

Policy Update

Fall 1994

Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994: Its Impact on Transition Services

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (P.L. 103-230) was recently signed into law. The DD Act is important to states' transition efforts because of its emphasis on stimulating improvement in service delivery systems for persons with developmental disabilities and their families. Over the years, special emphasis has been placed on advancing the principle of community integration for all individuals with developmental disabilities through expanded community-based services, supported employment, improved service coordination and case management strategies, and advocating for a full range of family supports and services. These are all critically important considerations in the national movement toward improved transition services. The purpose of this Policy Update is to describe these basic components and how systems change projects may use each to further the goal of improving transition services for youth with disabilities.

• Definition of Developmental Disabilities

Over the years, the definition of the Developmental Disabilities Act's (DD Act) targeted population has changed. The Act now uses a broad definition of *developmental disability*.

The term "developmental disability" means a severe, chronic disability of an individual 5 years of age or older that—

- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;*
- (B) is manifested before the individual attains age 22;*
- (C) is likely to continue indefinitely;*
- (D) results in substantial functional limitations in three or more of the following areas of major life activity—
 - (i) self-care;*
 - (ii) receptive and expressive language;*
 - (Hi) learning;*
 - (iv) mobility;*
 - (v) self-direction;**

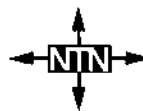
- (vi) capacity for independent living; and*
- (vii) economic self-sufficiency; and*
- (E) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated,...*

Programs and Priorities

The Act authorizes four basic programs: (1) State Developmental Disabilities Councils (DD Councils); (2) Protection and Advocacy (P&A) systems; (3) University Affiliated Programs (UAPs); and (4) projects of national significance. The activities of the DD Councils, P&A systems, and UAPs can have significant influence on individuals and families during the critical transition years.

• Developmental Disabilities Councils

The purpose of the DD Council is to "promote, through systemic change, capacity building, and advocacy activities... the development of a consumer and family-centered, comprehensive system and a coordinated array of culturally competent services, supports, and other assistance designed to achieve independence, productivity, and integration and inclusion into the community for individuals with developmental disabilities." This includes promotion of services and supports to young adults who have exited or are about to exit their secondary education program.



The National Transition Network is a collaboration of the University of Arkansas; Colorado State University; University of Illinois, Urbana-Champaign; University of Minnesota; PACER Center; Technical Assistance for Parent Programs; and the University of Vermont. Its headquarters are at the Institute on Community Integration (UAP), University of Minnesota, Pattee Hall, ISO Pillsbury Dr. SE, Minneapolis, MN 55455, (612) 626-8200.

Members of the DD Council are appointed by the Governor and, to the extent possible, must be geographically representative of the state and reflect the state's ethnic diversity. At least 50% of the DD Council members must be individuals with disabilities, their parents or a representative, or immediate relatives or guardians; of that, one-third must be individuals with developmental disabilities. In addition, the Council must include representatives of the rehabilitation and education agencies, the Social Security agency, any UAP in the state, and the P&A system. Involving young adults with disabilities, family members of secondary-school-aged children with disabilities, and professionals responsible for addressing the transition needs of young

people with disabilities on State DD Councils is an important means of ensuring that state and local agencies and programs focus on improving transition services.

The Council is given responsibility for four major activities:

- Systemic change, capacity building, and advocacy activities. These include policy development, training to promote and advocate employment in services, technical assistance, and other means.
- Conducting an examination of the state's provision of and need for, services in the four Federal priority areas (i.e., community living activities; employment activities; child development activities; and system coordination and community education activities) and an optional state priority area. This examination must be conducted at least every three years.
- Developing and submitting a state plan in collaboration with other state and local agencies and schools.
- Implementing the state plan.

The state plan must identify how it will address all of the Federal priority areas (and an optional state priority area) in the Council's systemic change, capacity building, and advocacy activities. The plan must ensure that funds provided to the state will be used to enhance independence, productivity, and integration and inclusion of individuals with disabilities; that special assistance will be provided to rural and urban poverty areas; and that the plan will reflect minority participation and needs. Also, there must be assurances that the state will

provide services in an individualized manner and will respect the human rights of those receiving services.

A variety of activities may be used to implement the state plan. Working collaboratively with state DD Councils in conducting these activities ensure that school-to-work transition services for youth with disabilities are included among state and local program development activities. Possible activities include:

- **Demonstration of new approaches.** State Councils may provide direct funding for innovative approaches, or help those conducting demonstrations to secure funding from other sources. Previous demonstrations in supported employment, case management, self-determination, and parent and professional collaboration are examples of these demonstration program activities.
- **Outreach.** Councils may conduct outreach activities to help individuals with developmental disabilities and their families, who might not otherwise come to the attention of the Council, to obtain services, supports, and other assistance. This is a particularly important activity in advocating and ensuring that young adults gain appropriate access to postsecondary education, employment and community living services, and supports they need.
- **Training.** The Council may conduct training for individuals with developmental disabilities, their families, and personnel. This training should be designed to promote the empowerment of individuals with disabilities and their families. Examples of this training have focused on self-determination, PASS (Plan for Achieving Self Support) planning, supported employment, person-centered planning, and other essential topics and themes.
- **Service Coordination and Support to Communities.** The Council may assist neighborhoods and communities to respond positively to individuals with developmental disabilities and their families by encouraging local networks to provide informal and formal supports, and enabling communities to offer such individuals and their families access, resources, and opportunities. Recent regional- or community-level interagency efforts to plan and improve transition programs and services are also activities that are or should be supported by DD Councils.
- **Advocating Meaningful Policies.** DD Councils play an important role in advocating for public policies that support the independence, productivity, and community integration of persons with disabilities and their families. These include: (a) barrier elimination, systems design, and citizen participation; (b) informing policymakers; (c) public education and coalition development; and (d) coordination with related councils, committees, and programs.

