Disability Policy Research Brief

Center for Studying DISABILITY POLICY

Number 09-01 • March 2009

Transforming Disability Policy for Youth and Young Adults with Disabilities

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The transition to adulthood can be difficult for youth, particularly those who have disabilities severe enough that they receive Supplemental Security Income (SSI), Social Security Disability Insurance (DI), or other disability program benefits. Besides the issues facing all transition-age youth, young people with disabilities face a host of special challenges: health problems, social isolation, service needs, and lack of supports. These challenges complicate their planning for the future and often lead to poor educational and employment outcomes, long-term dependency, and a lifetime of poverty. In this policy brief, we highlight the importance of improving transition policy for youth with disabilities, review lessons from recent research, and consider transformative policy changes and why and how such changes might be tested.

Importance of Improving Transition Policy

Policy improvements for youth with disabilities are needed for several reasons:

- The costs of low adult employment have a devastating effect on the quality of life for these youth and their families, including long-term dependency and lifelong poverty. The lifetime economic advantage of work over dependency is particularly high for youth because they have many years ahead of them when they potentially could work (Rangarajan et al. 2009).
- Employment outcomes for young adults with disabilities are deteriorating. From 1989 to 2000—both peak business-cycle years—the employment rate for persons ages 25 to 34 with self-reported work limitations fell from 57.5 to 40.9 percent (Houtenville and Daly 2003).
- A rising number of individuals rely on income from SSI and DI, and the cost to federal and state government continues to grow. About 1.3 million persons ages 14 to 30 received SSI disability benefits in December 2007, at an estimated annual cost of $8.0 billion, and more than 300,000 received DI benefits in June 2008, at an estimated annual cost of more than $2 billion.[1] On average, people who enter SSI before age 18 remain on the rolls for 27 years, receiving a stream of benefits worth more than $100,000 per youth (Rupp and Scott 1996).
- Among all disability beneficiaries, youth are a particularly promising target population for policy reform. Youth with disabilities may eagerly consider employment because they have not become fully entrenched in dependency and because most of their nondisabled peers are making a transition to work.

Lessons from Prior Research

Much of what we know about the transition of youth with disabilities comes from two demonstration projects that focused on competitive employment and included rigorous evaluations. The U.S. Department of Labor's Structured Training and Employment Transitional Services (STETS) demonstration was targeted at youth ages 18 to 24 who had IQ scores be-

[1] SSI statistics are based on the online version of SSA's *Annual Supplement to the Social Security Bulletin*, tables 7.A1 and 7.E3 (www.ssa.gov/policy/docs/statcomps/supplement/2008). The number of 14-year-old recipients was imputed as one-third of the number between ages 15 and 17, and the number of 30-year-olds was imputed as one-tenth of the number between ages 30 and 39. Benefit amounts are based on mean monthly benefits by age group (under 18 and 18 to 64) and include state supplements. SSDI statistics are based on detailed statistical tables for individual years of age, provided online by SSA's Office of the Actuary (www.ssa.gov/OACT/ProgData/byage.html). Both sources were accessed on December 11, 2008.

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tween 40 and 80. It consisted of an introductory work exposure period, followed by actual employment with on-the-job training (or supported employment), postemployment followup, and job supports. The Social Security Administration's (SSA's) Transitional Employment Training Demonstration (TETD) provided similar employment services to SSI recipients ages 18 to 40 who had been diagnosed with mental retardation, along with waivers to preserve their SSI benefits.

Three more recent demonstration evaluations focusing on adults with disabilities also offer important insights. The State Partnership Initiative (SPI) promoted employment and economic self-sufficiency among disability beneficiaries through benefits counseling and care coordination services to SSI recipients. Project NetWork tested the provision of case management to promote employment among SSI and DI beneficiaries. The Individual Placement and Support model for people with psychiatric disabilities included competitive employment, consumer choice, rapid job search, and the integration of health and rehabilitation supports.

