

A Perspective from Youth with Disabilities: Benefits in a World of Employment

Youth Advisory Committee Recommendations to the National Council on Disability

March 2007

“Focus on the possibilities, not the disability.” [1]

Executive Summary

This document provides information about existing programs related to disability employment benefits and provides youth insight about problems, challenges, and proposed resolution associated with the federal benefits system.^[2] This document also makes seven key recommendations to the National Council on Disability (NCD) from its Youth Advisory Committee (YAC) on how the federal government can improve systems so that the programs and services can be most beneficial for youth^[3] with disabilities who wish to become employed.

The recommendations address seven areas of action for appropriate federal agencies, the Administration, and Congress. They include:

- (1) Tracking and reporting the employment rate of youth with disabilities;
- (2) Addressing employer training and tax incentive needs;
- (3) Requiring benefits planning in IEP and school transition processes;
- (4) Incorporating youth with disabilities in federal employment campaigns;
- (5) Raising income earnings limits under benefits programs;
- (6) Creating easy-to-read materials about benefits; and
- (7) Involving young people with disabilities in drafting a uniform definition of disability.

Introduction

For young people in America, having a job is very important. It provides money and a sense of dignity and responsibility. A United States Department of Education report documents that employment is the norm in American society. The report also states that with nearly 80 percent of youth in high school holding jobs, little was systematically collected and made known about the employment of youth with disabilities, prior to the reports from the 1987-1990 National Longitudinal Transition Study (NLTS) and NLTS-2 ten-year study that began in 2001.^[4] Having a job is also an important way of moving

ahead in American society. Whether a person needs help with getting to work, paying medical bills, or maintaining a home, the Federal Government has a wide range of programs that can help youth with disabilities find successful careers.

The Federal Government realizes that opportunity for employment is an important way to give people with disabilities the means to provide for themselves, while lowering federal support costs. There are several unique programs such as the Work Incentives Planning and Assistance (WIPA)^[5] program, the Plan to Achieve Self-Support (PASS), and the Ticket to Work that have been set up to help people with disabilities succeed at work while maintaining their benefits. The disability employment benefits system can assist with housing, jobs, medical costs, and career security.

There also are some observations about the current disability employment benefits system pertaining to healthcare that people should know. Some employers do not offer health benefits that an employee with a disability may need. Although discrimination against people with disabilities is illegal, behaviors that give the appearance of discrimination based on disability may affect the chances of a person with a disability being hired. Some government programs reduce the amount of aid they provide to a person with a disability if he or she becomes employed. Other programs stop providing aid after a person has maintained a job for a certain period.^[6] Some jobs, for example, may not pay enough to cover all medical expenses related to a disability, but they also may provide too much income for that employee to be eligible for government assistance through the existing benefits system.

Youth Perspectives and the Focus of this Paper

“Be proud of your disability. It [is] just a part of who you are.”^[7]

During the 2006 fiscal year, the YAC planned and hosted its first national level Next Generation Roundtable to hear concerns and suggestions directly from youth with disabilities on youth leadership and employment. When asked their perspectives on the challenges facing youth with disabilities who seek employment, Roundtable participants talked about the need for youth-friendly language, less bureaucracy in the benefits

system, enforcement of existing federal laws and regulations, the need for more internships, as well as other concerns.^[8] One summary point from the roundtable discussion was that existing benefits programs and services have both negative and positive aspects. Since the roundtable, input from other young people is also included under Advantages, Cautions, and Disadvantages sections of this paper.

Advantages

Youth with disabilities, for the most part, begin their transition from school to work with government support. This support comes in several forms [e.g., Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and Medicare] and is used by many young people as a springboard into employment and getting off the so-called “government dole.”

Some benefits, such as the Ticket to Work program, provide funds to allow an eligible young person (as well as people of other ages) with a disability to use the services of a Vocational Rehabilitation Agency to create an Individual Plan for Employment (IPE). A comprehensive review of the Ticket to Work program and guidance^[9] can be found at www.ssa.gov/work/ResourcesToolkit/legisregfact.html and <http://wdr.doleta.gov/directives/attach/TEGL.15-04.pdf>.

Many youth with disabilities find the school-to-work transition period difficult for various reasons.^[10] To help eligible individuals (SSDI or SSI recipients), including youth, in using the Ticket to Work, the Benefits Planning, Assistance, and Outreach (BPAO) program was established and as indicated above is now called the WIPA program. Under this program, a benefits counselor helps people make informed choices about employment goals and how best to use Social Security benefits. A directory of groups that provide this service is available at: www.socialsecurity.gov/work/ServiceProviders/WIPADirectory.html.

