



Early Intensive Intervention Services for Alaska Children with Autism: A Policy Analysis

The Governor's Council on Disabilities & Special Education

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August 2007



Introduction

Autism is the fastest growing developmental disorder and affects more children than those with diabetes, AIDS and cancer combined.

From the covers of Time and Newsweek magazines, to the Centers for Disease Control and Prevention's Morbidity and Mortality Weekly Report, autism is in the news (Centers for Disease Control and Prevention, 2007c; Kantrowitz & Scelfo, 2006; Nash, 2002). It is the fastest growing developmental disorder and affects more children than those with diabetes, AIDS and cancer combined (Kennedy Krieger Institute, 2007). No longer considered a rare disorder, autism impacts a wider and wider segment of our society. This pervasive developmental disorder affects communication, behavior, social skills and play, and is diagnosed in the early childhood years.

In Alaska, the growing prevalence of autism has resulted in a groundswell of advocacy for improved services for children. When a child is diagnosed, families learn there are evidence-based intervention options but quickly discover the services are not generally available and/or financially accessible, especially in Alaska. Even more disheartening is that intervention is most effective when delivered as soon as the diagnosis is made, accentuating the urgency for services.

In response to frequent public testimony about this need, the Governor's Council on Disabilities and Special Education formed an Ad Hoc Committee on Autism in 2005 to develop recommendations for the Alaska Legislature and the administration. A report of this Committee suggests

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four high priority recommendations — universal screening for autism, enhanced diagnostic capacity, expanded resource and referral services, and time-limited intervention services (Governor’s Council on Disabilities & Special Education, 2006). The Council successfully advocated for increased funding for identifying and diagnosing children with autism as well as for additional resource and referral services. Activities are underway to develop universal screening. The final recommendation — a mechanism to provide time-limited, intensive early intervention services — is the topic of this policy analysis.

Purpose

This policy paper provides the state of Alaska with an analysis of options for the provision of time-limited, early intensive intervention services for children with autism.

The following five options for developing time-limited interventions for young children were reviewed:

- 1) exploring the options for offering autism services under the Deficit Reduction Act;
- 2) applying to the Centers for Medicare and Medicaid Services for an Autism Waiver;
- 3) attaching intensive autism intervention services to an overhaul of the entire Medicaid system in Alaska through an 1115a waiver;
- 4) offering intensive early intervention as part of the existing Medicaid program, e.g., by designating treatment through the EPSDT program; and
- 5) mandating that insurance companies coverage for autism services.

Background

Autism is a pervasive, life-long, brain-based disorder that is present from birth or the early stages of development. It affects thinking, social interaction, communication, imagination, and relationships with others (Centers for Disease Control and Prevention, 2007d; Lord & McGee, 2001; National Institute of Mental Health, 2005). Differences in sensory processing and unusual behaviors and interests are also symptomatic of autism (Centers for Disease Control and Prevention, 2007d). Language development ranges from limited or no use of speech, to unusual speech patterns such as echolalia. About 30 percent of individuals with autism are nonverbal (Akshoomoff & Stahmer, 2006).

Intellectual functioning varies among people with autism from mental retardation to above average intelligence. Some individuals become very knowledgeable about a subject of interest to them. Play is often restricted to a narrow range of interests, such as a preoccupation or atypical attachments with objects such as trains or cars. Rather than playing with other children, a child with autism may choose to play repetitively with objects in unusual ways.

These characteristics are manifested as a spectrum in individuals with autism, ranging in severity, symptoms and age of onset. Autism is classified as a group of pervasive developmental disorders, or Autism Spectrum Disorders (ASD). This group of disorders includes Pervasive Developmental Disabilities — Not Otherwise Specified (PDD-NOS), Autistic Disorder, and Asperger Syndrome. While each of these disorders share some characteristics, they manifest in individuals at different ages, and vary in the nature and severity of these symptoms. For example, children with Autistic Disorder are typically diagnosed in early childhood, while Asperger Syndrome is diagnosed during the school years. Some children with Autistic Disorder are essentially nonverbal, while children with Asperger Syndrome develop speech but differ in their use of language.

Prevalence

As is happening across the country, increasing numbers of children in Alaska are diagnosed with an ASD. Recently released national prevalence data reveal that one in 150 children have an ASD (Centers for Disease Control and Prevention, 2007a).

While Alaska does not track autism prevalence, in 1994, 37 children enrolled in special education were classified as having autism; in 2006 that number had grown to 477, an increase of approximately, 1200% (Alaska Department of Education & Early Development, 1994, 2006). It should be noted that autism was not used as a classification within special education until 1993 and for students to receive services under the category of autism a diagnosis of Autistic Disorder is required. Asperger Syndrome and Pervasive Developmental Disorder — Not Otherwise Specified do not qualify as autism according to the Department of Education & Early Development, although these children may be receiving special education under a different category. Previous to 1993, all children with ASD were classified in categories such as Other Health Impaired, Severely Emotionally Disturbed, Mentally Retarded, or Developmentally Delayed.

