

# Wisconsin Children's Long -Term Support Council

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## ESTABLISHING A STATEWIDE ACCESS FRAMEWORK FOR CHILDREN WITH DISABILITIES

### Family Support and Disability Resource Center – Organizational Structure <sup>(9/18)</sup>

In July 2018 the DHS Children's Long-Term Support Council (CCLTS) made recommendations for a budget initiative to create Family Support and Disability Resource Centers (FSDRCs). This paper adds specific recommendations for implementing the centers, including the use of existing infrastructure.

#### Why Do We Need FSDRCs?

Families of children with disabilities, including physical, developmental or behavioral disabilities, support opportunities for their child to develop, be healthy, included and meaningfully connected within their community. Families are the most important resource to accomplish these goals. When families have access to appropriate information, training and navigation assistance, their success increases. Yet, the current system does not have the structure or resources necessary to support families and ensure consistent statewide implementation that allows families to:

- Know about existing resources;
- Find what they need; and
- Get what they need once they are connected.

We believe that the right amount of support at the right time is the most effective way to support families, prevent crisis and the need for more costly services, and maximize the use of existing "generic" community, health and school-based supports while reducing and even eliminating reliance on formal disability services.

The Council recommends DHS develop and implement a statewide ACCESS network of *Family Support and Disability Resource Centers*<sup>i</sup> for Wisconsin children with disabilities. Key features of the FSDRC are based on successful work in other states<sup>ii</sup>. The FSDRCs will provide statewide, consistent:

- Accurate and comprehensive information and assistance;
- Family navigators to help with navigating health, community and school systems and transition;
- Family-to-family connections
- Core education and skills training for families
- Outreach and seamless access to eligibility determination for Wisconsin long-term supports and services for children.

#### Organizational Structure

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

1. The FSDRCs will use one statewide name, phone number and website so that no matter where families live, they can find and connect with this resource.

- Similar to ADRCs, an aggressive and sustained outreach and education campaign will be needed to assure that current and future families find the FSDRC when they seek accurate, timely and disability-specific information.

**2. FSDRCs should be co-located with existing ADRCs.**

- FSDRCs should not be subject to a state procurement process that results in changes in location, provider, name or services.
- Investigate co-locating Regional Children and Youth with Special Health Care Needs Centers with FSDRCs.
- We recommend at least 12 FSDRCs to serve families in different regions of the state with 2 FSDRCs focused on serving culturally diverse groups. (More may be necessary once more is known about where underutilization is occurring.)
- If co-located with ADRCs, the FSDRC must be a separate program with a primary focus on supporting families, utilizing staff, including qualified family members and children’s benefits specialists, with demonstrated expertise in working with families, children’s systems and services including private insurance, childcare, special education, SSI, Medicaid and long-term supports and other programs that are unique to the children’s system.

**3. Core services of the FSDRCs will include access to comprehensive information and referral, problem-solving, family navigators, short term service coordination, family education, family-to-family connections, eligibility determination and benefits counseling.**

- FSDRCs will better meet families’ needs because they will provide all of the key services and eligibility determination under one roof.
- Currently some of these services are available through a patchwork of organizations, with limited funding, making it hard for families to find the right door at the right time.
  - Regional Children and Youth with Special Health Care Needs (CYSHCN) Centers have limited funding to provide most of these services in 5 regions of Wisconsin for families of children with special health care needs 0-21 and ADRCs provide some of these services to individuals over 18.
  - Through small federal grants and state contracts family led organizations such as Family Voices of Wisconsin and Wisconsin Family Ties currently provide many of the above mentioned core services although with limited capacity due to funding. With adequate resources, family led organizations could partner with FSDRCs to provide some or all of the core services statewide.

**4. Core training will be available for all FSDRC staff as well as technical assistance when staff have questions about complex situations or need legal interpretation or assistance.**

- FSDRC staff will be able to refer families to benefits counseling or assistance with appeals or denials of eligibility or services when their need for assistance is beyond the expertise of FSDRC staff.
- The Regional CYSHCN Center currently have the knowledge and expertise to provide core training; ABC for Health and Disability Rights Wisconsin both serve in a limited

technical assistance and advocacy capacity for the current Regional CYSHCN Centers and the ADRCs respectively.

