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QTA – A brief analysis of a critical issue in special education

Autism: Challenges Relating to Secondary Transition

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Overview

Throughout the nation, states report unprecedented growth in the numbers of students identified with autism and other autism spectrum disorders¹ (U.S. Department of Education, 1994, 2002). As a result, states are focusing increasing attention on intervention programs for young children with autism. However, there is less attention being paid to the challenges faced by students with autism who are making the transition to post-secondary education or work. The purpose of this document is to describe the efforts of several state education agencies (SEAs) to address the needs of transition-aged students with autism, describe the major barriers to providing effective secondary transition services to this population and generate policy recommendations.

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Background & Legislation

This section provides a brief overview of the Individuals with Disabilities Education Act (IDEA) regulations pertaining to both autism and transition. It also includes information on the numbers of transition-aged students with autism and summarizes findings from the few studies that examine secondary school experiences and post-school outcomes for individuals with autism.

Autism was added to the list of federal disability categories in 1990. IDEA regulations provide the following definition:

(1)(i) *Autism* means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated

¹ The National Institute of Mental Health (NIMH) provides the following definition for autism spectrum disorders: "Autism spectrum disorders (ASDs), also known as Pervasive Developmental Disorders (PDDs), cause severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. These disorders are usually first diagnosed in early childhood and range from a severe form, called autistic disorder, through pervasive disorder not otherwise specified (PDD-NOS), to a much milder form, Asperger syndrome. They also include two rare disorders, Rett syndrome and childhood disintegrative disorder." This definition was downloaded on May 13, 2004 from the NIMH website at www.nimh.nih.gov/healthinformation/autismmenu/cfm.

with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (b)(4) of this section.

(ii) A child who manifests the characteristics of "autism" after age 3 could be diagnosed as having "autism" if the criteria in paragraph (c)(1)(i) of this section are satisfied. [34 CFR §300.7 (b)(1)(i)]

The number of students identified with autism continues to grow exponentially. During 1992-93 (the first required reporting year for the category of autism) only 1,532 students with autism aged 12 through 21 were served under IDEA (U.S. Department of Education, 1994). This number grew to 44,322 students with autism aged 12 through 21 during the 2002-03 school year – 29 times the number identified 10 years earlier.² Although some of this growth in numbers may be attributed to the fact that it often takes several years for state data systems to accommodate changes, this certainly does not account for such extreme growth in numbers.

IDEA regulations provide the following definition for transition services:

(a) As used in this part, *transition services* means a coordinated set of activities for a student with a disability that –

(1) Is designed within an outcome-oriented process, that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(2) Is based on the individual student's needs, taking into account the student's preferences and interests; and

(3) Includes –

(i) Instruction;

(ii) Related services;

(iii) Community experiences;

(iv) The development of employment and other post-school adult living objectives; and

(v) If appropriate, acquisition of daily living skills and functional vocational evaluation.

(b) Transition services for students may be special education, if provided as specially designed instruction, or related services, if required to assist a student with a disability to benefit from special education. [34 CFR §300.29(a)]

According to federal regulations, a number of requirements must be met pertaining to secondary transition for each student with a disability, including students with autism. For example, starting at age 14, the individualized education program (IEP) for each student with a disability must include an annually updated statement of the transition needs of the student (e.g., participation in advanced-placement courses or a vocational education program) and beginning at age 16, a statement of needed transition services for the student must be developed, including, if

² Downloaded on March 22, 2004 from www.ideadata.org.

appropriate, a statement of the interagency responsibilities or any needed linkages [34 CFR §300.347(b)].

Secondary transition poses unique challenges for students with autism. The National Longitudinal Transition Study–2 (NLTS2) compared transition experiences of students from all 13 federal disability categories and found that students with autism differ from students with other types of disability in a number of significant ways. For example, students with autism experience greater difficulty with social adjustment and are least likely to socialize with their peers, engage in extracurricular activities (e.g., sports or special interest groups), participate in transition planning and assume high levels of responsibility within their households (Wagner, Cadwallader et al., 2003; Wagner, Marder et al., 2003). Furthermore, although students with autism are among the most likely to be engaged in *work study* employment, they are the least likely to hold regular *paid* jobs (Wagner, Cadwallader et al., 2003).

Post-school outcomes for adults with autism and other autism spectrum disorders are often discouraging (Goode, Rutter & Howlin, 1994 as cited in Nesbitt, 2000; Howlin, 2000; Müller, Schuler, Burton & Yates, 2003). One study, for example, found that despite having the potential to work, few individuals with Asperger Syndrome were in regular employment and that even among those with formal qualifications, employment levels were disappointing and occupational status was low (Goode, Rutter & Howlin, 1994 as cited in Nesbitt, 2000). A second study found that adults with autism often experienced high levels of unemployment and under-employment, and that lack of social skills frequently led to poor outcomes including being fired from jobs (Müller, Schuler, Burton & Yates, 2003).

