

## **The New Directions Medicaid Waiver – A Waiver That Works**

In 1999 the Supreme Court ruled that people with developmental disabilities have the right to receive public benefits and services in the most integrated setting appropriate to their needs ( Olmstead v. L.C. 527 U.S. 581, 1999). Most individuals with developmental disabilities will need supports and services in order to live in the community, and Medicaid is an important source of funding to for these services. Title XIX of the Social Security Act and its regulations authorize multiple waivers that allow states flexibility in operating Medicaid programs, by “waiving” the need for individuals to receive long-term supports and services in an institution. Services are offered through 1915 (c) Home and Community-Based Services Waivers (HCBS) in 48 states and the District of Columbia, and Arizona operates a similar program under a different authority, for a total of about 287 active waiver programs. The State of Maryland has operated several HCBS waivers since 1992, including its most recently implemented waiver program, New Directions. This is an innovative waiver that is based on person-centered planning, and one that we know about and are living.

New Directions started in 2005 as a pilot program serving 100 people statewide during the first year. These individuals eligible for services under the Developmental Disabilities Administration (DDA) (the agency in the State of Maryland that coordinates and monitors services for individuals with developmental disabilities), chose not to live in an institution but instead in their own community, and chose to self-direct their services. Self-directing one’s services has been said to mean, “Nothing about me without me!” Self-directing follows the principles of self determination,<sup>1</sup> and this waiver allows more flexibility and choice than other waivers. The individual serves as his or her own “provider” agency, so to speak, and has the authority to hire, manage and fire employees who will support him or her, choose how his or her allocated funds will be spent, and choose outcomes and goals that he or she wants to accomplish in work, living, and life. These goals are created by the individual and supported by friends, family and other support personnel like a resource coordinator.

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<sup>1</sup> Self Determination Principles:

- Freedom: To exercise the same rights as all citizens and to make decisions about one’s own life
- Authority: To have control over the funds needed for support.
- Support: The organization of resources for support, as determined by the person.
- Responsibility: The wise use of funds. The usual obligations of all American citizens.
- Confirmation: Of the important leadership that self advocates must hold in a newly designed system.

### **What the waiver does:**

- A person-centered plan (and toolbox) is developed by the individual along with supporters in his or her life, such as family and friends. The plan is the foundation of services and provides a road map of what an individual wants in his or her life, along with tips and strategies on how to get there. The toolbox identifies information that will help the team focus on the individual's likes and desires, such as how they communicate and what their favorite recreational activities are. For instance, my daughter, a New Directions Waiver participant, wanted more friends and to go to college. These were her desired outcomes. She and her team developed goals and strategies to expose her to opportunities to meet more people and develop friendships. She now attends the Graduate Transition Program (GTP) at Montgomery College for individuals with developmental disabilities who have finished high school and want a college experience. She is making friends, learning skills and gaining independence. She also wanted to work in the radio or T.V. industry, so she joined a youth video group in her community that is exposing her to "movie-making." She met contacts for this group while attending classes at our community college.
- A resource coordinator works with my daughter to help her identify and coordinate programs and resources, such as the waiver program, employment programs and housing programs.
- A budget must be developed and approved by the DDA. The level of funding will be the same as previous funding when services were provided through a "provider agency." In my daughter's case, I have been told that her level of funding is too low for her level of needs, however, for now, we are working with it. There are mechanisms in place to increase the funding, although it is not an easy process, and you will need help from your resource coordinator to justify and request an increase. In the budget, the New Directions Waiver participant will decide how he or she wants to spend his/her own funds. Indeed, if, for example, he or she decided to hire a job coach, he/she can hire the services of an independent job coach, or apply for and purchase services through an established DDA provider agency.

### **With a Plan and Budget in Place:**

- Since each person becomes an employer, taxes and wages have to be paid to those the individual hires. A fiscal intermediary agency (FMS) must also be hired to handle payments, including wages for hired supporters, vendor payments and tax payments. The individual must first obtain a federal tax ID, and is an employer who pays taxes, just like any other employer. The FMS carries out these fiscal functions and the cost of the FMS services is a part of the budget.
- Each individual must also have a support broker who helps navigate the process, including the hiring of support staff, which can be a somewhat

- complicated process. The support broker is also paid from the individual's budget, although, an individual can also have an unpaid support broker, such as a parent.
- With the business side of having the freedom to run your own life, each individual will need a good system of keeping up. Earlier I suggested that the New Directions Participant serves as his or her own "provider agency." This means that he or she (or his or her supporters) must be responsible for ensuring that employees and vendors get paid in a timely manner and be accountable to ensure that spending stays within the budget and no fraud or other funny stuff goes on. However, this is a small price to pay for the freedom of choice about one's own life.

### **Our Experience:**

We are (obviously, I think) big supporters of the New Directions Waiver. Although the waiver experience has not been completely smooth, it's been positive and promising. Our previous experience with provider agencies was very negative – several agencies would not accept my daughter as a client because she didn't want to work in a "sheltered workshop" and they didn't want to invest in community employment and supports for her. When my daughter was unclear about what she wanted to do exactly, we requested that our provider agency give her a few job exposure experiences where she could get an idea of real life work settings. They either would or could not do this. When we went shopping for other providers, another agency suggested that since my daughter did not ride Metro Access independently, she was really not ready for nor independent enough for the type of community employment program they offered. They suggested that she could learn skills while participating in their sheltered workshop program. And yet another provider agency said that although they technically could work with my daughter, they doubted that DDA would provide enough funding to cover the job coaching and other services she would need for community employment, and therefore turned her down for services.

Yet, with the same amount of money that was paid to an ineffective agency, through the New Directions Waiver we have been able to hire supporters, purchase services and give my daughter a chance to enjoy life more and contribute to her community.

We are sharing the experience of the New Directions waiver in Maryland with hopes that these lessons are transferable and will lead to a service delivery system for individuals with developmental disabilities that is responsive to their needs through innovative approaches, self-directed services and supporters who "think outside the box."

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