

-BIENNIAL BUDGET PROPOSAL-

Disability Resource Center for Children and Families

SUMMARY

Families who have children with disabilities struggle daily to navigate complex systems of supports and services such as health care, long-term supports, education, community resources and Medicaid. Wisconsin has no statewide, coordinated effort to connect these children and families to information, assistance, and services. Lack of access to these resources can lead to lost jobs, lost opportunities for child development, lost income for families and missed opportunities for future employment and community participation for young adults with disabilities.

When families have access to the right information, training, and navigation assistance, their success increases. 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 the need for more costly services and maximizes the use of existing community, health, and school-based supports.

\$2.9 M in state funding is needed to develop and implement a statewide *Disability Resource Center for Children and Families*. DRCCFs include web-based resource information and regional staff families can talk with to get help navigating complex systems.

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 etc.).

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. While Wisconsin has the statewide Regional Centers for Children and Youth with Special Health Care Needs that fulfill some of these functions, they have limited capacity. Most resources 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 2600 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, 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

THE NEED

The role of family is unique and essential in the support and care provided to 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.

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?

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

Providing information is frequently more than a simple phone number and requires a deep understanding of supports, services, family experience and the interaction between different systems as well as interviewing skills to understand what families are

seeking. 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.

RECOMMENDATION

Provide \$2.9M in state funding and direct DHS to develop and implement a statewide **Disability Resource Center for Children and Families**. DRCCFs include web-based resource information, and regional staff families can talk with to get help navigating complex systems including:

- *Comprehensive Information and assistance* providing accurate, timely, and family-centered help from a trusted resource
- *Family Navigators with lived experience* to provide culturally competent assistance
- *Advocacy and benefits counseling* to assist with appeals and denials of eligibility or services
- *Family Education* to provide system navigation information and skills in family-friendly language
- *Seamless access to eligibility determination* for long-term supports, services, and Medicaid
- *Aggressive Marketing and outreach* to promote access for families

IMPACT

Wisconsin families who have a child with disabilities will: **1.** know where to go for help, **2.** will get the help they need (not always a service), **3.** will feel more capable and effective, and **4.** will have access to help no matter where they live. Proactive outreach rather than the current crisis-based response system will engage families in problem-solving earlier and could prevent lost jobs, lost opportunities for child development, lost income for families and missed opportunities for future employment and community participation for young adults with disabilities.

Who supports this proposal?

Wisconsin County Human Service Association
Wisconsin Counties Association
Disability Rights Wisconsin
DHS Children's Long-Term Supports Council

Family Voices of Wisconsin
Survival Coalition of Wisconsin Disability Organizations