

- Have you ever had trouble finding the information you need to support your child?
- Have you made multiple phone calls to get the answer to a question?
- Are you wondering if there is a service that might help your child and family?
- Do you have Medicaid, but don't know what it pays for?
- Has your insurance denied a service for your child?

If you answered YES to any of these questions, now is the time to talk with [your legislator](#) about creating a **statewide Disability Resource Center for Children and Families** (DRCCF).

EDUCATE YOUR LEGISLATOR

\$2.9 million in state funding is needed to develop and implement a statewide Disability Resource Center for Children and Families so families know where to get the help they need. [Here](#) is information you can share with your legislator.

WHAT DO FAMILIES NEED?

Families want a reliable and trustworthy source of accurate information. Families benefit from one statewide name and one number to call. Create a statewide DRCCF to coordinate outreach, regional staff, referrals to county services, and a person who families can talk with to get help navigating complex systems including:

- Information, assistance, and resources to help families find available community resources, programs and services,
- Family navigators with lived experience to provide culturally competent assistance,
- Advocacy services and benefits counseling,
- Seamless access to eligibility determination for long-term supports, services, mental health supports and Medicaid.

SOME FACTS

Families struggle daily to navigate complex systems such as health care, long-term supports, education, community resources and Medicaid. Lack of information and support can lead to family crisis, lost jobs, lost opportunities for child development and lost economic stability. Wisconsin has no statewide, coordinated effort to connect children with disabilities and families to information, assistance and services.

- 56,000 children in Wisconsin have a disability requiring long-term supports.
- Only 25% of these are connected to a long-term support program.
- Current information and assistance resources serve about 5% of these families.
- The Wisconsin legislature made this commitment to adults and elders by funding Aging and Disability Resource Centers (ADRCs) in every county.
- ADRCs don't serve children.
- Without these services and supports the only option for a family who has critical needs is to place their child **out of home** either in an institution or specialized foster care.
- Supporting families prevents crisis and maximizes the use of existing community, health and school-based supports.

BACKGROUND

It is estimated that approximately 56,000 (DHS 2018) children in Wisconsin have a disability such as cerebral palsy, autism, Down Syndrome, or mental illness that could result in a need for long-term supports such as special equipment, respite, living skills training or family education. One or more of our long-term support programs currently serves approximately 14,400 of these children (e.g., Medicaid, Children’s Long-Term Support Waivers, Katie Beckett Program, Comprehensive Community Services or the Children’s Community Options Program).

In addition to the children’s long-term support program, a handful of disability specific information resources currently exist in Wisconsin. While some have a focus on supporting families of children with disabilities few have the capacity to provide comprehensive, cross program information and assistance services statewide. Most are grant funded with limited capacity. Recent data shows these organizations and state programs were able to serve less than 5% of the 41,600 who might need help. A 2019 study of 2,600 Wisconsin families and youth provided with navigation assistance showed a reduction in the need for public benefits and an increase in expectations around employment, connection to services and supports, and help achieving education, employment and financial self-sufficiency goals. Another study of 400 Wisconsin families with access to information and assistance showed over 80% of families felt more able to cope, navigate systems, knew where to turn to for help and better advocate for their child.

- 1 in 4 families of children with disabilities live below the FPL compared to 1 in 6 without children with disabilities.
- Over half report financial hardship.
- 1 in 4 have had to cut back or stop working to care for their child.
- 1 in 4 report high levels of stress compared to 1 in 20 of families without children with disabilities.

“I didn’t take a promotion at work because I thought if our income went up my daughter would lose Medicaid. Why didn’t anyone ever tell us about Katie Beckett Medicaid?”

The role of family is unique and essential in the support and care for children with disabilities. By providing medical, behavioral, financial and daily supports, families facilitate opportunities for their child to develop, be healthy, included and meaningfully connected within their community. But to do this well families need accurate information from a trusted

source that can help them support and advocate for their child. Unlike typical children, children and youth with significant disabilities may need unique supports to fully participate and benefit from school, work and community experiences that benefit all children. The programs that pay for these supports and services, like Medicaid and Medicaid waivers, are essential to family health and wellness.

Providing information is frequently more than a simple phone number. It requires a deep understanding of the supports, services, family experience and the interaction between different systems. It is critical families receive accurate, timely and comprehensive information that is based on a family’s identified need (family-centered) and is actionable based on the family’s skills and values.

“We’ve been living paycheck to paycheck. I didn’t know we could get help paying for my 6-year old’s diapers!”

WHO DEVELOPED THIS PROPOSAL?

Wisconsin County Human Service Association
Family Voices of Wisconsin
Disability Rights Wisconsin

DHS Children’s Long-Term Supports Council
Survival Coalition of Wisconsin Disability Organizations