New York Self-Determination Coalition Position Paper on Self-Directed Services

The New York Self-Determination Coalition is an ad hoc group of parents and professionals dedicated to promoting self-determination for persons with developmental disabilities who require support through NYS OPWDD’S 1915(c) HCBS waiver program.

We share OPWDD’s mission: **Giving people with developmental disabilities as much individual choice and control over their own lives as possible**

Many New Yorkers have seen their family and community members with developmental disabilities grow and flourish when they have the freedom to direct their lives using the person-centered planning, a circle of support, and budget and manager authority provided under the HCBS waiver. They see people with developmental disabilities from their neighborhood working at the store, volunteering at the nursing home, in their exercise class at the Y. Because an individual they recognize is not in hidden an enclave, they have the chance to speak with them and get to know them We look forward to the time when community spaces are not arbitrarily labeled as “disabled” and “normal, ” and applaud OPWDD’s efforts in this direction.

We are optimistic that OPWDD, through the waiver, has the tools to

reinvest in truly self-directed models and move forward the dream of self-determination for thousands of people with developmental disabilities.

From the perspective of parents and professionals who have been “the boots on the ground,“ developing plans and living with them, we would like to offer some recommendations to further this goal.

POLICY ISSUES

Self-directed, self-determined services have 3 critical components:

* Robust Person–Centered Planning
* Circle of Support
* Employer and Budget Authority

1.Person-Centered Planning is the foundation of any program designed to support people with developmental disabilities in an individualized way. The need is obvious in a person with communication differences or significant intellectual disabilities who is unable to express himself conventionally. However, it’s essential even for those able to clearly voice their opinions. Done properly, PCP is a way of thinking and a process, not a document. It can help an individual discover what brings them satisfaction and a sense of purpose. On a more pragmatic level, involving people with different perspectives in the planning process widens options and helps to find the right fit for an individual, increasing the chance that a new undertaking will be successful.

2. Circle of support

If person-centered planning is the foundation of self-determination, the circle of support is the frame of the house, always there, no matter what redecoration is necessary. A circle includes people who know and care about the individual and are able to translate or her aspirations and needs into a practical plan based in the person’s own community. Especially in these times, when families and schools have expended effort and funds to involve a student in local paid or volunteer work and community centers, and, most importantly, encouraged them to develop relationships with shopkeepers, librarians, and the waitress at the local coffee shop, it makes no sense to have them disappear each morning on a bus to the next town.

Also, practically speaking, because self-determined plans are very specifically community based, and many MSCs and brokers may have limited knowledge of a specific area, the presence of people who come from the same neighborhood or town adds necessary local information to the planning process. The circle also supplies natural supports, not necessarily direct support, but connections for jobs, volunteer positions, and an opportunity for natural peer supports such as college students.

3. Employer and Budget authority

The components of both of these are clearly spelled out in the waiver.

The only constant in life is change. People become ill, want to change jobs or get fired, develop new interests, want to live somewhere else. A robust circle of support using person-centered planning tools, as well as employer and budget authority, is the best way to provide the flexibility, adaptability and rapid response necessary in the changing circumstances that characterize everyone’s life.

OPERATIONAL ISSUES

1. Funds should be portable, and follow the person

Suggestions about exactly how to do this are above our pay grade at this point. However, it is our understanding that Medicaid money is meant for the benefit of the individual using it for services, and that the waiver specifies portability.

2. Application and budget processes should be streamlined

Even its biggest cheerleaders (us!) agree that the application and budget requirements of CSS are extremely daunting and unnecessarily cumbersome. Portal, although lacking the requirement for person-centered planning and a circle of support has a much more efficient budget process.

3. Self-advocates and their families should be given the facts they need to make an informed decision about services in an unbiased way

Self-directed programs work. They provide increased satisfaction for participants, families, and staff, and tend to be cost saving as well. We should be shouting their praises from the rooftops! OPWDD’s planned conference on October is an excellent move in this direction.

We suggest:

Increased efforts to get timely information about all options under the waiver to MSCs and families.

Most self-advocates and parents do not go to the OPWDD website to get information; they rely on their MSC. (However, we have noted with appreciation recent efforts to make the website more family friendly).

The high rate of turnover of service coordinators suggests that it would be useful to create a database of programs and services that could be accessed by anyone through the internet. The MSC would enter basic information (the person’s location, interests, support needs, etc.). The database would present an annotated list of all options under the waiver, including a summary of the service and the necessary contact information. This would ensure that MSCs would have all of the information necessary to help the person they are serving to have the most amount of choice. (Service providers could even list openings in their programs!)

Preserve and strengthen the function of the start-up and support broker.

They bring the vision and the planning skills, as well as the resources to support and modify the plan through the individual’s life

Promote an understanding throughout the DDSOs of the requirements of the HCBS Waiver

We believe that informing DDSOs around the state of their obligations under the waiver contract would be the most effective way to assure full access to self-directed programs with both employer and budget authority.

*(All italics below are from “Request for a Renewal to a §1915(c) Home and Community-Based Services Waiver,” Approved effective date 10/01/09)*

All options for waiver services should be available throughout the State.

See: *4. Waiver(s) Requested*

*C. Statewideness****.*** *Indicate whether the State requests a waiver of the statewideness requirements in §1902(a)(1) of the Act (select one):*

1. *No**is selected***.**

Every person enrolled in the waiver should be informed of all of his or her options.

See: *5*. *Assurances*

***I****n accordance with 42 CFR §441.302, the State provides the following**assurances to CMS:*

1. *Choice of Alternatives: The State assures that when an individual is determined to be likely to require the level of care specified for this waiver and is in a target group specified in Appendix B, the individual (or, legal representative, if applicable) is:*
   1. *Informed of any feasible alternatives under the waiver . . .*

Every waiver participant should have access to any waiver service

Se*e: 6. Additional Requirements*

*D. Access to Services. The State does not limit or restrict participant access to waiver services except as provided in Appendix C.*

1. and, finally,
2. ***Election of Participant Direction.*** *Election of participant direction is subject to the following policy:*

***“the waiver is designed to afford every participant (or the participant’s representative) the opportunity to elect to direct waiver services. . . “***

See: *Appendix E: Participant Direction of Services*

*E-1: Overview (3 of 13)*

Our current system of supports and services for people with developmental disabilities was developed under the stress of rapid deinstitutionalization, and clearly improved the lives of those affected. We believe that faced with the prospect of growing needs and decreasing resources, legacy programs will no longer be affordable, appropriate and flexible enough to serve all persons with developmental disabilities in New York State.

Just as Willowbrook leveraged dramatic positive change, New York State’s current and future challenges gives us the unique opportunity to create an innovative, cutting edge service system in which individuals with developmental disabilities can, in the words of OPWDD’s mission, “live richer lives.” This effort will also best serve their families, direct support professionals, and the taxpayers of New York.