The Plan to Achieve Self-Support (PASS) was designed to help people with disabilities return to work. PASS is a program in which a Social Security benefits recipient is

allowed to set aside funds for reaching a work goal. For example, a person could decide to purchase things like a computer, a car, or a wheelchair, as long as the item is related to the work goal. More detailed information and application procedures are available online at: <http://www.ssa.gov/disabilityresearch/wi/pass.htm>.

The U.S. Department of Housing and Urban Development runs several programs to help individuals independently purchase a home or rent a home or apartment. The Federal Housing Administration (FHA) runs one such program. In the program, the FHA insures your loan, and your lender can give you a better deal such as a lower interest rate and lower monthly payments than other borrowers pay. The FHA also runs the Section 8 housing program, which is designed to assist individuals with disabilities or individuals of low income make their rental payments. More information on these and other housing programs can be found at <http://www.hud.gov/>.

On a positive note, a student from the West Coast noted the following about his experience with SSI benefits: “SSI helped greatly with money during college so that I didn't have to work at the same time. Although working and going to school at the same time is hard for anyone, it would've been especially hard for me because it took so much more time to do my schoolwork.” From another view, other youth remain solely on SSI or SSDI without seeking employment and point to programmatic challenges to using these benefits as a temporary help. In the Cautions and the Disadvantages sections below are specific references to these challenges.

Cautions

The U.S. Department of Education, Office of Special Education and Rehabilitative Services, has reported that “up to two years after leaving high school, about four in 10 youths with disabilities are employed as compared to six in 10 same-age out-of-school youths in the general population.”^[11]

Employment is a status symbol in America. A question asked in all walks of life is: “What do you do for a living?” Employment is associated with self-sufficiency, buying

power, social circles, and opportunities. People also make judgments and assumptions based on one's job, what kind of house you live in, and what type of education you have. Furthermore, it has long been said that people who are unemployed and receiving benefits should "stop being lazy and find a job." For some youth, it is not always that simple. The livelihoods of many youth with disabilities are tied to the benefits they receive. Some youth need personal care assistants who help them get ready in the morning. Others need critical health care drugs on a daily basis. When someone becomes employed, it often means that benefits needed for self-sufficiency are greatly reduced, or even cut off completely. For some people, this makes employment seem impossible, because they cannot afford to pay for necessary medical and/or personal care needs without a benefits program or package. Data on employed versus unemployed youth with disabilities were not available in labor force reports.^[12]

A male college student, when asked how benefits planning has helped or held him back in his job-seeking activities, explained that SSI and SSDI earning limits have hindered his job-seeking activities. "For example, this summer I plan to do an internship in D.C. for the Federal Government, hopefully [an identified federal agency]," he said. "I will have basic expenses such as room and board at [an identified] University. I cannot figure out how I can get paid so that I can pay for additional expenses, while at the same time not losing my SSI and SSDI." Such earning limits can stand in the way of employment and internship opportunities, as youth with disabilities cannot afford to lose SSI or SSDI funds.

There are many more stories like this across America where youth are trying to better their lives by working. However, with the barriers facing them, many youth with disabilities are choosing not to work. As one example, federal benefits might cover upwards of \$50,000 a year in health and medical care necessary for a youth with a disability. Once the recipient is off benefits, usually he/she is expected to provide for him/herself. With that added responsibility, a job paying \$46,000 a year for a young worker might not be enough to make ends meet, let alone live as comfortably as middle-income Americans do. Even the most skilled workers with disabilities sometimes

hesitate about becoming employed because of the reality and/or risk of having to live without a safety net. Many times health care coverage for employees becomes effective only after a set waiting period. For some youth with disabilities, getting a job that does not provide medical benefits for the first few months of employment would be a risk. So, why not consider raising the limits that people on SSI and SSDI can earn by working before their benefits are reduced? As Next Generation Roundtable participants discussed these matters, they also talked about drawing from economics and policy backgrounds, and suggesting solutions across different disabilities.

