

For autism, early action is critical

New study hails young diagnosis

By **ROY GERSTENBERGER**
For the Monitor

The past two decades have seen a rapid increase in the percentage of children diagnosed with autism spectrum disorder. Whether the increase reflects more actual cases or just more use of the diagnosis by specialists, experts agree on one thing: Early intervention is critical and can help reduce the services a child will need later in life. However, finding the right combination of timing, services and service providers remains a challenge for many families.

Services vary widely and should be determined by the child's needs, not the availability. In New Hampshire, these services, which can be directed toward the child or the entire family, may include special instruction, such as applied behavioral analysis; speech and language instruction; occupational therapy; physical therapy; and psychological evaluation. Early intervention services for families should help the family focus on their child's strengths, offer options for positive growth and development and encourage them to maintain self-reliance, inclusion and interdependence as a family.

The importance of early intervention is a fairly recent concept, with the benefits scientifically researched and proven only in the past few

years. Researchers and pediatricians increasingly believed "the earlier, the better" about treatment, but the first controlled study on early intervention for children younger than 2½ with autism was published in the journal *Pediatrics* in November 2009.

The study found that early intervention for very young children with autism is effective for improving IQ, language and social interaction.

"Given that the American Academy of Pediatrics recommends that all 18- and 24-month-old children be screened for autism, it is crucial that we can offer parents effective therapies for children in this age range," said Geraldine Dawson, the study's lead author. "By starting as soon as the toddler is diagnosed, we hope to maximize the positive impact of the intervention."

In addition to benefiting children and their families, researchers have found that early intervention also saves taxpayers in the long run. A 2007 study by Harvard School of Public Health researcher Michael Ganz estimated that for a single individual, the lifetime cost of support services associated with autism is \$3.2 million. If early treatment is provided, the cost could be reduced by as much as two-thirds.

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Despite the benefits of early intervention services, families looking for assistance often find themselves unable to receive help at their time of need. Long waits for appointments to diagnose or treat their child can create a cascade of delayed interventions and access to resources.

According to a report by the New Hampshire Commission on Autism Spectrum Disorders, "Delayed access to autism specialists and clinics remains a serious

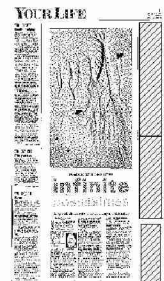
obstacle to timely diagnoses. Shortages of experienced diagnosticians, limited coordination of existing resources, poor reimbursement for team evaluations, and the absence of geographically accessible diagnostic clinics underlie the problem."

What can be done to ensure that infants and toddlers receive the support they need when they need it?

The commission states that "new sources of funding, new models of collaboration between specialists and primary care physicians, and the implementation of an integrated system of care will be necessary to overcome the diagnosis bottleneck and assure a true continuum of care." The commission's goal is that all New Hampshire children will be screened for autism spectrum disorders before age 2 and that any child suspected of having ASD will be referred immediately for early supports and services. After a diagnosis, the commission recommends the child begin a vigorous intervention and treatment program within 45 days.

While the commission continues to lobby for new legislation regarding the timeliness of diagnosis and treatment, a huge battle to ease the financial burden faced by many parents was overcome in July 2010. Connor's Law, signed by Gov. John Lynch, requires insurance companies subject to state regulations to cover testing to diagnose ASD and treatments, including structured behavioral therapies, speech, occupational and physical therapy, pharmacy care and care provided by a psychologist or psychiatrist.

While advocates and lawmakers are making great strides toward making resources more available,



there remains a challenge for families who do receive support services. While parents do their best to get the most effective treatment for their child, the manner in which services are offered can determine whether they feel stronger and more confident or whether they are left feeling as though they are bad parents or not doing enough for their child.

Kathie Snow, author of *Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities*, recommends several approaches that can create an appropriate and helpful partnership with the family. Because being a parent of a child with delays or diagnosed ASD can be extremely challenging, it is important for families to work with an agency whose philosophy is that parents are the primary decision-makers and they have control of their child's services. Providers must work with infants and toddlers in their natural home setting or childcare setting and focus on family members and other people close to the child. They should enhance and encourage development.

When selecting an organization, it is important that its early intervention program take into account not only what is best for the child, but also what is best for the family as a whole. Early intervention staff should help parents understand how their child grows and develops, how to play and talk to their child, and how to best work with their child's behavior. It is also helpful if they provide access to a parent support

network. Keeping in mind that the infant or toddler will likely need services past age 3, it is helpful to work with an organization that helps with the transition to public school and to other community supports and services.

While there is no known cause or cure for autism spectrum disorder, increases in resources and improvements in services will help children and their families live happy, fulfilling, interdependent lives.

(Roy Gerstenberger is executive director of Community Bridges in Concord.)

WHERE TO LOOK FOR HELP

- The Parent Information Center: 224-7005
- Community Support Network Inc.: 229-1982
- The Institute on Disability: 228-2084
- The New Hampshire Association for Infant Mental Health: Ellyn Schreiber, 226-3212, ext. 278
- The Autism Society of New Hampshire: 679-2424
- New Hampshire Bureau of Developmental Services, Child and Family Supports and Services: 271-5019