Lessons from these prior demonstrations include:

- STETS and TETD, which randomly assigned eligible youth to receive either demonstration services or the mix of otherwise available standard services, found that transitional employment supports for youth that emphasize competitive employment can improve adult employment outcomes (Kerachsky and Thornton 1987; Decker and Thornton 1995). Nonrandomized studies also indicate that early exposure to employment and training experiences can improve long-term employment outcomes. Youth who participate in occupational education and special education in integrated settings are more likely to be competitively employed than youth who have not participated in such activities (Blackorby and Wagner 1996; Luecking and Fabian 2000).
- Providing individualized supports is more effective in promoting employment outcomes and program retention than standard, one-size-fits-all approaches. Impacts on employment and earnings were largest in projects that matched jobs and participants carefully and were flexible in response to the individual's needs (Blackorby and Wagner 1996; Decker and Thornton 1995; Luecking and Fabian 2000).
- Helping participants locate permanent jobs well-matched to their capabilities increases long-term employment. Rapidly moving youth into well-matched jobs with growth potential led to an increase in job retention (Cook et al. 2005; Luecking and Fabian 2000).
- Fragmentation must be reduced. Numerous studies underscore the importance of coordinating services across agencies, particularly linking disability-specific services with other school and health services and connecting mental health services with employment services (Cook et al. 2005; Schuyler and White 2005).
- Counseling is necessary, but policy changes that increase the payoff to work are also needed. Youth and their advisors need benefits counseling to understand how they can increase their income while maintaining key supports, but counseling alone is not enough. In fact, benefits counseling prompts some beneficiaries to keep their earnings low to avoid loss of benefits (Peikes et al. 2005). While this practice might be the best way to maximize income under current program rules, it runs counter to the long-term objective of greater economic independence. Policy changes are needed that allow beneficiaries to keep more of their earnings and health insurance without benefit reductions.
- Increasing income might be easier than reducing public expenditures. Despite some success in promoting employment, no large-scale project has demonstrated an ability to reduce SSA benefit receipt. Even projects with the largest impacts on earnings showed only small reductions in benefit amounts because earnings were still too low to terminate benefits (Kornfeld and Rupp 2000; Peikes et al. 2005).

Valuable lessons will also be learned from ongoing tests of policy interventions designed to improve employment of people with disabilities. These include SSA's Youth Transition Demonstration (YTD), Accelerated Benefits Demonstration, and Mental Health Treatment Study as well as the Centers for Medicare and Medicaid Services' Demonstration to Maintain Independence and Employment (DMIE) (Livermore and Goodman 2009).

Panel Recommends Transformative Change

Policymakers, researchers, and advocates are examining various ways to improve transitions for youth with disabilities. One notable example is presented in the final report of the Ticket to Work and Work Incentives Improvement Act Advisory Panel.[2] The panel recommended developing and testing a transformative new policy for youth and young adults with disabilities: Transition to Economic Self-Sufficiency (TESS). TESS would be a new program for persons with disabilities ages 14 to 30 who face significant barriers to work but who could increase self-sufficiency if given adequate supports. TESS would establish unified rules for SSI and DI that (1) provide a graduated cash payment to address the effects of disability-related barriers on income, (2) increase the availability of and consumer control over employment-related services, (3) promote optimal educational outcomes, and (4) enable program participants to maximize income and assets without fear of losing critical supports. SSI and DI beneficiaries would be allowed to keep significantly more

[2] The Ticket to Work and Work Incentives Improvement Act Advisory Panel was established by the Ticket Act from 2000 to 2007 to advise the president, Congress, and the commissioner of SSA on issues related to the Ticket Act and other SSA programs.

of their earnings than they can under current program rules. Participants in TESS would be guaranteed access to affordable coverage for health care and long-term services and supports; such coverage would be comprehensive, portable, supported by beneficiary contributions when appropriate, available even if income support is terminated, and coordinated with employer-sponsored benefits. Participants also would receive financial literacy training on money management, tax credits, and work incentives (Ticket to Work Advisory Panel 2007).

The panel also recommended that SSA and Congress modernize the SSA definition of disability, which determines SSI/DI eligibility. The current law, conceptually unchanged since 1956, defines disability as a physical or mental impairment that prevents the individual from engaging in substantial work—a definition that discourages applicants and beneficiaries from seeking employment. The panel pointed out that this definition has particularly tragic consequences for youth; it sends a strong message that they are not expected to attempt work because they are inherently unable to support themselves. Rather, the panel recommends that eligibility be defined to reflect 21st-century thinking about disability, acknowledging an emerging social consensus toward encouraging all people to achieve their full potential. One option is to focus program eligibility on individuals who face substantial employment barriers, such as a need for accessible transportation, job modifications, or other supports (Ticket to Work Advisory Panel 2007).

