**Choice Brings Enhanced Lives for People with Developmental Disabilities**

By Susan Platkin

I have two daughters. My 24 year old daughter Ruth loves sports, playing monopoly, and parties. She works at Walgreens; when her supervisor transferred to another store she requested that Ruth come with her. Ruth has volunteered over a 1000 hours at a nursing home, where she wheels patients to their therapies, and has helped out at a preschool, where she tutored a 4 year old who was having difficulty learning his letters.

She grocery shops, (carefully checking ads for coupons and sales), and prepares meals. Some days she goes to the library, buys stamps at the post office, or picks up food for the cats. Sports are her passion; she plays basketball, soccer, runs 5k races, and swims.

My other 24 year old daughter has diagnoses of intellectual disability and bipolar disorder. In high school, she frequently had to be removed from her classroom because of screaming, cursing, or other disruptive behaviors. Out of school now, she needs to have someone with her constantly, as her understanding of the world is limited, and her judgment is poor.

Although these sound like 2 different individuals, I have but **one** 24 year old daughter, Ruth. The rich life Ruth has now as an employee, friend, and contributing member of her community can be largely attributed to the Office of People with Developmental Disabilities’ (OPWDD) self-determination program, Consolidated Supports and Services (CSS).

CSS is funded through the Medicaid HCBS 1915(c) waiver. Implemented in New York in 1991, the program “waives” usual Medicaid requirements and gives states the ability to use Medicaid funding to support people in communities instead of institutions.

Eligibility for HCBS 1915 (c) waiver services in New York State requires:

* Developmental disability (see below)
* Eligibility for intermediate care facilities for people with mental retardation (ICF/MR) level of care
* Medicaid enrollment
* Individual living in their own or family’s home, Family Care Home, Individual Residential Alternative, or a Community Residence
* Availability of services (not an entitlement)

The definition of “Developmental Disability” in New York State is found in

Subdivision 22 of section 1.03 of the Mental Hygiene Law, as amended by

Chapter 269 of the Laws of 1990. The most recent amendment of this law was

enacted on July 31, 2002.

Developmental disability means a disability of a person which:

(a) (1) is attributable to mental retardation, cerebral palsy, epilepsy,

neurological impairment, familial dysautonomia or autism;

(2) is attributable to any other condition of a person found to be

closely related to mental retardation because such condition

results in similar impairment of general intellectual functioning or

adaptive behavior to that of mentally retarded persons or requires

treatment and services similar to those required for such person; or

(3) is attributable to dyslexia resulting from a disability described in

subparagraph (1) or (2) of this paragraph;

(b) originates before such person attains age twenty-two;

(c) has continued or can be expected to continue indefinitely;

and

(d) constitutes a substantial handicap to such person’s ability to function

normally in society.”

Therefore, CSS is funded similarly to traditional day and residential services. However, because CSS participants are given both employer and budget authority over their funds, they are able, with the help of family, friends, and chosen professionals, to control choices as large as where and with whom to live, work, and play, and as small as what to make for dinner and when to get up on Sunday morning. Unfortunately, these choices that we take for granted, have been, and often continue to be, denied to people with developmental disabilities.

Self-determination for people with developmental disabilities was first piloted on a large scale in 1996 through a grant by the Robert Wood Johnson Foundation to 18 states. A study of the project results by the Center for Outcome Analysis showed not only increased participant satisfaction, but also lower costs, important in these tough economic times.[[1]](#endnote-1)

What are the benefits of self-determination? People’s everyday lives reflect who they are as individuals. David (the names are changed) who is a night owl and loves airplanes works the midnight to eight AM shift at an airport, with the one to one support he needs. Jane, who loves to sing, hires a graduate voice student for support, and gets voice coaching thrown in. Mark’s dream was to be a deejay, but is thrilled to have a paid job at a local rock station. Three young women live together in an apartment, each with their own day support, sharing evening and night staff. None of these outcomes would be possible without the flexibility and control that self-directed services provide.

More advantages? When my daughter has a difficult day, we can adapt her schedule, without losing necessary staff support. If she loses a job, instead of sitting at home, as would happen with traditional supported employment, her staff will work with her to find a new one. If someone working with her is not a good fit, we can hire someone who is better suited to her. This level of flexibility is helpful for anyone, but critical for people with complex needs.

Last week I was in a store with Ruth, when an elderly man came up to us and greeted her by name; he looked at me a bit suspiciously. It turned out he was the owner of a local restaurant where my daughter had frequently eaten with one of her support staff. I have no doubt that if he saw my daughter being yelled at, or led out of the store unwillingly, he would have checked to see what was going on. As a parent, this meeting reassured me that others are looking out for my child.

How do people access self-determination in New York State? Currently, “the waiver is designed to afford every participant (or the participant’s representative) the opportunity to elect to direct waiver services . . . “[[2]](#endnote-2) Each Developmental Disabilities Service Office has a liaison for CSS; just call your local office. Of note, OPWDD is beginning a 5 year plan to subsume 1915(c) Waiver services under an 1115 Research and Demonstration Waiver. However, indications are that self-directed services will still be an option.

In reality I have two daughters. Both have jobs they love, passionate interests, and friends, and both give back to their communities. One has achieved her successes the conventional way, while the other has achieved hers through self-determination, funded through the Medicaid Waiver.

For further information on self-determination, see the NY Self-Determination Coalition website at www.nyselfd.org.

1. James W. Conroy et al, *Outcomes of the Robert Wood Johnson Foundation’s National Initiative on Self-Determination for Persons with Developmental Disabilities*, Center for Outcome Analysis (2002), *available at* http://www.outcomeanalysis.com/DL/pubs/RWJ-SD-Final-Report.PDF [↑](#endnote-ref-1)
2. Application for 1915(c) HCBS Waiver: NY.0238.R04.00 - Oct 01, 2009

   Appendix E: Participant Direction of Services, E-1: Overview (3 of 13*)***,** *available at*

   https://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/itemdetail.asp?filterType=none&filterByDID=-99&sortByDID=2&sortOrder=ascending&itemID=CMS1229194&intNumPerPage=10

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   Over the past 20 years she has advocated on both state and local levels for the inclusion of children and adults with disabilities in their schools and communities. [↑](#endnote-ref-2)