Disadvantages

Like other workers with disabilities, young people with disabilities often face discrimination in the hiring process for a variety of reasons. For one example, there is the old stigma against people with disabilities. The word 'disabled' expresses a stereotypical mentality with an emphasis on 'inability.' Additionally, some employees may find it difficult to educate employers about available resources to lessen financial strains on the business. Oftentimes, employees find that they must take it upon themselves to educate the employer about the affordability of providing necessary job accommodations. Many of these accommodations can be mutually beneficial to the employee and the employer.

Of course, some disabilities are less obvious than others are, but sometimes disclosure is necessary in order to receive benefits and/or accommodations, therefore ensuring the employer will know one's individual needs for support in the workplace. Even worse, some employers do not offer sufficient health care packages, or sometimes do not offer them to new hires. This makes successful employment difficult for many youth with disabilities. In addition, it can take a while to get back on benefits (become eligible again)—perhaps as long as a few months before one can sign up for government benefits. For a person with a disability, this can make employment without the benefit safety net a serious risk. If employment does not work out or if one loses his/her job, it can impose significantly inadequate services for an extended period. It poses the questions: Who would provide support during this unstable time? Would one ask family

or friends for support? These concerns seem to call for additional employer tax incentives focused on youth with disabilities.

It might come as a surprise to some young people (or other readers) that when employment is successful, the system can be risky. For instance, people with middle-income earnings could possibly receive little or no government support. This can make it seem more of an advantage to be on the welfare system, for example, than to work. This is in part because the benefits are reduced as the salary increases and the employed person with a disability needs to pay personally for pricey support/care needed each day to reach and keep a job. A person should not have to go into poverty in order to have safe, quality health care. The same goes for transportation, personal assistants, or assistive technology needs and other supports for self-sufficiency. Instead of “taking care” of youth with disabilities in the community, we should be given them the tools to take care of ourselves. The first step is to listen to what youth say they need most to be successful in life and to see that federal laws are enforced.

A young person with a disability in California said this about the challenges of her transition from school to work: “I am currently facing the obstacles of joining the workforce with far more concerns than my non-disabled peers. For those who think that living on public benefits is easy or that people with disabilities are just lazy for not working, I am here to challenge that assumption. In the state of California, I am fortunate to receive Supplemental Security Income (with the additional California state enhancement), In-Home Supportive Services (to pay for attendant care), and Medi-Cal (California's version of Medicaid). While I am grateful to have these public benefits that allow my independence, they create finding employment far more challenging. It is not sufficient just to get a job (not that this task is easy these days). I have to ensure that my employer's benefits package cares for my needs or that I can earn enough to bear [costs] myself.”

Raising Awareness

Finally, much of the information about transition from benefit programs to work is not widely known. Among people in the disability community, including youth, there is need for increasing awareness about how to manage successfully the use of benefits alongside employment. Many of these benefits start after age 18, meaning youth find it challenging to start early enough to become fully familiar with the system. Education about the federal system needs to start early in the school years. People with disabilities continue to struggle in finding successful employment as shown by a widening employment gap between working age people with and without disabilities.^[13] We need to spread the word to youth with disabilities about the protection of laws, as well as the available programs and services provided in ways that also respect the changing culture and language needs across America.

Recommendations

As youth, we see a need for a system that fosters self-determination and the employment outcomes of young people with disabilities. Given a need to change the current system to address some of the concerns addressed in this paper, our recommendations to NCD are for seven key actions at the federal level. The YAC recommends that NCD should consider ways under its authority to call attention to the need for actions as follows:

1. Federal data collection needs to include more specific information about young people with disabilities. For example, the U.S. Department of Labor (DOL), Bureau of Labor Statistics should track and report the employment rate of youth with disabilities. DOL also needs to track information that starts at a younger age than the agency now uses.
2. Congress should: (a) authorize the Small Business Administration to promote cultural and language appropriate trainings geared toward hiring and working with youth with disabilities; and (b) authorize the Internal Revenue Service to provide tax incentives to employers that hire youth with disabilities.

3. The U.S. Department of Education, Office of Special Education and Rehabilitative Services, should ensure that guidance to education agencies receiving funding assistance to provide special education and related services will include benefits planning as a key component of the Individual Education Program and school transition process for each eligible student with a disability.

4. The Equal Employment Opportunity Commission should expand its aggressive efforts to address the falling numbers of people with disabilities in the federal workforce. It is recommended further that NCD call for an Executive Order that federal agencies target youth with disabilities in their annual hiring procedures to not only increase the number of people with disabilities in the federal workforce but to address the rising age of the federal workforce.

