

THE DISABILITY COALITION
A Coalition of Persons with Disabilities, Family Members, and Advocates

The Developmental Disabilities Waiver

September 2011

- The term “developmental disability” refers to a wide range of conditions including Down syndrome, autism, cerebral palsy and others.
- According to the Americans with Disabilities Act, people with developmental disabilities have the right to services in the most integrated setting appropriate to their needs. The DD community also has established principles relating to self-determination, informed choice, person-directed supports, and dignified lives.
- New Mexico is recognized as a national leader in serving people with developmental disabilities in the community. Large state-operated institutions were closed in the 1990s in favor of providing home- and community-based supports to all individuals with developmental disabilities, regardless of the nature or severity of their needs.
- The primary program serving people with developmental disabilities is the DD waiver, a Medicaid 1915c waiver program. The waiver is administered by the Department of Health (DOH) and is funded through an appropriation directly to that department, separate from general Medicaid funding to the Human Services Department.
 - The waiver provides individualized supports that assist adults with developmental disabilities with all aspects of daily living and that help families care for their children with disabilities at home. Services include family support, respite, employment and residential programs.
 - Services provided to each waiver recipient are determined through an individualized assessment and development of an individual service plan to ensure that appropriate supports are designed around the person’s needs.
 - Waiver services help people with developmental disabilities to be as independent as possible and improve their daily living skills so they can live successfully in the community.
 - Approximately 3,200 individuals receive services through the DD waiver. The state is authorized to “cap” the number of individuals served.
 - More than 5,000 people are on the waiting list to receive DD waiver services. (See below for more information on the waitlist.)
- DOH is in the process of implementing significant changes to the waiver that were proposed in the renewal application that was recently approved by CMS.
 - Those changes were developed pursuant to an extensive process of stakeholder involvement that began more than two years ago and is ongoing as implementation proceeds.
 - Changes include:
 - Use of a new assessment tool, the Supports Intensity Scale (SIS), which is currently being piloted.
 - Tying service budget amounts more closely to individual needs.
 - Changes to the menu of services and the criteria for receiving some of them.
 - Streamlining paperwork.
- The average cost of services to individuals on the waiver is expected to be reduced somewhat as a result of the changes made in the renewal.
 - The Disability Coalition does not object to achieving savings by ensuring that services are tied to individual need and that waiver recipients do not receive unnecessary or

excessive services. However, we believe that any changes in the services provided to an individual should be based on actual need. We strongly object to arbitrary cuts intended simply to reduce expenditures.

- We also believe that any savings achieved should stay in the DD waiver and be used to serve more individuals on the waiver.

- Pursuant to the Jackson lawsuit, the state has an obligation to provide an appropriate level of services to approximately 350 class members (former residents of state institutions) who rely on the DD waiver for services and supports. DOH generally applies the same rules and protections to all waiver recipients regardless of whether they are Jackson class members or not.

The Waiting List for the DD Waiver

- More than 5,400 individuals are on the waiting list (also called the Central Registry) for DD waiver services. Every county in New Mexico has people on the waitlist.
- Each year approximately 1,000 people apply for services; about 300 meet the screening criteria for developmental disability and are added to the list.
- When a waiver slot becomes available, people on the waitlist are selected in order from the list based on their date of application, with limited exceptions for emergency and crisis situations. The wait time currently is over 8 years.
- Once people begin receiving waiver services, they typically remain in services for the rest of their lives. As a result, very few waiver “slots” open up through attrition.
- Increasing the number of people receiving waiver services depends on receiving additional appropriations for the program. Due to a high level of legislative support for the waiver, it has consistently received annual appropriations for the waitlist, though DOH has not always used these funds as intended to move more people into service. The amount of the new money has varied over the years but ranged from \$2 million to as much as \$10 million in the twelve-year period from 1999 to 2010. However, due to this year’s tight budget situation, the new appropriation for FY12 was only \$1 million. DOH reports that this will allow them to add 50 people to the waiver. At that rate, it would take more than 100 years to serve everyone now on the waiting list.
- People with developmental disabilities need waiver services to provide the supports and help them develop the skills they need to live as independently as possible and to participate fully in their communities. Their families also need help in meeting the challenges posed in raising a child or providing a home for an adult with a disability. Having a child with a disability often means that a parent must leave the workforce in order to become a full-time caregiver, and aging parents worry about what will happen to their adult children when the parents can no longer care for them.
- DOH this year ended the Self-Directed Family Support program that had provided a limited level of help to some of the people on the DD waiver waitlist. For more than a decade, the program, funded with state dollars, provided a small budget of up to \$2,300 a year for goods and services. The funds went to a limited number of individuals (fewer than 200) and their families near the top of the waitlist, as a form of transitional assistance as they moved toward waiver services.