

## **Independence, Self-Sufficiency, Freedom: The Collaboration to Promote Self-Determination**

By Serena Lowe

The first generation of individuals with developmental disabilities who entered the educational system since the enactment of the Individuals with Disabilities Education Act (IDEA) in 2004 has now started graduating from high school. The implementation of IDEA was a long and winding road for families facing the task of educating school officials and advocating on behalf of their children. The premise that all individuals are entitled to participate in the public educational setting, regardless of disability, has become engrained in the majority of primary and secondary educational institutions in the U.S.

Families now 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 challenge has emerged: few services are available to support these individuals as they make the transition from youth to adulthood. In fact, the support system has become so convoluted with bureaucratic restrictions that it is the very opposite of what was intended. The system now penalizes, rather than rewards, individuals who wish to attain an adult life of partial self-sufficiency and independence.

### **Growing Paradox**

We have come a long way since the days when institutionalization was the dominant strategy to address the needs of adults with intellectual disabilities. We still have a long way to go, however, before these individuals have the same opportunities to determine their destinies with respect to employment, education, asset development, long-term growth and overall development. Within the next decade, approximately 500,000 individuals in the U.S. with intellectual disabilities will transition into adulthood. We must take steps to ensure that these individuals receive the individualized assistance they need to live fulfilling, productive lives.

The problem is not a lack of investment in the intellectually disabled. 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.<sup>1</sup> The inherent problem is that there are significant inequities in the distribution of financial support and services among states, communities, families and individual disabled consumers. Tens of thousands of persons with intellectual disabilities continue to live in institutions and nursing homes, despite their ability to live in partially or fully independent situations. Family support and integrated employment programs receive limited funding, and individuals are often penalized for working or saving by having benefits reduced or completely eliminated when they earn an income.

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<sup>1</sup> Braddock, D. "Washington Rises: Public Financial Support for Intellectual Disability in the United States: 1955-2004." *Mental Retardation and Developmental Disabilities Research Reviews*. (2007): 13/169-177.

This counterproductive cycle deters many intellectually disabled individuals from seeking meaningful education or employment opportunities because they fear loss of their public assistance. This income is necessary, since employment alone will likely never provide enough income for them to live independently and plan for the future. Thus, a vicious cycle of poverty continues among individuals with intellectual disabilities, because of their limited ability to earn and save without fear of penalty.

Despite living in the “land of the free,” says Thomas Nerney, executive director of the Center for Self-Determination in Ann Arbor, MI, a “person with a disability is bereft of basic human freedom in exchange for other-directed human supports/services.”<sup>2</sup> This stunning lack of freedom is a high price to pay in exchange for public assistance. The current system creates additional barriers for individuals with intellectual disabilities to pursue universal needs that make life worth living: the contemplation and quest for a meaningful life suffused with relationships and membership in one's community. Our human services system places so many restrictions on individuals that people with intellectual disabilities are seen as dependent and thus become dependent. This is a direct result of the current paradigm in America's treatment of the intellectually disabled, a population that is growing at exponential rates.

### **The Collaboration to Promote Self-Determination**

In March of 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 by creating public policies that promote self-determination. Four key challenges were identified:

- Disincentives to employment and asset accumulation
- Barriers to portability and flexibility in benefits
- Lack of coordination of services focused on the individual
- No eligibility v. buy-In option to long-term care benefit structure

The outcome of this meeting was the commitment to establish an aggressive advocacy campaign to raise consciousness about empowering individuals with complex intellectual, developmental and cognitive disabilities that require significant support. The campaign would promote regulatory and legislative reforms to support adults living with intellectual disabilities. From this discussion grew an advocacy movement that is becoming the most significant collective action of the intellectual disability community since the campaign to create the Americans with Disabilities Act (ADA) that began in the late 1980s.

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<sup>2</sup> Nerney, Thomas. “The Poverty of Human [Services](#),” Center for Self-Determination, Working Paper: 2001. [www.self-determination.com](http://www.self-determination.com) (extracted March 2007).

Within six months of this initial dialogue, the Collaboration to Promote Self-Determination (CPSD) was created. It is an informal network of approximately 12 national organizations working together to promote opportunities for those with intellectual disabilities and to eliminate barriers to their working and saving, while ensuring the expansion of supports and continuation of benefits (when necessary). This requires an environment of “continued attachment” for individuals who have achieved partial self-sufficiency.

The vision of the CPSD is to create a system that rewards individuals who achieve partial self-sufficiency instead of penalizing them and their families by eliminating their public assistance and support services. The CPSD is committed to ensuring that every adult living with complex intellectual, developmental and cognitive disabilities has the opportunity, encouragement, and support required to lead an independent, productive life.

### **Mission Statement of the CPSD**

The Collaboration to Promote Self-Determination will promote high-impact public policy reform aimed at:

- Eliminating current obstacles & potential barriers to empowering individuals with complex intellectual, developmental and cognitive disabilities requiring significant support;
- Creating incentives that specifically address the unique needs of these individuals;
- Empowering adults living with intellectual disabilities by providing opportunities for meaningful engagement in the areas of employment, education, social interaction, and/or community engagement; and
- Focusing efforts directly on the long-term interests of the individual.

