

Wisconsin Children's Long-Term Support Council

Family Support and Disability Resource Centers

- Establishing Statewide Access for Children with Disabilities-

RECOMMENDATION

The Children's Council recommends that the Governor and Wisconsin legislature direct DHS to develop and implement a statewide access network of *Family Support and Disability Resource Centers (FSDRC)* for Wisconsin children with disabilities and their families.

Key features of the FSDRCs must be statewide, uniform, and incorporate the following:

- Accurate and comprehensive information, assistance, and benefits counseling
- Family navigators to help with navigating health, community, and school systems and transition
- An infrastructure to establish family-to-family connections
- Core education and skills training for families
- Outreach and seamless access to eligibility determination for children's long-term supports and services

Families of children with disabilities, including physical, developmental or behavioral disabilities are the most important resource to ensure their child is healthy, included and connected with their community. **When families have access to the right information, training, and navigation assistance, their success increases.** Supporting families, prevents crisis and the need for more costly services and maximize the use of existing "generic" community, health and school-based supports. This can reduce or even eliminate reliance on formal disability services.

WHY FSDRCs?

-The current system doesn't have enough resources to support families so that:

- (a) Families **know** that supports and services exist
- (b) Families can **find** supports and services that they need
- (c) Families can **access** these supports and services once they are connected.

56,000 Children in Wisconsin have a disability that likely makes them eligible for LTSS (WI DHS 2018)

41,600	14,400	1,388
Not served in Disability Services System	Receiving service/s	Waiting for services

PROPOSAL

#1: How can families find the information they need?

- The FSDRCs will: ^(a) be co-located with ADRCs; ^(b) use one statewide name, phone number, and website; ^(c) include all the key features listed below; and ^(d) engage staff with expertise in multiple children's systems

#2: How can families "get through the door" to services?

- The FSDRCs will: ^(a) provide eligibility determination for multiple programs; ^(b) connect families with someone to initiate the eligibility process; and ^(c) connect families to begin planning for supports and services

#3: How can families get the supports or services they are eligible to receive?

- For eligible children, the FSDRCs will: ^(a) connect families to a service coordinator. DHS and counties will ^(b) support the service coordinator with comprehensive training and assistance; and ^(c) ensure consistency with oversight of county LTSS programs

FUNDING

The Council encourages DHS to explore pooling existing funding across disability, education, health and public health programs to fund *Family Support and Disability Resource Centers (FSDRC)* for Wisconsin children with disabilities and their families. This includes:

- Consolidating the Medicaid and Children's waiver funding for **eligibility determination** for the FSDRCs
- Pooling a portion of funding for **family outreach** and connections with resources

- Using the **“No Wrong Door”** reimbursement strategy to cover FSDRC Medicaid allowable services

Key features of the FSDRCs will include:

KEY FEATURES

- (1) **Comprehensive Information and assistance** in an accurate, timely, and family-centered manner
 - Avoids conflicting information and families needing to contact multiple agencies to get the “right” answer
- (2) **Family Navigators** to assist with a family’s specific concerns in a culturally-competent manner
 - Consider co-location or coordination between Regional CYSHCN centers, ADRCs, and county service coordinators
- (3) Statewide **Family Education** strategies to empower families, offer system navigation training, and ensure access to services in culturally-sensitive and family-friendly language
 - Help children and families be part of their neighborhood and school community, participate in childcare, attend child enriching opportunities with their peers, plan for a future that includes work and community participation, and assure their child has access to services for which they are eligible
- (4) **Family-to-Family Networks** to connect with other families who have “walked-the-walk”
 - Support family-to-family connections to develop creative solutions that are not available within service systems
- (5) A uniform, statewide process to improve seamless and equitable access to **Eligibility Determination** for LTSS
 - Simplifies county-to-county differences in accessing the eligibility process for long-term supports and services
- (6) **Marketing and Outreach** campaign to launch the FSDRC and promote access for families

STRUCTURE

The Council recommends a structure that includes all the key features proposed above for at least 12 local, regional, and statewide Family Support and Disability Resource Centers (FSDRC) for Wisconsin children with disabilities and their families. Support for the FSDRC structure includes:

- **Training to ensure knowledgeable staff** with a comprehensive working knowledge of national, statewide, and local supports and services
- A seamless **eligibility determination process**
- **Technical specialists** and legal expertise to support family navigators (e.g. benefits counseling and insurance denials)

A DAY IN THE LIFE OF ONE FAMILY

*Kelly’s daughter, Hope, is 3 years old and has complex health care needs and disabilities. She is on the **wait list for the Children’s waiver** and currently has no access to an ally who helps her navigate resources. Recently, Hope’s doctor recommended continuous glucose monitoring to help fine tune her diabetes management, but was not able to help with how to pay for the device. The provider of this **equipment gave her inaccurate information** saying the device was not covered by Wisconsin Medicaid and would not pursue a prior authorization. Kelly had accrued private insurance copays and deductibles for the insulin pump which she had paid. She was not able to cover the **additional out-of-pocket costs** for the new recommended monitoring equipment. Kelly attended a community training offered by a parent run organization who provided an **overview of health and community supports and services** for children with disabilities and special health care needs. She learned about the Children’s waiver and a Medicaid service called Health Check Other Services. Kelly followed up with the trainer to get more information. The trainer, also a parent, coached her regarding the steps to try and the language she needed to use with her provider to **navigate her private and public insurance**. Following a series of conversations with the parent trainer, Kelly got approval for the glucose monitoring device from Medicaid. She was reimbursed from the pump provider for the copays and deductibles that should have billed to Medicaid. **If Kelly had access to a FSDRC she could have had help navigating her insurance and avoiding financial hardship. Without the delays due to inaccurate information, Hope’s health would have stabilized much sooner.***