5. The Social Security Administration (SSA) should raise the earnings limit on Supplemental Security Income and Social Security Disability Insurance to bring those limits in line with inflation. The YAC further recommends that the U.S. Congress should authorize SSA to raise the limit of annual earnings based on the Cost of Living Adjustment.

6. SSA should produce youth-friendly versions of publications so that youth with disabilities have clearer and uncomplicated descriptions to assist their understanding of the benefits available to them.

7. Congress should involve members of the disability community in drafting a uniform standard of defining disability. This definition should be used for tracking people with disabilities in the decennial census, the labor market, and in other areas where federal data on people with disabilities is not standard.

Conclusion

Perceptions of youth with disabilities have changed over the last 50 years. The community that people once referred to as a “class of invalids” has now joined the ranks

of American workers and is becoming a more visible part of an ever-changing America. Youth are talented, motivated, and driven people who want to make decisions for our own lives in order to live independently. Many support programs remain tied to the outdated thinking that youth with disabilities “need to be cared for.”

Legislators and other federal officials should listen to what youth with disabilities identify as needs/priorities. Often, a need is not about material possessions or more money, but much more about self-determination and self-empowerment. It is important to get perspectives directly from youth with disabilities regarding concerns about unmet needs in transition from school-to-work, daily living, and employment. As young people, we want to work side by side with other Americans, go to college, purchase our first home, and become productive citizens. We are equal members of society. We recognize the many advances and social programs created to assist us in gaining independence and meaningful employment, and for these we are thankful. However, we need to take the next step in creating equal opportunities. Meaningful actions that result in changing negative perceptions or attitudes and leveling the playing field for health care options, enforcing the laws, and revising the benefits system can usher an increased number of youth with disabilities into the working world.

Youth Advisory Committee Members 2007:

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Michael D. Murray, Ari Ne'eman, Andrew Phillips (Post-secondary Students) Gary R. Goosman, Vice Chair; Reagan D. Lynch, Secretary; Stephanie Orlando, Chair (Post-secondary Graduates)

^[1] Next Generation Roundtable participant comment, July 25, 2006 Hyatt Regency, Arlington, VA.

^[2] Benefits are defined in this paper as programs designed to help a person with a disability earn enough money so that he or she can become financially independent:

<http://www.ssa.gov/pubs/10061.html>.

^[3] Youth in this paper includes people below 30 years of age and the National Council on Disability's YAC by-laws call for members ages 16-25 years. See

<http://www.ncd.gov/newsroom/advisory/youth/youth.htm>.

^[4] Data Brief, Reports from the National Longitudinal Transition Study. December 2003, Vol. 2, Issue 2, "Youth Employment" Renee Cameto, Camille Marder, Mary Wagner, and Denise Cardoso.

^[5] Formerly known as the Benefits Planning, Assistance, and Outreach Program or BPOA, the change to WIPA including program funding, length, and training requirements became effective October 1, 2006.

^[6] One example is Medicare coverage. Information can be found at <http://www.ssa.gov/work/>.

^[7] Next Generation Roundtable participant comments on July 25, 2006 Hyatt Regency, Arlington, VA.

^[8] Summary Next Generation Roundtable, July 2, 2006.

http://www.ncd.gov/newsroom/advisory/youth/yac_roundtable.htm.

^[9] Training and Employment Guidance Letter, January 31, 2005, Employment and Training Administration Advising System, U.S. Department of Labor.

^[10] The National Council on Disability and Social Security Administration report: *Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Post-Secondary Education and Employment*, November 1, 2000

http://www.ncd.gov/newsroom/publications/2000/transition_11-01-00.htm.

^[11] Improving the Postsecondary and Employment Outcomes of Youth with Disabilities. Federal Register: February 15, 2007, (Volume 72, Number 31). Pages 7427-

7430. <http://www.ed.gov/legislation/FedRegister/proprule/2007-1/021507a.html>.

^[12] Labor force status of 2005 high school graduates and 2004-05 high school dropouts 16-24 years old by school enrollment, sex, race and ethnicity. U.S. Bureau of Labor Statistics, October 2005; Updated online March 2006. <http://www.bls.gov/news.release/hsgec.t01.htm>.

^[13] Myers, Linda. "Gap widens between working-age people with and without disabilities in the workforce, report shows" *Chronicle Online* October 5, 2005
www.news.cornell.edu/stories/Oct05/Disab.work.rpt.html.