Methodology

Information for this document was gathered in three phases. First, an Internet search was conducted to locate SEA initiatives that address the needs of transition-aged students with autism. Second, representatives from three states that have initiatives in place were interviewed (Illinois, Minnesota, and Rhode Island). Third, additional interviewees were selected to further explore a number of policy issues. The additional interviewees included the South Carolina State Director of Special Education, who is also the parent of an adult child with autism; North Carolina's state Autism Specialist, who works closely with the Treatment and Education of Autistic and Related Communication Handicapped Children program (more typically known as the TEACCH program); a service provider from Illinois with expertise in autism and secondary transition; and an adult with Asperger Syndrome from Oregon, who assists young adults with autism in negotiating the transition from school to post-school life.

Findings

State Education Agency Efforts

SEAs appear to be doing very little that specifically focuses on secondary transition for students with autism. A number of discrete efforts are underway, however, and three are described below.

- Illinois has an Autism Training and Technical Assistance Project that offers, among other things, two days of team training focused on individualized education program planning and transition planning for high school-aged students. During 2002-03, approximately 30 teams participated and these teams are each expected to return to their districts and conduct at least three additional team trainings over the next few years. The Autism Training and Technical Assistance Project also offers workshops for families that include a transition component.
- Minnesota sponsors a statewide Autism Network and one or two day-long promising practices workshops, as well as shorter workshops, all of which focus on the provision of services to transition-aged students with autism. These workshops are paid for, in part, using IDEA discretionary funds set aside for low-incidence disabilities. More than 600 educators and vocational rehabilitation personnel have participated in these workshops thus far. Minnesota also distributes four mini-grants per year to schools throughout the state that provide exemplary services for transition-aged students with autism. Schools receive between \$1,500 and \$2,000 and are encouraged to generate user-friendly materials (e.g., handbooks or videotapes) with information on how to implement best practices.
- Rhode Island offers a series of two-hour autism training workshops, one of which focuses on secondary transition and vocational issues. Approximately 100 teachers and related school personnel have participated in this particular workshop. Rhode Island also has a number of informal demonstration sites and hopes to add a model high school classroom for students with autism in the coming school year – a classroom that teachers throughout the region would be encouraged to visit.

State interviewees also described local efforts to address the needs of transition-aged students with autism. For instance, one or more interviewees described the following types of services being offered at the local level:

- itinerant autism and/or transition consultants;
- transition programs that include an autism specialist as part of the staff; and
- social skills groups for students with Asperger Syndrome and other autism spectrum disorders.

State interviewees also described comprehensive transition programs designed to meet the needs of *all* students with disabilities and noted that, in most cases, students with autism are successfully accessing these same services. As one interviewee noted, “Rarely do we do something that is solely related to one disability, such as autism.”

Barriers

Interviewees listed a wide range of barriers to effective secondary transition services for students with autism. These barriers are described below.

Lack of Autism Expertise

All interviewees remarked on the lack of autism expertise on the part of general and special education teachers and vocational rehabilitation counselors. As one interviewee noted, “Despite the exploding numbers overall, there’s still a lack of understanding about autism.” This lack of understanding can be attributed in part to the limited availability of training resources specifically targeted to professionals who work with transition-aged students with autism. Another interviewee noted, “Even when you have the best transition specialists, they’re clamoring for information [on autism] and there’s very little out there.” High staff turnover also contributes to lack of autism expertise and results in the need for constant training and retraining.

Lack of Personnel Preparation

Interviewees agreed that autism-specific professional preparation at state institutions of higher education (IHEs) is lacking. Most interviewees reported that IHEs offer limited, if any, coursework on autism and none *require* such coursework for transition specialists. For instance, transition specialists are often unprepared to assess the social demands of particular work sites. If this type of assessment is not properly conducted, students with autism are likely to be placed in jobs where they are unable to meet the social demands and are therefore less likely to succeed.

Personnel preparation is also not keeping up with the growth in numbers of students identified with autism. As one interviewee noted, referring to both special educators and vocational rehabilitation counselors who work with transition-aged students with autism, “There’s a real shortage of staff on both sides of the line.” Another interviewee noted that it is also difficult to find personnel who are qualified to teach university-level courses on the topic of autism and secondary transition (i.e., individuals with expertise in both areas).

Focus on Early Intervention

All interviewees detailed extensive efforts to provide early intervention services for young children with autism, but admitted that few dollars and/or limited programming are currently targeted to transition-aged students with autism. One interviewee assessed the status of such services as follows: “We’re doing a better job for preschool-aged children, doing okay for elementary, [but] it begins to get diluted when it gets to middle school and there’s very little out there when [students with autism] become adults.”

