



It's not too late... Find the Wait!



Fund the Department of Intellectual and Developmental Disabilities (DIDD) waiting list for people with intellectual disabilities who need home and community based waiver services (HCBS)

The need for expanding home and community services for people with intellectual disabilities in Tennessee is at a critical stage. Nearly 7,000 adults and children are waiting for Home and Community Based Waiver Services (HCBS) many of whom have been on waiting lists for years. Without supports, young people with intellectual disabilities sit at home, losing all the skills they developed during their school years. Parents, siblings or other relatives are forced to quit work to support their family members with an intellectual disability. Family members neglect their own health trying to “do it all,” especially as they and their loved ones face the challenges of aging. Many families are forced into poverty by the added costs of support. The result is thousands of Tennessee families suffering from extraordinary stress.

Tennessee must address the needs of these citizens.

People on the DIDD* Waiting List	October 2014
<i>By level of need</i>	
Crisis: homeless, no caregiver, imminent danger to self or others, needs services immediately	38
Urgent: significant risk of abuse/neglect, caregiver aging or in ill health, needs services soon	570
Active: requested services but does not meet Crisis/Urgent criteria	4,814
Deferred: requesting services more than 12 months in the future	1312
Total	6,734

*Department of Intellectual and Developmental Disabilities Data Management Report October 2014

As of October 2014, 6,734 individuals have applied for and have tentatively met the criteria for waiver services (diagnosis of intellectual disability and no more than \$2000 in assets) through the DIDD but were placed on the Waiting List.

- Approximately 80% of those on the Waiting List are adults living at home who have minimal to no services at all.
- The remaining 20% are children whose families need support when their child is not in school, children in DCS custody, and people in mental health institutions



During Fiscal Year 2013-2014:

- 486 individuals were added to the Waiting List for an average of 41 per month.
- **Only 363 individuals on the Waiting List received services – an average of 31 per month!**
- The Waiting List grows at a much faster pace than people are moved into services, with a net increase of an additional 10 people per month.

Legislative Action

The General Assembly can have a positive impact on the Waiting List Crisis. End the wait for individuals with intellectual disabilities and their families by:

- Appropriating at least \$3.5 million in recurring state funds to provide services and supports for the 400+ people on the waiting list with primary caregivers age 75 and older;
- Requiring the development and implementation of a long range plan that significantly reduces or eliminates the waiting list
- Ensuring that sufficient funds are allocated to ensure that those currently receiving supports and service continue to have their needs met
- Creating a task force of state leaders, family members, self-advocates, advocacy organizations, community providers and educational leaders to assist with development of the long range plan

Administrative Action

The wait **MUST** end. Individuals with disabilities and their families must have a light at the end of the tunnel. To significantly reduce the Waiting List over the next five years, Tennessee must:

- Establish reasonable, maximum waiting periods for each category of need:
 - Individuals in the **Crisis** category should begin the enrollment process for waiver services within 10 working days
 - Individuals in the **Urgent** category should begin the enrollment process for waiver services within 120 calendar days
- Develop and implement a process to assess the specific needs of each person on the waiting list
- Develop a service delivery system responsive to those individual needs
- Ensure that the current and newly proposed HCBS Waivers include:
 - Effective person-centered planning processes that respect individual choice;
 - Self-directed options and family/individual budget control;
 - Flexibility in service delivery, location and timing through the elimination of unnecessary restrictions
 - Provisions that balance cost effectiveness with individual need
 - Services based on the individual's assessed functional levels of need rather than on program criteria



For more detailed recommendations on services and supports for Tennesseans with intellectual and/or developmental disabilities, please call Carrie Hobbs Guiden at The Arc Tennessee at 615-248-5878 or 800-835-7077 or email at cguiden@thearctn.org.

This document was prepared by:



Achieve with us.

