



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



Fund the 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. Over 7,000 adults and children are waiting for services, 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 often forced to quit work to care for their family members with an intellectual disability. Many families are forced into poverty by the added costs of care. 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

| | Statewide | | Haywood County |
|---|--------------|---------------|----------------|
| | June 2012 | June 2013 | January 2014 |
| By level of need | | | |
| Crisis: homeless, no caregiver, imminent danger to self or others, needs services immediately | 79 | 47 | 0 |
| Urgent: significant risk of abuse/neglect, caregiver aging or in ill health, needs services soon | 796 | 784 | 0 |
| Active: requested services but does not meet Crisis/Urgent criteria | 4,808 | 4,832 | 137 |
| Deferred: requesting services more than 12 months in the future | 1,496 | 1,417 | 11 |
| Total | 7,179 | 7,080 | 148 |
| By Category | | | |
| School Age (0-21, excluding DCS) | 2,614 | 2,300 | |
| Dept. of Children's Services (0-21) | 92 | 81 | |
| Nursing Homes | 112 | 13 | |
| Regional Mental Health Institutes | 11 | 7 | |
| Adults – no services | 4,350 | 4,679 | |
| Total | 7,179 | 7,080* | |

Department of intellectual and Developmental Disabilities Data Management Reports, June 2012 and June 2013, DIDD January 2014; *people currently residing out of state have been removed from the numbers

As of June 2013, 7,165 individuals have applied for waiver services through the Department of Intellectual and Developmental Disabilities (DIDD) but were placed on the Waiting List.

- 67% of those on the Waiting List are adults living at home who have no services at all.
- 32% are children whose families need support when their child is not in school.
- The remaining 1% is children in DCS custody and people in nursing homes or in mental health institutes.



During Fiscal Year 2012-2013:

- 467 individuals were added to the Waiting List for an average of 39 per month.
- **Only 238 individuals on the Waiting List received services – an average of 20 per month!**
- The Waiting List grows at a much faster pace than people are moved into services, with a net increase of an additional 19 people per month.

POLICY RECOMMENDATIONS:

- ✓ Establish reasonable, maximum waiting periods for “Crisis” category of the Waiting List
- ✓ Create small capped support services waiver for all eligible students with ID exiting school
- ✓ Automatically enroll every person on the waiting list with caregivers over 75 in the Self-Determination waiver
- ✓ Develop and implement a needs assessment process for each individual on the Waiting List to appropriately manage expansion of the service system
- ✓ Revise current Medicaid Home- and Community-Based Waivers to include:
 - Person-Centered Planning;
 - Flexibility, cost effectiveness and cost containment;
 - Self-directed options and family/individual budget control;
 - Services based on the individual’s assessed functional levels of need rather than on program criteria

For additional recommendations on services and supports for Tennesseans with intellectual and/or developmental disabilities, please call Carrie Hobbs Guiden at The Arc TN at 615-248-5878 or 800-835-7077 x14 or email her at cguiden@thearc.org.

This document was prepared by:



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