Service Use for Young Children with Autism Starts Strong but Declines with Age
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Autism spectrum disorder (ASD) affects 1 in 88 children in the United States. In other words, most elementary schools with 500 children will have five to six children with ASD. A complex collection of behaviors, including difficulty with social interaction and obsessive focus, autism emerges early in life, typically by age 2, and the most successful interventions begin early in life. Pre-K settings, therefore, are a frequent site for services.

Families face a daunting task in securing appropriate services for their children. Services vary widely from state to state or school to school. Funding levels also vary dramatically, and the recession and its aftermath led to serious shortfalls in many states and district budgets, forcing severe cuts to both general and special education funding. Parents must become experts in the ins and outs of Title I, Medicaid, and the Individuals with Disabilities Education Act (IDEA)—all sources of funding for children with ASD.

Perhaps, then it is no wonder that, as this brief reveals, service use falls off from age 3 to 6 among children with ASD. This brief outlines the first nationally representative study of access to and use of services in and out of school for young children with ASD. Findings also reveal very low use of behavioral therapy.

Speech Therapy Is Most Common; Behavior Therapy Least Common

Parents have two main options for their children: they can seek services in pre-K programs at public or private schools via an Individualized Education Program, or they can find (and pay for) private interventions outside of school. Most parents, it appears, turn first to schools.

Speech therapy was the most common service, which is not surprising given that autism affects early language development and social communication. Approximately 90 percent of children received speech therapy in 2003-04, and slightly more than three-fourths of those received therapy at school.

3 Few pre-K programs appear to use Title I funds. In the 2010-2011 school year, 2.5 percent of children attending Title I-funded education programs were labeled as “pre-K students,” according to U.S. Department of Education officials. See http://fepb.newamerica.net/background-analysis/pre-k-funding
More surprising, however, is how few children received behavioral therapy. Despite being considered one of the most effective interventions for children with ASD, only about 5 percent of children in the study were receiving behavioral therapy, and even fewer (1.3 percent) were receiving such services at school. Studies show, for example, that early, intensive behavioral therapy for toddlers with ASD (25-40 hours a week over two years) can significantly boost language and mental abilities, although even briefer, targeted behavioral therapy helps social communication in toddlers and young children. Behavioral therapies can also reduce anxiety and aggression.

Mental health and social work services were also rare, with only about 10 percent of children receiving it. About three in ten children received physical therapy, and 58 percent of children receive occupational therapy mostly at school.

Overall, the school setting seems to be effective in reaching children with ASD regardless of income or several other distinctions (parents’, the child’s, or the school). For example, 90 percent of African American children with autism were receiving services in school, a rate identical to white children. There was, however, one distinction. Children whose mother had at least some college were much more likely to be receiving one of the five services both inside and outside of school. This distinction by education might belie the complexity of the system of care. Those with more education may be better able to navigate the bureaucracy and more effectively advocate on behalf of their children.

Service Use Declines with Age

While the findings point to fairly wide access to services among children with ASD, service use declines with age. By 2005-06, for example, only 75 percent of students were receiving speech therapy, down from 90 percent three years earlier. Fewer children were attending speech therapy exclusively at school. As with speech therapy, physical and occupational therapy decline with time, and again, more students continue to seek access beyond school.

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4 These numbers are so low that they could not reliably be measured in the study. Therefore, they should be considered only a preliminary figure.

The decline in service is worrisome, as it is not fully being replaced by therapies outside of school. Indeed, the share of children receiving no services at all increased with time, from 10 percent at the outset of the study to 32 percent three years later.

**Policy Implications**

Schools appear to be a lifeline for parents seeking support and therapy for their children with ASD, particularly for speech and occupational therapy. However, few are finding behavioral services in schools, despite its effectiveness as a therapy. Less than 5 percent of the children in this national study were receiving behavioral therapy either in school or in other settings.

Also worrisome is the falloff in service use as children age, given the continued need, in general, among children with autism. Although this study was not designed to explore why service use declines, the complexity and lack of centralized coordination of services may be contributing to this decline, as may the limited funding and confusion among parents and providers over “what works.”

**Finding and accessing services** in the private sector is a complicated affair, and parents are often on their own to navigate the service options, including primary and specialty health care, early intervention and special education services, social, public health and home health services and other community resources such as child care and respite care. They are also on their own to figure out insurance policies, which often have sharp distinctions across policies.

In school, the many funding streams complicate things, as do the number of people and service providers involved. The system is highly fragmented with numerous providers across multiple sites and settings. This variety can lead to gaps in service or confusion over available services and rules and regulations.

Given the complexity of accessing services, a **“medical home”** might help streamline and centralize service options. In addition, medical homes could centralize services and information across CBOs. Medical homes serve as centralized health care providers that focus on whole-person care, improved access to care, and work to coordinate care across all caregivers and related services, both in the community and in the health care system. Within this model, a family has only one point of entry to access to services, and a specific plan for care and treatment is designed and implemented across the variety of health care and other professionals serving the family. However, only about one-fourth of children with autism currently receive care through a medical home. The Affordable Care Act promotes medical homes and authorizes states to encourage Medicaid

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beneficiaries with chronic conditions to use a medical home. The federal government provides a significant funding match for states that implement such homes.

Funding for school-based services is insufficient to meet the growing need, yet the Government Accountability Office (GAO) projects declining state revenue through 2060. Therefore, doing more with less, more efficiently, will be an ongoing requirement. Improved communication with parents about effective interventions can save money and improve outcomes for children.

Finally, physicians and psychologists play a central role in access to service. In most states, eligibility for services starts with a diagnosis from a physician or psychologist. Further, Medicaid and private insurance will not reimburse for treatment or supportive services unless provided by the licensed personnel. Yet, physicians report that they feel less competent to care for children with ASD than they were other complex medical issues. Enhancing physician awareness and training can help families gain needed access to services early-on, when they are most cost-effective.

One promising initiative is being undertaken through the Combatting Autism Act of 2006. The Maternal and Child Health Bureau of the Health Resources Service Administration (HRSA) has designated $47.7 million to support HRSA’s implementation of the Combating Autism Act of 2006. The goal is to increase awareness, promote evidence-based interventions, and reduce barriers to screening and diagnosis. The efforts also focus on training, screening, and building systems of care.

Data and Study
The data for study are from the Pre-Elementary Longitudinal Study (PEELS), a six-year longitudinal panel study of children receiving preschool special education services. The data include a nationally representative sample of 3,104 pre-school aged children (3-5 years) who were followed across 5 waves of data beginning in the 2003-04 school year. The data in the current analysis consist of children in the first 3 waves of data (2003-04, 2004-05, and 2005-06 school years). Data from PEELS are obtained from questionnaires completed by parents and teachers regarding utilized services that the children receive both in and out of the school setting.

The study sample included 250 children with parent or teacher identified ASD across the first 3 waves of data. The sample was predominantly male, consistent with the higher

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incidence of ASD seen among the male population. The majority of children were white (73 percent), 20 percent were Hispanic, and 7 percent were African American. The majority (60 percent) had less severe forms of autism. Nearly all children had health insurance (27 percent public, 49 percent private only, and 21 percent with multiple types of health insurance). The majority of the children lived with two, married parents, and most mothers had at least some postsecondary education. Incomes were distributed fairly evenly along a spectrum, with slightly more families with incomes above $50,000 a year (39 percent). School districts of different sizes and wealth were also fairly evenly represented, with a slight tendency toward larger districts.