Issue Brief: *Supporting the Transition to Adult Life for Youth with Significant Disabilities Receiving Medicaid Funding*

Preparing youth for a transition from school to adult life can be seen as one of the primary goals of public education. Whether students graduate from high school to pursue postsecondary education, go directly into a job, or a combination thereof, the process of transitioning into adulthood can be challenging and exciting for the student as well as his or her parents. For students with disabilities, this transition time adds additional challenges as they and their parents learn to navigate a new range of support systems with their own unique set of requirements, options, policies, and procedures. In the mid 1990's as the concept of transition services were added to the requirements of the Individuals with Disabilities Education Act (IDEA, 1990), parents described their struggles with learning to navigate the adult service world as being "the second shock,"[1] or the equivalent to the identification of their child as having a disability. This policy brief will describe the current landscape of policies that impact this transition planning process for youth with disabilities and their parents.

School-based policies and procedures

The education of students with disabilities has, in recent years, become increasingly influenced by educational policies for all students attending public schools. The No Child Left Behind Act (NCLB, 2001), was the first to require that students with and without identified disabilities receive instruction in a common academic curriculum and be assessed on their progress in learning that content. In response to those requirements, the subsequent reauthorization of IDEA (2004) further aligned expectations for the education of students identified as having disabilities to the general education curriculum, in addition to preparing students for a successful transition from school to adult life. IDEA (2004) defines transition planning as "a coordinated set of activities for a student with a disability that is designed to be within a results

orientated process that is focused on improving the academic and functional achievement…to facilitate the movement from school to post-school activities…"[2]

Typically, school districts comply with transition planning and service requirements by including transition planning as part of the annual process of developing a student's individualized education program, using the results of a comprehensive transition assessment process to identify postschool goals, and the supports and services designed to help the student meet those goals. Besides the student, school personnel, and parents, representatives of adult service agencies that might be involved in providing services to the student with disability after exiting high school are invited to attend the meetings as well. This practice was required as part of the transition planning process to help provide guidance to the student and his or her parents about the range of supports and services that could be available after high school, as well as information about the eligibility and application requirements. However, too often this does not occur as adult service agency staff members have large caseloads and limited time to attend meetings for individuals who are not yet found to be eligible to receive services. In addition, this puts the responsibility for identifying those possible adult agency providers on the school's shoulders and often results in identifying those supports that exist for individuals with disabilities to the exclusion of those supports and services that exist for the community at large.

Policies for Adults with Disabilities

Providing a free and appropriate education for all children and youth with disabilities was first required of all public school districts with the passage of the Education of All Handicapped Children Act (EHA, 1975) and is a central component of all reauthorizations of that historic legislation through current policy. However, most national policies that address supports and services for adults with disabilities are not as universal; many of them address a specific sub-group of individuals with disabilities, or provide a limited appropriation that restricts the number of individuals who are able to receive services. The limited funding for many of these programs further complicates the process of understanding the navigating the maze of supports and services that could provide needed resources to help transition-aged youth and their parents achieve their goals for adult life in the areas of employment, community living, recreation and leisure, postsecondary education, and community integration. In addition to supports in these traditional transition areas, youth with disabilities and their parents must also address financial and health care needs, many of which can impact their ability to reach their other transition goals. For example, an individual might need a number of supports to make a specific employment goal a reality, from transportation to get to the job, to personal care assistance to take care of hygiene needs during the work schedule, and a series of modifications

to a home or apartment to provide access out of the domicile to get to work. The interconnection between these components and diverse and distinct sources of support to assure that they are in place further complicates the process of piecing together supports needed to help him or her attain a preferred adult lifestyle. Table 1 provides a list of national policies that can be considered as part of the jigsaw puzzle that can support a preferred lifestyle for adults with disabilities.

Table 1

Policy/Court Decision	Intent	Supports	For More Information
Olmstead Decision (1999)	To assure that individuals with disabilities have options to be included in their communities if desired.	Each state was required to outline their plan to provide inclusive community options, with a timeline for implementation.	ADA.gov
Medicaid Waiver	To provide flexibility to states wishing to provide long-term medical services in home and community settings.	Each state can apply for a waiver that provides community or home-based services for a specific group of individuals needing long-term medical care.	Medicaid.gov
Workforce Investment Act (1998)	Provides funding from the Department of Labor to provide services for unemployed individuals to support training, job seeking and job retention services.	A series of "one-stop" career centers were developed to provide employment training for individuals with and without disabilities seeking employment.	DOL.gov
Vocational Rehabilitation Act Amendments	Provides employment training, services, and grant projects designed to promote employment of individuals with disabilities.	States are provided with funding to operate vocational rehabilitation services for individuals with disabilities. Services can include employment counseling, case management, education and training, assistive technology,	RSA.ED.gov

		as well as other supports related to helping an individual obtain and keep a career.	
Developmental Disabilities Act 2000	Designed to provide support for state efforts to meet the needs of individuals with developmental disabilities.	Provides funding for protection and advocacy centers, University Centers for Excellence in DD, State DD councils, and advocacy training for individuals and their families.	ACL.gov
Higher Education Act (2008).	Provides guidance for postsecondary institutions regarding the use of federal funding, training of teachers, and other accountability measures.	For youth with disabilities, allows the use of federal funding for approved, inclusive postsecondary programs for students with intellectual disabilities.	ED.gov
Affordable Care Act	Was designed to assure that all citizens have access to health care.	For transition-aged youth with disabilities, provides the option for them to remain on their parent's policy, assures coverage for those with pre-existing conditions, and addresses many of the reasons why individuals with disabilities were dropped from health insurance plans.	Healthcare.gov
Section 8 Housing	Funded through the Department of Housing and Urban Development, provides assistance for low income individuals and families for housing.	Provides rental assistance to low income individuals and families, as well as a number of programs designed to improve low income housing options.	HUD.gov

Challenges for Transition Planning

There are a number of challenges that youth with disabilities and their families face as they try to plan for and achieve their goals for adult lives. The government has not funded IDEA fully since its inception, but it is an entitlement program, so educational services must be provided despite its lack of funding. However, most of the policies that address supports and services to

adults with disabilities are not entitlement programs. Instead, these programs receive a set funding allocation and develop an often complicated process to establish eligibility criteria that determine which individuals may receive services. Therefore, funding is a major challenge to the transition planning process and understanding the different eligibility criteria and policies and procedures for the local agencies that are funded under the various national policies. While the national policies provide guidelines, states and local agencies also have greater control over their policies and procedures as well as the nature of the supports and services they provide. The table above provides basic information about how these policies impact transition but there can be a wide range of options from state to state, or from agency to agency.

Recommendations for Transition Planning

Youth with disabilities and their families need supports and services to help them achieve their goals for the transition from school to adult life that empowers them to be in the lead of this important milestone. At a minimum, this would include assuring that existing policies are funded at levels that allow schools and community agencies to address the needs that exist. In addition, efforts to help youth and families identify and understand the options that exist for them, to choose supports that are needed, and to navigate the eligibility process are essential. Agencies would also benefit from an effort to help them work together to blend funding and/or minimize the possibility of duplication of services.

References

[1] Hanley-Maxwell, C., Whitney-Thomas, J., & Pogoloff, S. (1995). The second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life. The Journal of the Association for Persons with Severe Handicaps, 2, 3–15.
2 Individuals with Disabilities Education Improvement Act (IDEA) of 2004. PL 108-446, 20 U.S.C. § 1400 et seq.