For Further Information...

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Because of the broad range of activities that the DD Council may engage in to achieve its goals and objectives, there is a variety of possible collaborative strategies that systems change projects may use to pool resources for improving transition services.

• **Protection and Advocacy Systems**

The DD Act also provides funding for P&A systems in each state. These must be independent of any state agency, and are directed to pursue legal, administrative, and other appropriate remedies to protect the rights of individuals with developmental disabilities. P&A systems may:

- Provide information and referral services. This includes assisting a young adult in identifying needed postsecondary transition services and supports in postsecondary education programs, employment agencies, residential services, and others.
- Investigate incidents of abuse and neglect of individuals with developmental disabilities in all areas of postsecondary education, employment, residential placement, and other facets of community living.
- Establish a grievance procedure for consumers or prospective consumers of services (e.g., when a young adult attempts to enter a postsecondary educational program and is denied access).
- Bring suit on behalf of individuals with developmental disabilities against a state or a state agency.

Protection and Advocacy systems are an important component of states' efforts to ensure that the rights of individuals with developmental disabilities are protected, and that such individuals are represented in disagreements with agencies over service delivery. As such, it is important that professionals involved with transition service delivery recognize the role played by P&A systems.

• **University Affiliated Programs**

The DD Act also authorizes funding for UAPs, which may be established at universities or at non-profit public entities associated with a college or university. UAPs have three major purposes:

- To provide interdisciplinary preservice preparation of students and fellows.
- To conduct community service activities, including community training and technical assistance for or with individuals with developmental disabilities, their families, professionals and paraprofessionals, students, and volunteers. Training may focus on family and individual support; personal assistance services; and educational, vocational, clinical, health, prevention, or other direct services.
- To disseminate information and research findings.

Each UAP must establish a consumer advisory committee composed of individuals with developmental disabilities and their families, a representative of the P&A system, representatives of the DD Council, and groups and agencies providing services to individuals with developmental disabilities. The council may include a representative of a parent training and information center, and must reflect the ethnic diversity of the area served by the UAP.

UAPs are required to conduct training in areas of emerging national significance. These include:

- Community transition training to improve policies, procedures, systems, and other mechanisms that prepare youth with developmental disabilities to enter adult life. This training must be coordinated with the state's transition project where such projects exist.
- Community services that enhance direct supports and services. Such training may be provided to community members, individuals with developmental disabilities and their families, and community-based service providers.
- Positive behavioral supports. Training may be directed to families and service providers, and should focus on the use of supports which enhance individuals' independence, productivity, and community integration and inclusion.
- Assistive technology services. This training may be directed to personnel who provide or will provide assistive technology to individuals with developmental disabilities and their families. Training must be coordinated with state technology coordinating councils where such councils exist. Stipends and tuition assistance may be granted.
- Americans with Disabilities Act training for service providers. This training should address the provisions of the Americans with Disabilities Act of 1990. Training should be targeted to personnel who provide, or will provide services to individuals with developmental disabilities and others.
- Early Intervention and Aging are also areas for which training activities are targeted.

Collaborative efforts in these areas between the state systems change project and the UAP may have a significant impact on the service delivery system in a state.

• **Projects of National Significance**

The DD Act also provides funds for projects of national significance that support the development of national and state policy to enhance the independence, productivity, and community integration and inclusion of individuals with developmental disabilities. These may be research projects; technical assistance projects directed at DD Councils, P&A systems, or UAPs; or projects designed to provide technical assistance for the development of information and referral systems, provide

education for policymakers, enhance minority participation, improve transition; or projects to explore the expansion of programs to individuals with severe disabilities other than developmental disabilities.

• **Conclusion**

The resources funded by the DD Act should make significant contributions to the state systems change projects on transition. It has become more and more apparent that numerous forces relate to the achievement of positive transition outcomes for youth with disabilities. First, attention needs to be directed at community-level factors. Such attention may take the form of funding priorities for establishing research programs or model projects to determine effective strategies for implementing change and removing or circumventing barriers at the community level. Second, researchers and model project developers should be encouraged to address transition issues at all levels of influence when designing either education or employment programs for youths with disabilities. Third, persons involved in transition planning and program development should be stimulated to utilize the multilevel- system approach. By utilizing this system as a framework for planning and evaluation, researchers, policymakers, and project directors may be more able to develop working partnerships across levels that facilitate cooperation in program implementation. The DD Act funds could certainly enhance this type of activity.

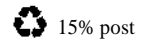
Presently, the Act funds several statewide service and planning activities which benefit youth with disabilities who are leaving the public school system. Coordination and collaboration with DD Councils, the P&A systems, UAPs, and projects of national significance can lead to increased effectiveness for your systems change efforts.

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