Invisibility of Population

Most interviewees mentioned that although the incidence of autism is very high among elementary school-aged students, the bubble has not yet reached high schools. Several warned that high schools are ill prepared to meet the needs of the many students with autism who will soon be enrolling. One interviewee expressed frustration that states only seem to be willing to budget monies for autism once the numbers have gotten out of control. He said, “I’ve been preaching this message for seven years....these kids are coming and you need to get ready. This is not a condition that kids outgrow and most secondary programs need to have more preparation to be ready.”

Two interviewees also noted that parents of transition-aged students with autism are less well-organized in terms of advocacy than are parents of younger students with autism. Without strong advocacy on their behalf, transition-aged students remain a relatively invisible population. As one interviewee noted, “It’s the squeaky wheel that gets the grease.”

Lack of Interagency Collaboration

Several interviewees noted that outside agencies, such as vocational rehabilitation, are often unwilling or unable to get involved in the transition process until a student turns 18. As one interviewee said, “The other agencies that should be involved don’t have the resources or aren’t willing to commit the resources at the level individuals with autism need in order to succeed.” This lack of early and sustained collaboration between schools and outside agencies makes it difficult to facilitate a seamless transition to post-school life for many students with autism. Interviewees also expressed frustration at the lack of joint training efforts, commenting on the difficulty of getting staff from vocational rehabilitation agencies to participate in such trainings.

Generic Transition Services

Several interviewees noted that the trend towards non-categorical services has sometimes resulted in a generic or one-size-fits-all approach to transition programming, making it difficult to meet the unique needs of students with autism. Interviewees were careful to add that this did not mean they support a return to categorical services, merely that it is important to provide a truly *individualized* approach to services. Several stressed that social skills training is absolutely necessary for students with autism. According to one interviewee, however, there is often a “lack of social skills training as part of the generic transition model,” an oversight which tends to have a disproportionately negative impact on students with autism.

Other interviewees noted that while movement away from categorical certification (e.g., certification of autism specialists) has contributed to more inclusive programming, this trend has also greatly reduced the number of professionals who are sensitive to the unique secondary transition needs of students with autism.

Misidentification

Two interviewees said that federal and/or state definitions of autism that do not include all autism spectrum disorders are too limited and occasionally result in misidentification. For instance, one interviewee noted that, in her state, high functioning students with Asperger Syndrome are frequently misidentified as emotionally disturbed, occasionally leading to the provision of inappropriate transition services.

Budgetary Constraints

Interviewees reported that dwindling resources at the state and local levels make it difficult to start new initiatives, hire adequate staff to provide consultation services or even maintain services at existing levels. Budget deficits also mean that the number of vocational rehabilitation

counselors is down, negatively impacting the ability of vocational rehabilitation agencies to provide needed supports to transition-aged students with autism.

Recommendations from Interviewees

In the course of the interviews conducted for this document, each interviewee was asked for recommendations to address the barriers he or she identified. These recommendations include the following:

- Explore the possibility of having state-level support for autism coordination and ensure that any state-level infrastructures for serving students with autism also address the needs of *older* students with autism.
- Offer professional development opportunities on the topic of autism and secondary transition that jointly serve education personnel and vocational rehabilitation counselors.
- Strengthen the legal requirements for the participation of outside agencies in transition planning (e.g., require that representatives from agencies such as vocational rehabilitation attend all transition meetings starting at a student's 14th birthday).
- Foster collaborations between SEA, vocational rehabilitation agencies and IHEs to provide social supports and accommodations for college students with autism similar to accommodations available for college students with other disabilities.
- Make social skills training available, as appropriate, for all secondary transition-aged students, including students with autism.
- Earmark state funds for transition-aged students with autism, in addition to generic funds for autism and/or secondary transition.
- Work with IHEs to ensure that information on autism is integrated into teacher training courses on secondary transition and that information on secondary transition is integrated into courses on autism.
- Encourage IHEs to require at least minimal coursework on autism for all special educators and rehabilitation counselors.
- Revise Medicaid standards to allow reimbursement of specialized supports for individuals with autism.
- Revise vocational rehabilitation regulations to allow for more than 90 days of services for individuals with autism – allotting the same number of total hours, but permitting hours to be extended over a longer period of time.
- Expand federal and/or state definitions of autism to include all autism spectrum disorders (e.g., Asperger Syndrome and PDD-NOS).
- Convene a state-level advisory panel of parents, teachers and students with autism to address the needs of transition-aged students with autism.
- Encourage the Office of Special Education and Rehabilitative Services (OSERS) to offer grants that address secondary transition for students with autism and are jointly administered by OSEP and the Department of Vocational Rehabilitation.

Concluding Remarks

Although few resources are currently directed specifically at transition-aged students with autism, their numbers continue to grow exponentially. State and local policymakers are advised to give increased consideration to the unique needs of this rapidly growing population – ensuring that individualized services, including social skills training, are readily available to them. Interagency collaboration is key, as is the preparation of both special education and vocational rehabilitation personnel to provide appropriate transition supports for students with autism.

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