stages Questionnaire: Social-Emotional, Parents’ Evaluation of Developmental Status, PEDS: Developmental Milestones and the Checklist for Autism in Toddlers (M-CHAT) are online. Tools like these examine specific behaviors associated with ASD in very young children such as eye contact, pointing, social-emotional behaviors and communication.

Having physicians be proactive in testing for autism is critical. “The average age for a diagnosis of autism is 4 to 5 years,” says Halliday. “But most parents are concerned before their child reaches age 2. They can see something is amiss even if they don’t know it is autism but they may not know how to express their concern or even who to express it to.”

Greater Challenges

Minorities and low-income parents face even greater problems in having their child diagnosed at an early age. While the average age for all children to be diagnosed is an already-too-old 4 to 5 years of age, the average for African Americans and Hispanic children is 6 to 7 years of age. That gap is where Herrera’s pilot 211 Developmental Screening and Care Coordination Project hopes to have impact.

The screening project was initially envisioned by the Early Identification and Intervention Collaborative of Los Angeles County, which is a group of more than 300 organizations across multiple sectors dedicated to improving and expanding timely identification and intervention for children with or at risk of barriers to development. 211 LA County, a 30-year-old non-profit that is dedicated to helping low-income families in Los Angeles find help and resources and is a member of EII, averages about 500,000 calls per year with some 8,000 of those calls being related to children age 0 to 5. With all those phone calls, the group saw a prime opportunity to quickly provide immediate screening and help with navigating systems for parents. The project helps parents access free developmental assessments or diagnostic evaluations and timely and effective intervention services. “It’s a powerful program,” says Herrera. “These low-income families, who have the highest risk of not receiving a diagnosis and getting treatment and who have the least resources, are already at our doorstep. Here’s how the program works.

When a parent calls in with a need, such as loss of a job, and can be identified as having a child 0 to 5 years of age, the 211 LA Information and Referral Specialist asks them at the end of the call if they would like to answer a parent questionnaire about how their child is developing for their age. Since a relationship has already been built, 80 percent of the parents say “yes.” The parent is transferred to a care coordinator who asks them several simple questions based on the PEDS or M-CHAT questionnaire, depending on the child’s age. If results are positive for autism or at high risk, the care coordinator creates an action plan for the parent right then. This includes services that a sub-3-year-old is eligible for such as the Federal Early Start program for children under 36 months, free pre-school programs for 3 and 4 year olds, and specialized services through the California Regional Center system. For children over 3 years of age with a potential diagnosis of autism or any other developmental disability.

Currently, the pilot project is screening about 3,000 children per year using three care coordinators. And it has proven effective—results from the screenings are 2.5 times the national average. Now, the goal is to make the screening project sustainable over time and scale it up. “We know the potential reach and know this is an effective way to connect kids with the most needed services,” says Herrera. “We want to be able to screen up to 20,000 kids per year and provide coordinated care so we are looking at avenues of partnership to expand the program.”

Other initiatives that aim to lower the age of detection abound. Autism Speaks’ Move the Needle initiative has a goal of bringing together everything that different agencies including large national ones such as the CDC and AAP provide and ensure that the information, tools and resources are being disseminated and used across the country and the world. Because autism can now be detected in children as young as 18 months to two years of age, the group would like to see the average age for diagnosis and intervention lowered to two or three years of age.

Still, other research is aimed at lowering the age at which autism can be reliably detected to less than 18 months. For example, Connie Kasari, PhD, of the renowned UCLA Center for Autism Research and Treatment, has researched an evidence-based communication therapy nicknamed JASPER for Joint Attention, Symbolic Play, Engagement and Regulation. The therapy has already proven effective for pre-school age children and is now being re-adapted and tested on children 12 to 24 months of age. Although still in the pilot phase, the results are looking positive so far.

A Difficult System to Navigate

Even when a child is diagnosed, parents can still be in a loss as to how to navigate the system. Says’ two boys were diagnosed with autism at ages 2 and 3 years old. “Neither one spoke,” says Sayers. “My physician gave me a referral for speech
therapy and that evaluation came back with a diagnosis of autism.

Sayers was directed to one of the 21 non-profit regional centers run by the State Department of Developmental Services, which offers services for people with developmental disabilities. But the center required a referral before accepting her son—a referral that Sayers was finding elusive to track down. Finally, the Individualized Education Program, which is mandated by the Individuals with Disabilities Education Act to meet the special educational needs of a child with a disability gave Sayers the recommendation she needed.

