N.H. Needs to Spend More on Autism

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This is the age of autism. The disorder, first identified in 1943, was rare for five decades. Initial studies estimated that 1 in 2,500 children showed the disturbing signs: withdrawal from people, limited or non-existent language, rigid narrow interests, and incomprehensible private terrors. But since around 1990, autism has surged from the rare to the almost common. The Center for Disease Control now reports that 1 in 166 children have either classic autism or a related condition.

What's fueling the increase? Environmental toxins or vaccinations? Genetic mutations? Some other unidentified source? Is there even a real increase? Some experts wonder if better identification, a broader definition of autism, and diagnostic fads are behind the skyrocketing number of autistic children. However, consensus says that these factors don't fully explain the surge. Something is happening to our kids.

While these and other aspects of autism are debated, one is not: the earlier the child starts treatment, the more progress he makes and the more likely it is that he will rejoin his peers in school and play. Gone are the days when a diagnosis of autism meant lifelong screaming, rocking, and isolation in an institution. Most treatments don't promise a cure, but early intensive help gives the autistic child genuine hope for a fulfilling life.

This power of early treatment makes sense, given all we know about the young child's rapidly developing brain. The brain and mind do not thrive without social interaction. The baby, who misses this essential human contact, either because he fails to form a vital link or at some point withdraws, will not develop. Treatment interrupts this withdrawal and forces the child to deal with people. Treatments also alert parents to strategies for reaching their child. The sooner these occur, the less entrenched the autism becomes and the earlier the child begins to learn from social reality. Early identification is the key to solving the public health crisis of autism.

Infants are the new frontier in fighting autism because red flags can appear in the child's first year. A 9-month-old might consistently ignore his name or point at something desired without looking to his caregiver to assure she's received his message. A placid and floppy baby, or a stiff baby who constantly screams, is sounding alarms. A child of any age who avoids eye contact or stares glassy-eyed is a child in trouble. Humans are hard-wired to connect with other humans. When this drive is not vigorous, or has disappeared, the baby needs help.

Here in the Upper Valley, Kathy Marshall is following trends in the identification of autism. Marshall coordinates the Early Supports and Services program (formerly of United Developmental Services, now merged with Developmental Services of Sullivan County) for children birth to age 3 in lower Grafton County. She reports that children with suspected autism are referred between 17 and 30 months of age; most children come for help around age 2. According to Marshall, pediatricians are now more aware of autism and can identify difficulties with social interaction.

Despite this progress, some children are overlooked. Preschool special educators tell stories of children who don't get help until after age 3. Some parents say their pediatricians dismiss their concerns. Kirsten Murphy, director of Autism Resources for Community and Home of the Upper Valley, notes that physicians, believing that an older child is easier to diagnose and that diagnosticians are scarce, may wait to refer troubling cases for further evaluation. Sometimes the physician expresses concern, but parents hesitate to pursue the assessment, according to Althea

Upper Valley, notes that physicians, believing that an older child is easier to diagnose and that diagnosticians are scarce, may wait to refer troubling cases for further evaluation. Sometimes the physician expresses concern, but parents hesitate to pursue the assessment, according to Althea Goundrey, Child Development Program Coordinator at Children's Hospital at Dartmouth (CHAD). Although the number of Upper Valley school-age children with an autism-spectrum disorder matches national prevalence estimates of 1 per 166 children, the number of autistic under-threes in our locale is lower. In the last year, Marshall has seen four autistic children, approximately one per 250 of under-3s in the region. Local children are missing critical help at a critical time.

A new Lebanon-based project, Healthy Babies/Healthy Children, aims to change this. Healthy Babies has placed Connie O'Leary, a nurse and mental health counselor, in the Alice Peck Day Community Care Center pediatric practice. With O'Leary's help, the practice is implementing a recent recommendation of the American Academy of Pediatrics: standardized developmental screenings at 9 and 18 months. O'Leary also meets with parents who want strategies for promoting healthy development or who worry about their young child. Healthy Babies was a response to the parental plea: "I knew something was wrong, but I didn't know where to turn."

Even when autism is identified, families face barriers in getting formal evaluation. Families report waiting up to 6-9 months for an appointment at the Child Development Program at the Children's Hospital at Dartmouth. Dr. Carol Little says that the staff has made efforts to expedite the process, and families now wait two to three months. Staffing for the clinic, however, remains tight. The costly evaluations are poorly reimbursed by insurance, and the clinic loses money for ChaD.

Treatment, too, is hard to find and fund. Marshall notes that specialized autism services are still scarce, despite the growing number of autistic children. Funding for early intervention is a mix of family insurance and state and federal money. In contrast to other states, New Hampshire doesn't require private insurance companies to reimburse treatment to the under-3s. A Senate Bill attempting to change this is on hold; advocates are working to secure the voluntary cooperation of insurers.

Several years ago, New Hampshire decided to earmark $200,000 of federal special education money annually for the intensive treatment of autistic children under 3. The number of requests overwhelmed the fund, however, and so the per-child grants have been cut by over 50%. A task force is seeking other funding for treatment, but it remains an unsolved problem.

Why not, then, add state money to insure that autistic children get help? Matthew Ertas division director of the state's Bureau of Developmental Services, says that he's struggling to fund the basic level of early intervention services because enrollment has increased about 10% in each of the last two years. His 08-09 budget requests a $2.9 million increase in early intervention funds, raising the budget from $4.5 to $7.4 million. He says frugal New Hampshire legislators question the value of early intervention, and he's not sure they'll provide the additional money.

Early intervention makes fiscal sense. For every dollar spent on high-risk infants and toddlers in a home-visiting program, more than $4 are saved by their 15th birthday. For autistic children, almost half respond to intensive early treatment and outgrow the need for special education. Treating a single autistic child for three years saves the state an estimated $150,000 by the child's 22nd birthday and at least $600,000 by his 55th.

Policymakers repeatedly ignore connections between what a person experiences as an infant and the adult he becomes. It is, after all, human nature to deny things that involve effort, expense or pain. In this case, public servants of a cost-conscious state close their eyes to a costly problem. Over a decade into the public health crisis of autism, New Hampshire still has no plan to fund intensive early treatment for these children.

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