

Pushing for Policy to Promote Self-Determination: *Part I*

By *Serena Lowe, M.P.H.*

Public policy and practice toward segregated settings for adults with significant disabilities continues to be biased — despite the fact that self-advocates and their families have increasingly higher expectations about participating in an inclusive workforce and in the economic mainstream.

As a result, working-age adults with disabilities are 3 times more likely than their non-disabled peers to live at or below the poverty line. Additionally, only 21% of taxpayers with disabilities have incomes over \$40,000. Enduring poverty for individuals with significant disabilities and a lack of economic empowerment diminishes freedom, opportunity, and it leads to an overall deterioration of quality of life.

It's true that the U.S. *has* come a long way since the days when institutionalization was the dominant way of addressing the needs of adults with significant disabilities. However, additional public policy reform is required before these individuals have the same opportunities to determine their destinies with respect to working, generating an income, building savings, and pursuing goals that the general population enjoys.

It's also a fact that families have a legal framework to ensure that children with intellectual disabilities receive the support and encouragement necessary to succeed in an integrated educational setting. However, as more post-*IDEA* students graduate from high school, another significant set of challenges await them — that is, few services are available to support these individuals as they transition from youth to adulthood. In fact, by restricting their ability to work, earn, and save by jeopardizing their eligibility for critical long-term supports, public policy *penalizes* rather than *rewards* individuals who wish to attain an adult life of self-sufficiency.

The problem is not due to a lack of money. Public financing to support adults living with intellectual disabilities in the U.S. grew from \$2.3 billion in 1955 to \$82.6 billion in 2004. The problem lies with significant

inequities in the distribution of financial support and services for this population. As a result, thousands of individuals with disabilities continue to live in institutions, nursing homes, and other residential facilities despite their ability and desire to live in partially- or fully-independent situations. Family support and integrated employment programs receive limited funding and, as noted, individuals are often penalized for working or saving by having benefits reduced or eliminated when they earn an income.

This problem will only get worse if something isn't done. Within the next decade, another 500,000 persons with disabilities are expected to transition from youth into adulthood. Clearly, steps must be taken to ensure that these individuals receive the services and supports necessary to attain fulfilling, productive lives.

The Collaboration to Promote Self-Determination

In March 2007, a small group of leaders representing the National Fragile X Foundation, National Down Syndrome Society, and Autism Society of America, met in Washington, D.C. to discuss an emerging challenge facing all three organizations: *how to address the growing needs of adults with intellectual disabilities to work, earn, save, and live independently in inclusive community settings with meaningful, long-lasting social relationships.*

The answer was to advocate for public policy reform that promotes self-determination and choices, which result in persons with disabilities with disabilities living and working in integrated settings similar to their peers who do *not* have disabilities. Four key challenges were identified:

- 1) Chronic disincentives to income generation and asset accumulation;
- 2) Barriers to portability and flexibility in benefits;
- 3) Disconnect among various partners in the effective transition of youth into an inclusive employment; and

- 4) Lack of a sustainable long-term care support structure aimed specifically at promoting the unique needs of individuals with significant disabilities.

The outcome of this meeting was to launch an aggressive national public policy reform campaign focused on promoting regulatory and legislative reforms to support adults living with complex intellectual, cognitive, and developmental disabilities. Within six months of the initial dialogue, the *Collaboration to Promote Self-Determination (CPSD)* was created. The CPSD is an informal network of approximately 12 national organizations working together to promote opportunities for individuals with severe disabilities, and to eliminate barriers to their ability to work and save...while simultaneously expanding individualized supports and continuation of benefits (when necessary).

Achieving this vision requires an environment of “continued attachment” for individuals who have achieved partial self-sufficiency. The CPSD believes that the control of funding for supports required in all aspects of a person’s life — combined with gainful employment — provide the two most important components necessary to alleviate both the poverty of individuals served by the present system and their lack of meaningful relationships and community associations. This is the backdrop under which the CPSD was created in 2007, and it will continue to guide the CPSD as it moves forward.

It is the intent of the CPSD to create a system that *rewards* individuals for pursuing optimal self-sufficiency instead of *penalizing* them (and their families) through various barriers and disincentives. The CPSD is committed to ensuring that every adult living with significant disabilities has the opportunity, encouragement, and support required to lead an independent, productive life.

The CPSD is focused on promoting high-impact public policy reform aimed at:

- *Eliminating current obstacles and potential barriers* to empowering individuals with significant disabilities requiring significant support;
- *Creating incentives* that specifically address the unique needs of these individuals;
- *Empowering adults living with significant disabilities* by providing opportunities for meaningful engagement in the areas of employment, education,

asset development, social interaction, and community engagement; and

➤ *Focusing efforts directly on the long-term self-sufficiency* and sustainability of the individual.

With this vision in mind, the CPSD has been working for the past three years in five core areas:

- 1) National Systems Change;
- 2) Employment;
- 3) Transition;
- 4) Asset Development; and
- 5) Long Term Supports & Services.

NATIONAL SYSTEMS CHANGE

Lack of Coordination Across Federal Agencies

There are more than 200 programs in 23 federal agencies that provide public disability benefit programs. These programs and policies are not consistently aligned to encourage work, income generation and preservation, and stimulate development of human and financial capital. Poor coordination between agencies and the complexity of rules to overcome disincentives to work and savings has led to *worse* employment outcomes for youth and adults with significant disabilities.

Public policy — both disability-specific and generic — that cuts across federal authorities currently does not provide consistent encouragement for income production, savings and advancing of self-sufficiency; rewards and incentives for cross-agency collaboration; or promotion of individual choice and self-direction of individual budgets to produce improved employment and economic status.

As a result, the CPSD is committed to working with federal agencies to foster greater informal *collaboration* among various partners that support citizens with disabilities, and pushing for progressive public policy reform through legislation designed to promote:

- ❖ Additional practices of blended and braided resources (at the state level);
- ❖ Improved coordination of services focused on the individual; and
- ❖ More consistent processes related to goal setting, data collection, performance measurement, and evaluation. ■

NEXT MONTH: The remaining four core areas will be covered.

Serena Lowe is the co-founder of the Collaboration to Promote Self-Determination. She is also the founder and principal of Aneres Strategies, a Washington, D.C.-based consulting firm specializing in government relations, public policy, organizational development, and strategic planning. To find out more, or for a list of references used in this article, contact Serena at EwolAneres@gmail.com.

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