The Anchorage School District estimates that one in 80 of their students has an ASD, and that one of nine special education students in the district has an ASD (Comeau, 2007).

Literature Review

Many individuals with ASD require lifelong supports at a cost estimated at \$3.2 million per person (Ganz, 2006). Governments and society often bear the cost of this care in paying for early intervention, special education, and then adult services such as habilitation, supported living and supported work. There is also an expense to society related to lost productivity of the individual with autism as well as his or her family, and behaviors that sometimes lead to involvement with the criminal justice system (Ganz, 2006).

Two studies documented similar cost-savings associated with early intensive behavioral intervention. Researchers in Texas found the state could expect a total savings of \$84,300 per child in state-budgeted funds, and \$208,500 per child in the actual costs (including local, state and federal), achieved over total school years when children with autism received early intensive intervention

(Chasson, Harris, & Neely, 2007) . In Pennsylvania, the average savings to the educational system per child ranged from \$274,700 to \$282,690 with inflation (Jacobson, Mulick, & Green, 1998). This study projected cost savings to age 55 with inflation ranging from approximately \$2,439,700 to \$2,816,500 per person.

Although there is a body of evidence supporting the effectiveness of early intervention, no single treatment approach has gained acceptance as the best-practice model for all children with ASD (Canadian Paediatric Society, 2004; Dawson & Osterling, 1997; Feinberg & Vacca, 2000; Lord & McGee, 2001; Steuernagel, 2005). However, the essential elements of successful intervention models have been defined (Dawson & Osterling, 1997; Lord & McGee, 2001).

- Intervention begins early and is intensive in hours.
- Families are active participants in their child's intervention.
- Staff are well-trained and knowledgeable about autism.
- There is objective evaluation of the child's progress.
- The curricula is highly structured resulting in a predictable daily routine and is focused on developing communication skills as well as other developmental skill areas.
- Teaching procedures emphasize generalization and maintenance of skills.
- Transitions to school are carefully planned and well supported.

Autism has significant impacts on the family (Hastings et al., 2005; Lord & McGee, 2001). Beyond typical parenting roles, children with autism may demand hypervigilance from their caregivers to ensure their safety. Other behavioral issues, such as smearing feces, limited tolerances for food and impaired communication are challenges most parents do not have to face. These behaviors make it very difficult for family members to engage in ordinary, day-to-day activities such as grocery shopping, visiting friends, working, sleeping, eating out and even taking a shower. The additional burden on families raising a child with autism is important in policy discussions. Families need to be able to choose an intervention program that fits with their values, lifestyle and available time.

Options for Financing Early Intensive Intervention

Currently there are four ways families typically receive services:

- 1) through the Early Intervention/Infant Learning Program up to age three;
- 2) through the school district from ages 3-21;
- 3) through Senior and Disabilities Services for home and community based Medicaid waiver or grant funded services; and
- 4) through private therapists and/or paraprofessionals.

Recommended intervention models for autism involve intensive instruction requiring active engagement with the child for a minimum of 25 hours a week, 12 months per year (Lord & McGee, 2001). These interventions are generally not available at that level of intensity in Alaska. The following options suggest ways to finance additional services to supplement what is already provided to children with autism.

Deficit Reduction Act (DRA). Section 6086 of the DRA contains provisions for expanding home and community-based services typically offered under a waiver to individuals with disabilities. States may adopt these services through a State Plan Amendment. There are several new options for states under the DRA.

First, states may offer home-and-community-based services, without applying for a waiver, to eligible individuals who meet Medicaid financial guidelines (currently at 150 percent of the federal poverty level). Currently only individuals receiving services under a Medicaid waiver are eligible for these services.

Second, a less stringent disability standard is required for home-and-community-based services under the DRA, broadening the group of individuals who may access these services. Recipients do not need to demonstrate that an institutional level of care would otherwise be needed. Rather, states must adopt criteria that are more restrictive for waivers than for services through the DRA.

Third, services now available through Medicaid waivers are allowed under the DRA, but states may set limits. These services include case management, homemaker, personal care, adult day health, habilitation, respite care and day treatment (Mollica, 2006).

In addition to the changes to services, there are numerous other provisions of Section 6086 of the DRA that need to be considered. States can set caps on enrollment and establish waiting lists. They may also change the criteria by which level of need is established. This means that individuals may begin receiving services, but when

criteria are modified, would no longer qualify. If this were to occur, individuals continue to receive services for at least 12 months from the date services began, not from the date the criteria changed.

The primary advantage to the DRA option is the ability to extend services to individuals with less severe disabilities. The state is offered more flexibility and may change eligibility and eliminate or reduce services without seeking approval from the Centers for Medicare and Medicaid Services. The state may also impose waiting lists and caps on services. Financial eligibility is more restrictive, meaning those with income above 150 percent of the federal poverty level would not qualify.

Medicaid 1915(c) Waiver. Another option is to apply for a Medicaid waiver specific to children with autism. This would allow children to receive time-limited services (typically for three years). An autism waiver requires that individuals meet an institutional level of care and therefore would be targeted to those with more severe forms of autism. As with other waivers, the state will set a cap on the number of individuals to be served, maintain a waiting list, and must prove that the cost of service is less than what would be incurred in an institutional setting.