But Sayers and her boys were still far from out of the woods. "The school system will do some things, insurance will do some things and the regional centers will do some things but they all cut off at certain ages," says Sayers. Sayers continues to define the problem saying, "And the regional centers didn't hand me a list of resources—I had to find out what to do from other parents. It took me until Matthew was 9 to get him into Floortime therapy, which the regional center paid for."

Of course, parents can self-pay for help using services from Pacific Child & Family Associates, the Brain Balance Achievement Center or any other number of groups. But the cost for these services can be prohibitive for a parent that already has high ASD-related expenses. And, unless the services offer scholarships for low-income families, there's no chance they can afford them.

As you might anticipate it is even harder for low-income and underserved parents to navigate the complex government resource systems than for parents from middle- or upper-classes. "Even if a low-income parent has been given a diagnosis and a list of resources," says Herrera, "they most likely won't take advantage of them because the systems are very hard to navigate and these parents are the ones most likely to be stressed with other issues like getting enough food or coping with violence."

In a four-part series on "Discovering Autism," the Los Angeles Times found a number of shocking statistics on just how wide the disparity is between expenditures on whites versus other ethnicities. Two of the more telling are:

- For autistic children 8 to 14—a critical period for treating the disorder—the State Department of Developmental Services last year spent an average of $11,723 per child on whites, compared with $11,063 on Asians, $7,634 on Latinos and $6,503 on blacks.
- The divide is even starker when it comes to the most coveted service—a behavioral aide from a private company to accompany a child throughout each school day, at a cost that often reaches $60,000 a year. In the state's largest school district, Los Angeles Unified, white elementary school students on the city's affluent Westside have such aides at more than 10 times the rate of Latinos on the Eastside.

Who's Got the Money?

A study released this past March showed that the lifetime cost of providing care for each person with autism affected by intellectual disability is $2.3 million. The lifetime cost of caring for individuals who are not impacted by intellectual disability are $1.4 million. More telling, the study shows that autism costs the U.S. a massive $122 billion per year for all ASD cases combined—a number that has more than tripled since 2006. The Autism Speaks-funded research conducted by Martin Knapp, PhD, of the London School of Economics, and David Mandell, ScD, of the University of Pennsylvania.

A 2006 study from Michael Ganz, Assistant Professor of Society, Human Development, and Health at Harvard School of Public Health found slightly higher costs for raising a single child with ASD—$3.2 million—and compared it to $290,000 for raising a child with autism. He also found a significantly lower number for caring for all people with autism over their lifetimes—$35 billion per year—which is still staggering. He also found that historically the federal autism research budget has been less than $100 million compared to research budgets of $49 billion for Alzheimer's disease, $51 billion for mental retardation, and $27 billion for anxiety.

The costs of caring for an ASD child run so high because, besides the routine child-rearing costs, there are high-priced, one-on-one speech, occupational, behavioral and communication therapies, home repairs for damage caused by the child's meltdowns, specialized support at school, despite services and vocational training and supported employment. In many cases, at least one parent must give up a job because someone in the family has to be able to run at a moment’s notice to pick up their child due to some autism-related disaster. Sayers still has holes in the walls of her home where one of her sons began the habit of knocking the walls with his fist—and she's had to leave the holes in place to prove to that her son needs more behavioral therapy.

So thus the catch-22: The number of children being diagnosed with autism—a highly expensive condition for the health care community to treat—is exploding at a time when government budgets are being slashed. "The budgets for early interventions before the age of 3 were gutted in California under Gov. Schwarzenegger," says Wilson. "And one of the most effective therapies—applied behavioral analysis—is often denied by insurers."

There is some recent good news for insured parents of children with ASD. On July 1, California Senate Bill 946—dubbed the “Autism Bill”—took effect. The bill, authored by Senate President Pro Tem Darrell Steinberg, requires insurance companies to cover behavioral treatments for ASD patients. Some plans may still not offer the coverage, however, since companies that are self-insured—generally very large employers—are exempt from state regulations.

The other wrinkle is that as federal health care reform kicks in, essential health benefits will be established nationally to determine what treatments must be covered. If those benefits do not include behavioral treatment for autism, the new California law will automatically expire and insurers will no longer be required to cover the treatments. Autism experts, however, are optimistic that those benefits will be covered under federal law.

A Gap in Understanding

Because autism is typically considered a lifelong disorder, there is a lot of stigma and fear about how a diagnosis, or even about administering a test, is communicated to parents. "Even if a physician wants to approach the topic of autism, there is still a general lack of knowledge about what autism is, what resources exist, and what to do about it," says Halliday. "There is an even larger gap in the knowledge about autism in the underserved," she continues. Wilson agrees. "There is a huge gap in the understanding of autism," she says. "It's more than a medical condition—it's a family issue, a child issue, and a global issue."