### **Challenges of Reform**

A common mistake that occurs when enacting legislative and policy reform agendas is the limitation created, by either laws or activity, within the very reforms that we seek. Perhaps the greatest example of this in recent years has been the Americans with Disabilities Act (ADA). There are those who argue that the employment provisions of

the ADA contained significant unintended consequences because they have resulted in more harm than benefit to the ADA's intended beneficiaries.<sup>3</sup> The added cost of employing disabled workers under the accommodation mandate of the ADA has made disabled employees relatively unattractive to firms. Moreover, the threats of prosecution under the Equal Employment Opportunity Commission and litigation by disabled workers have led firms to avoid hiring some disabled workers. Finally, with new employees, the additional costs associated with the accommodation mandates are likely to result in lower wages than what would have previously been offered to the employee.

What can we learn from the ADA case study? First, in order for effective reform to occur, employers have to be at the table working side-by-side with the disability community during policy negotiations. The insights of various-sized companies during the policy-crafting process is critical for all parties to understand the implications of policies, and to determine whether they will result in enhanced employment opportunities for individuals with intellectual disabilities.

Second, leaders from state and human services organizations must be involved to ensure the goal is consistent among key stakeholders: To improve the lives of individuals with intellectual disabilities by creating opportunities for, and eliminating barriers to, self-determination. Adults with intellectual disabilities have had their lives compartmentalized by categories of program funding, which often have separate regulations and contradictory purposes.

Another example of poor public policy is Medicaid assistance and Social Security Income/Disability Income (SSI/SSDI), and the relationship between the two programs. First, with several agencies and agendas at work in the human services sector, there is competition for funding and no incentive to collaborate on behalf of the individual. Second, the general population does not distinguish between the needs of different populations when it comes to welfare assistance programs (specifically SSI/Medicaid). As a result, the intellectually disabled are viewed in the same manner as other individuals receiving assistance—which includes the biases and assumptions that sometimes accompany those views.

Therefore, for most adults of working age with intellectual disabilities, it is not practical to modify the Medicaid program without simultaneously removing some of the disincentives to work in the SSI and SSDI programs. Legislative changes are needed at the state and national levels to make it easier for states to accomplish these goals.

In a comprehensive review by the Institute of Research on Poverty in 1981, Danziger et al., concluded that when looking at the overall impact of public spending on income transfers, reforms could be designed to reduce work and savings disincentives without sacrificing the distributional effects that have been achieved. Additionally, reductions in, or the complete elimination of, current benefits once a minimal level of

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<sup>3</sup> Evidence from DeLeiere (2000), Gruber (2000) and Bound/Waidmann (2002) have contributed to research that calls into question the success of ADA with respect to guaranteeing better job opportunities for people with disabilities: DeLeiere, T. “*The Wage and Employment Effects of the Americans with Disabilities Act*,” *Journal of Human Resources* 35/4 (2000): 693; Gruber, J. “Disability Insurance Benefits and Labor Supply.” *Journal of Political Economy* 108/6 (December 2000): 1166; Bound, John and Timothy Waidmann. “Accounting for Recent Declines in Employment Rates among Working-Aged Men and Women with Disabilities.” *Journal of Human Resources* 37/2 (Spring 2002): 234.

asset development is achieved will increase income poverty overall and achieve only small increases in work effort and savings.<sup>4</sup>

Policymakers can address the fiscal impact of growing state Medicaid budgets in a way that recognizes the desire of individuals with intellectual disabilities to craft their own lives. However, it requires a paradigm shift to allow public assistance to be utilized on a continual basis to support individuals who have achieved partial self-sufficiency.

### **Viability of Self-Determination**

Self-Determination is a relatively new concept in policy reform. The Center for Self-Determination advocates for public policy reform based on the following principles:

#### **SELF-DETERMINATION: GUIDING PRINCIPLES**

1. A recognition that the present system severely limits the exercise of freedom and responsibility by most recipients of public long-term care supports.
2. A recognition that these reforms must result in **more cost-effective strategies that not only include cost neutrality but, in fact, propose lowering on average the per-person costs of the present system.**
3. The goal of achieving cost efficiencies is directly related to the creation of new partnerships between those with disabilities (and their allies) and state and national policymakers who realize that the present system is broken, too costly and not achieving positive, discernable, measurable outcomes.
4. That “savings” generated by this approach be redirected to serve those on waiting lists or underserved by the present system.
5. That we view non-productive and limited lives under the present system as a product of its organization and regulation, and not a result of the significance of individuals’ disabilities.
6. That the introduction of private and donated dollars be viewed as a positive factor, and not a reason to bar eligibility for public support, or reduce the benefits available.
7. That high expectations concurrent with the self-determination principles be introduced into the schools and especially into special education venues.