A Cross-Agency, Coordinated Demonstration

The demonstration of a comprehensive transition program like TESS is arguably the next logical step in the effort to improve transition policy for youth with disabilities. Although much has been learned from past efforts, success has been limited, perhaps largely because such efforts have taken a piecemeal rather than a holistic approach. Researchers and advocates have identified numerous barriers to employment, including (1) cash and health insurance programs that create work disincentives; (2) poorly publicized and complex work incentive features of existing programs; (3) limited education, job training, and expectations of beneficiaries; and (4) discrimination, misinformation, and other issues in the labor market that inhibit employer demand for workers with disabilities (Peikes et al. 2005). However, no large-scale demonstration has tested reforms that involve removing more than one or two barriers. A test of a transition program like TESS would do so. The demonstration would communicate high expectations for youth with disabilities while they are young, make work pay, offer meaningful choices in employment supports, integrate services from various agencies, and better inform the target population.

Tests are critical to developing effective national policy. A poorly designed and untested system could harm the people it is designed to help or be so costly and inefficient that it loses political support. SSA's Ticket to Work program provides an example of what can happen when an agency is directed by legislation to roll out a new program without prior testing. As directed by the Ticket Act, SSA provides disability beneficiaries with a ticket that they can deposit with a qualified provider of their choosing to obtain employment services. Nine years after the legislation was passed and six years after the rollout, participation is anemic, there is no evidence of a substantial impact on employment and benefits (Stapleton et al. 2008), and political support is low. New regulations, promulgated in July 2008, might invigorate the program, but much time, money, and momentum have been lost. Further, the lack of a Ticket to Work pilot study, with an appropriate comparison or control group, limited the lessons learned from the initial configuration of the program.

Conducting a well-designed test of a transformative policy change like TESS will be difficult, but there are some promising examples that can help guide the process. The difficulty of testing transformative policies stems from several factors. First, because they involve public service responsibilities that cut across agencies and levels of government, they must involve multiple agencies at the federal and state levels. Second, because many tests of specific transformative policies are likely to fail, multiple, preferably concurrent, tests of policy variants are needed. Third, because the impacts of any demonstration might take several years to materialize, the testing period will need to be lengthy.[3]

SPI, DMIE, and YTD provide small-scale models for how a demonstration might be conducted. In each case, a federal agency (YTD, DMIE) or group of agencies (SPI) allowed state and local governments or nonprofit agencies to test interventions targeted at specific populations. These interventions included features such as various federal program waivers.

We envision a more ambitious demonstration, perhaps rolled out in a few communities as a test, which will require cooperation among a larger set of federal and state agencies. A multiagency demonstration authority, authorized by Congress and with the strong support of the president, could encourage state governments to form multiagency groups that would propose specific versions of a comprehensive new program. The federal authority would ensure that each state's proposed intervention is faithful to the program model, grant waivers to test variations of rules for multiple federal programs, provide technical assistance, and help the states learn from each other. In addition, the federal authority would ensure that each demonstration is designed to support rigorous evaluation; ensure that a

[3] State demonstrations of strategies to reduce the Aid to Families with Dependent Children rolls in the 1990s and increase incomes among the target population provide one example of how demonstration results can shape national policy. Legislation to initiate the Temporary Assistance for Needy Families program was adopted only after evaluation of multiple state-level interventions, most of which were not successful (Weaver and Dickens 1995).

thorough, independent evaluation is conducted; and draw lessons from the evaluation for national implementation.

Enormous changes in the environment—advances in medicine and technology as well as changing attitudes about people with disabilities—offer the promise of better employment outcomes for youth with disabilities. Transformative policy change is needed to fulfill that promise. While even well-designed demonstrations of transformative changes will not always work the first time, they provide important guidance for future policy change. If just one demonstration proves successful, it could lead to a national policy that gives youth and young adults with disabilities the opportunity to live more rewarding and productive lives.

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