With waivers, states must seek approval for changes in the number of individuals to be served, eligibility and changes in services. While this is more cumbersome administratively, it also offers recipients a greater level of assurance that if changes are to occur, there will be a review from the federal government. More individuals would meet financial eligibility standards as they are higher than for the DRA.

The state would need to make decisions regarding eligible diagnoses, qualifying ages, qualifications of interventionists, number of waiver slots, caps on services, as well as determine which intervention models will be reimbursable.

Medicaid 1115a waiver. The Pacific Health Policy Group recommended the state consider applying for an 1115a waiver as part of overall Medicaid reform. More study is needed before a decision will be made about applying for this waiver, but autism services could be included in preliminary, exploratory activities.

The primary disadvantage to the state with an 1115a waiver is the assumption of financial risk. The state would need to negotiate an overall cap on all Medicaid spending, and should the state exceed that cap, it would not receive matching funds for any expenses

Options for Financing continued . . .

over the negotiated amount. However, in adopting a managed care model, the state would essentially become a managed care provider and thus pay itself a premium for every enrolled person. These funds can be used flexibly for other health-related activities, and might present an opportunity to provide autism services for a broader group.

Medicaid and Early Periodic Screening, Diagnosis and Treatment. Medicaid’s Early Periodic Screening, Diagnosis and Treatment (EPSDT) program entitles children under 21 to well child checks, hearing, vision, and dental screening as well as services to ameliorate any conditions discovered during screening and/or diagnosis. Providers may treat the condition, refer families to another provider, or recommend they seek treatment from a qualified provider.

EPSDT is intentionally broad and states that Medicaid

“requires that any medically necessary health care service listed at Section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State’s Medicaid plan to the rest of the Medicaid population.

“It also enables them to assess the child’s health needs through initial and periodic examinations and evaluations, and also to assure that the health problems found are diagnosed and treated early, before they become more complex and their treatment more costly” (Centers for Medicare and Medicaid Services).

At first glance, this appears to be a mechanism by which children with autism could receive intensive intervention services. However, there is controversy over whether autism intensive intervention services are permitted. EPSDT does not cover some services, such as respite care, and targeted case management. It also does not cover habilitation services — those services that help an individual acquire and or improve skills. EPSDT does, however, cover rehabilitation under mental health codes. Autism may be perceived to fall into an abyss between the two, with no coverage under either category. In fact, lawsuits seem to be the avenue by which a determination is made on a state-by-state basis.

Insurance Mandates. Sixteen states have enacted some form of autism insurance legislation. This ranges from designating autism as a mental health disorder or a neurological disorder, so that autism is reimbursed according to the same caps and co-pays applied to these conditions generally, to mandating coverage for autism intervention.

There is an emerging trend toward state legislative action around insurance for individuals with autism. More study is needed to determine whether services would be reimbursed at a higher rate if designated a neurological condition versus a mental health condition, which generally reimburses at 50 percent of the usual and customary charge.



Conclusion

It is in the best interests of the state as well as families to work quickly to establish a mechanism for providing care

While Infant Learning and School District providers in Alaska use a variety of treatment approaches, there is evidence that many providers are not offering services at the recommended level. This is expected given the level of financial support provided to districts and the Infant Learning Program, as well as the lack of Medicaid services for autism that potentially could supplement educational programming.

However, it is obvious that the responsibility for payment of services cannot be borne by a single service system. Blended or coordinated funding from Medicaid, Infant Learning, and special education is needed to provide intensive services. Due to the high cost of providing intensive intervention services, if one service system were to assume the entire expense, funding would be directed away from children with other disabilities who also need early intervention, educational, and Medicaid services.

New funding for enhanced resource and referral as well as diagnostic and screening for autism which was obtained through the advocacy of the Governor's Council will generate an even greater demand for services. It is in the best interests of the state as well as families to work quickly to establish a mechanism for providing care that is coordinated across the medical, early intervention and educational systems. The return on this investment will become apparent in future years, but will require an up-front infusion of funds.

Alaska has an opportunity to learn from other states with autism services, and to use the experiences of these states to develop a model that builds on lessons learned. In particular, it can be expected that workforce development will be a barrier, especially in rural Alaska. Setting provider standards to ensure quality



and availability of personnel will be especially challenging in Alaska.

Some options open up more risk than others. With Medicaid costs rising at an unsustainable rate, heightened scrutiny of any Medicaid service can be expected. Carefully choosing an option that does not place other Medicaid services at risk is an important policy consideration. A combination of options is also a strong possibility.

Finally, it is crucial to build a strong evaluation component. Accountability for public funds is essential, and there must be evidence of cost-effectiveness of the services. Evaluation should also be used to make mid-course corrections and to strengthen the services that children and families receive. Intervention strategies inherently employ data collection and it is reasonable to assume that this data be used to evaluate the efficacy of programs.

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