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<sup>4</sup> Danziger, Sheldon, Robert Haveman, and Robert Plotnick. “How Income Transfer Programs affect Work, Savings, and the Income Distribution: A Critical Review.” *Journal of Economic Literature* 19/3 (September 1981): 975-1028.

Self-determination is a reform movement that includes but is more comprehensive than self-direction (e.g., “cash and counseling”), and necessitates coordinating funding and program categories. Self-determination concentrates on four areas in terms of what is generally called person-centered planning (in this case also person-centered budgeting):

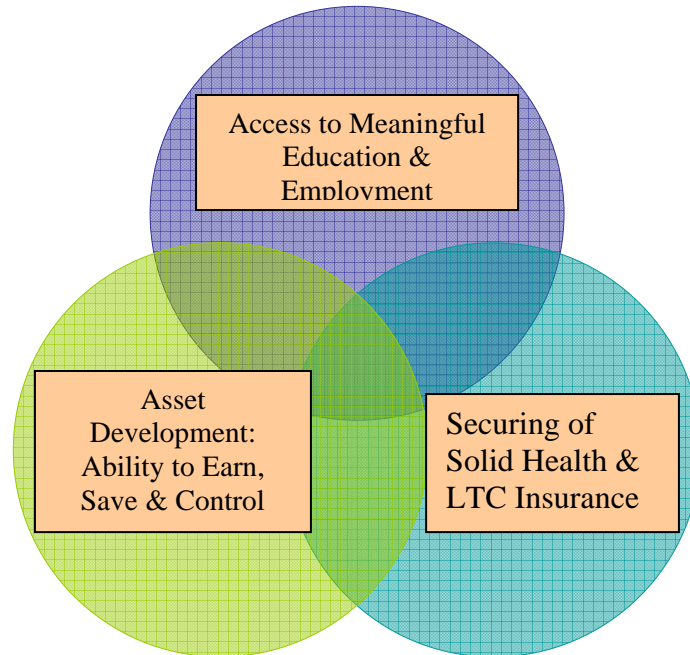
- Control over a place to call home—with meaningful authority for hiring support providers.
- Real membership in the community.
- Support for the continuation or the facilitation of long-term relationships.
- For adults with disabilities, the generation of private income through work or self-employment, including earnings from various investment strategies that include interest.

Control of human service dollars for supports required in all dimensions of one's life, combined with real, remunerative employment, provide what may be the two most important factors to alleviate both the poverty of individuals served by the present system and their lack of meaningful relationships and community associations.<sup>5</sup> This is the backdrop under which the Collaboration to Promote Self-Determination was created in 2007, and it will serve as the framework for the CPD moving forward.

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<sup>5</sup> Nerney, T. “Principles of Self-Determination,” Center for Self-Determination. [www.self-determination.com](http://www.self-determination.com). (March 2007)

## The CPSD Model for Promoting Self-Determination & Partial Self-Sufficiency



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### Future Directions

The primary effort of the CPSD in 2007-08 was to create a national dialogue about public policy innovation and reform that specifically addresses empowering adults living with complex intellectual, developmental and cognitive disabilities who require significant support. By working with federal agencies, state organizations and national political parties to elevate interest in promoting self-determination, the CPSD has built the base of support needed to move forward with the next stage of policy development.

The 2008 election campaign provided a significant political opportunity for the CPSD to publicize its agenda. The political will, timing and dynamics seem to be converging in a way that makes action inevitable. True reform, in this case, is likely to entail not so much a *revolution* as an *evolution*—one that may take place over several years. With this in mind, the CPSD is developing a campaign to raise public awareness about adults with intellectual disabilities, as well as advocating policy reform based on the following objectives:

1. Allow individuals with complex intellectual, development and/or cognitive disabilities requiring significant support to work and go above asset and income limitations without jeopardizing access to and control of an array of benefits (including but not limited to transportation, housing, job coaching).

2. Aggressively campaign for public policy that supports a blending of resources and coordination of services, aimed at promoting coherent planning centered on the individual, leading to employment and independent living.

3. Advocate for a mandatory program of long-term supports (separate and distinct from existing entitlement programs) for individuals with complex intellectual, developmental and/or cognitive disabilities requiring significant support, regardless of employment status or income level (providing assets on a sliding scale).

The CPSD has made great strides in a limited amount of time. For example, it solidified the support needed to ensure wide bipartisan support for the Financial Savings Accounts for Individuals with Disabilities Act in the 110<sup>th</sup> Congress, which is expected to move quickly through the legislative process in early 2009. The CPSD partnered with the Office of Disability Employment Policy (ODEP) within the U.S. Department of Labor to sponsor a two-day policy roundtable in October of 2008, which convened over 35 leaders from various stakeholder groups across the U.S. The primary aim of the roundtable was to develop key recommendations for the next Administration with respect to further reform in employment policy for the intellectually disabled. These policy recommendations will serve as a vehicle for drafting further legislation in the 111<sup>th</sup> Congress.

The CPSD will serve as an action vehicle on behalf of the intellectual disability community in the years to come. The National Fragile X Foundation's continued leadership, investment and support of the CPSD's work are critical components to its success and vitality.