



LONG-TERM SUPPORTS for CHILDREN

Ending Waiting Lists for Children with Significant Disabilities

BACKGROUND

Children’s Long-Term Supports (CLTS) provide necessary services and supports for families whose children have the highest and most complex levels of need.

Children and youth with significant disabilities can have extraordinary needs that require unique supports and services. Families often provide medical, behavioral, financial, and other daily supports beyond what most families provide. When families are well informed and have access to supports, they play a key role in identifying and securing opportunities for their children with disabilities to participate in meaningful ways within their community and ensuring access to self-determined lives. Unfortunately, for many families, the lack of access to information, supports, and services can compromise their quality of life, making it difficult and sometimes impossible for them to care for their children, maintain jobs, pay for health insurance, and keep their family intact.

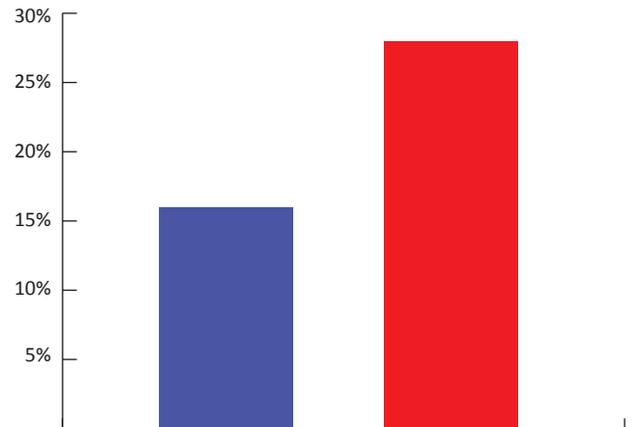
Some of the additional challenges families of children with significant disabilities face:

- More than one in four (28%) families who have children with disabilities live below the federal poverty level, compared to 16% of families who have children without disabilities. (The Arc, 2011)
- More than half (56%) of families raising children with disabilities report financial hardship related to their child’s care. (UNC School of Social Work, 2009)
- Providing care for a child with special needs was associated with an almost 4 times increased odds of having financial problems. (Journal of Pediatric Health Care, 2009)
- In Wisconsin, 24.5% of family members cut back or stop working, and for children with certain conditions, up to 55% of families reported an impact on employment. (2009/10 National Survey of Children with Special Health Care Needs)
- The odds of having a family member cut or quit work because of the child’s health were 2.7 times as large as they were for families who did not provide care for their child. (Journal of Pediatric Health Care, 2009)

Since my daughter was born, I had to quit my job to be her full-time caregiver. I love being with her, but we struggle to make ends meet.

- A Wisconsin Parent

FAMILIES LIVING BELOW POVERTY



Families who have children without disabilities

Families who have children with disabilities

Graph depicts percentage of families that live below the federal poverty level.

HOW DOES CLTS HELP FAMILIES?

CLTS can provide critical supports to families that allow them to participate in their communities, make their homes safe, and reduce their need for out-of-home placement. Examples include installation of a ramp or accessible shower or fencing for the backyard for children who are in danger of running away.

In addition to goods and services, for many families, one of most valuable supports is having someone who can help navigate services and supports. Short-term assistance in the form of service coordination can: reduce emergency room visits; maximize access to current resources such as school, Medicaid, and private insurance; coordinate benefits; and increase participation in inclusive community resources.

One study found families who experienced assistance with coordination of services were significantly less likely to report having financial or employment problems as a result of the child’s condition.



WAITLISTS CREATE INEQUALITIES

There are nearly 3,000 children and youth with significant disabilities whose families are waiting for essential supports and services. There are an additional 408 youth ages 18-21 waiting for long-term supports. The wait time for services for children ranges from 1-8 years depending where a family lives. Over one-third (37%) of children eligible for long-term supports are waiting, compared to 6% of eligible adults. Waiting for services means: missed opportunities for cognitive, physical, and behavioral growth and for learning skills for independence, unmet basic needs that harm children and create significant family stress, and an inability to meet less costly needs now, creating more expensive needs in the future.

For youth with disabilities exiting high school, waiting for supports can mean the loss of a job and job related skills, as well as the loss of potential income and employer-based health insurance. It can also mean a family member may have to stop working in order to provide support, losing both income and access to private health insurance. Facts about CLTS waitlists to consider:

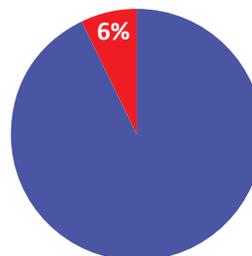
- 1 in 14 adults who are eligible for adult long-term care programs in Wisconsin are on waitlists, yet 1 in 3 eligible children are waiting for supports.
- CLTS waivers currently serve 5,096 children, while nearly 3,000 children are waiting.
- The average wait is 2 years, with some families waiting as long as 8 years.

RECOMMENDATIONS

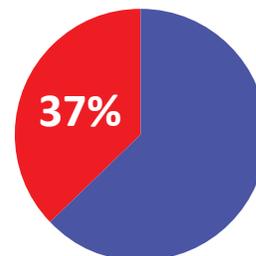
The Survival Coalition of Wisconsin Disability Organizations supports reducing waitlists for critical CLTS that allow families to stay together and reduce out-of-home placements.

- Renew the commitment to end waiting lists for children with significant disabilities by serving an additional 1,000 children during the next biennium. An increase of \$5.4M GPR over two years reduces wait lists by 1,000 children.
- Provide short term service coordination to 20% of families whose children are on waitlists. \$1.3M GPR matched to federal Medicaid would provide short-term assistance to 600 families on waiting lists in the next biennium.

WAITING for SUPPORTS and SERVICES



ADULTS



CHILDREN

- Receiving supports and services
- Waiting for supports and services

COUNTIES with the LARGEST WAITING LISTS

COUNTY	CHILDREN WAITING
Milwaukee	343
Brown	226
Waukesha	196
Dane	176
Jefferson	90
Rock	82
Walworth	76
La Crosse	75
Dodge	69
Barron	64

All Wisconsin counties report children waiting for services. This table depicts the 10 counties in Wisconsin with the highest number of children with significant disabilities who are waiting for supports and services.