### **How can families “get through the door” to services?**

- 1. If a family wants to pursue access to disability services, the FSDRC will be responsible for eligibility determination for multiple programs using one process (functional screen) and connect the family to a person who will initiate the eligibility determination process.**
  - The administration of the functional screen can be within the FSDRC or a separate entity, but it is critical that it appear and be experienced as a seamless step for families. The accountability for connecting with the family is with the FSDRC.
  - The functional screen is currently completed by multiple entities including CompassWisconsin, counties, Katie Beckett consultants and contract agencies. The final determination, completed by a public entity, is the county or the state.
  
- 2. Similar to CompassWisconsin now (in 17 Counties), eligibility for multiple programs will be completed in one process using the functional screen.**
  - Consider pooling existing state and county funding that is used to determine eligibility for children’s disability programs for Children’s Long-Term Supports (CLTS), Children’s Community Options Program (C-COP), Katie Beckett, Medicaid and Coordinated Community Services (CCS).
  
- 3. Once eligibility is determined, if a family wishes to pursue services, the FSDRC is responsible for explaining the different programs and connecting the family with the appropriate person or system designated to begin the planning process for supports and services.**
  - An important component of the discussion with families is an explanation of the different programs and which might be the best match for the family’s needs.
  - Additionally families may need to understand how a specific program operates for example Medicaid, and some of the language they may need to understand so they can successfully participate in the next step for ACCESS.

### **How can families get what they need?**

- 1. Once families are eligible for CLTS, CCS, or C-COP they have access to a service coordinator. Comprehensive training and technical assistance should be provided to counties to assure service coordinators receive consistent and accurate information to help families navigate disability programs, private and public insurance and school and community supports and services.** Parts of this function are currently provided by Bureau of Long-Term Supports staff.
  
- 2. State quality assurance and oversight of county-administered programs needs to reduce the variability of family experience between counties and assure statewide consistency and accountability.**
  - Compliance with waiver rules has led to some difficulty for counties being both family-centered and waiver-compliant.

- DHS staff need to be more involved in some counties and provide training and technical assistance to assure disability programs are implemented consistently based on the guidelines and procedures established by DHS.
- Use data to report on how programs are meeting the needs of children and families and use evaluation measures to inform quality improvement efforts.

## Funding

Pool appropriate funding across disability, education and public health programs to fund FSDRCs. For example, a portion of Medicaid and HCBS waivers is available for eligibility determination. Pull this into the FSDRC for this purpose. Similarly, all these programs have a charge to do outreach to families and connect them with resources. Pool a portion for funding from these resources for this purpose. Additionally, explore efficiencies to be gained by pooling funding to support other functions of the FSDRCs.

Some states are using Medicaid funding to cover the cost of some services provided through a “*No Wrong Door*”. We encourage DHS to explore this avenue of reimbursement for allowable services provided through the *Family Support and Disability Resource Center*.

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<sup>1</sup> **Key Features of a Wisconsin *Family Support and Disability Resource Center*** for families. (excerpt from Concept paper 7/18)

- **Comprehensive Information** – A regular comment from families finding out about a resource for the first time is “why didn’t anyone ever tell me about that!” Families report spending hours trying to get information and are often passed from person to person, agency-to-agency often hearing conflicting information. 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 and assistance that is based on a family’s identified need (family-centered) and is actionable based on the family’s skills and values.
- **Family Navigators** – Access to a person who can provide comprehensive information, assistance and advocacy, including benefits counseling is consistently the number one request families have when seeking help. In addition to information, families often ask to talk with someone reflective of their culture who can understand the complexities of their situation and help think through options and strategies to address their concerns. This takes information to the next step and can result in intensive, but often short-term assistance. The knowledge and skills of the assistor are much deeper than for example 211. Navigators could be co-located in the Regional CYSHCN center or ADRCs. An additional option is to expand the role of county service coordinators to assist families who are not currently connected to children’s long-term supports.
- **Family Education** - Many families are advocates for their child with disabilities but need information about how systems work and skills to be effective advocates. Similarly, families can be agents of change when they have a vision for their child’s future that is based on possibilities rather than what is available in their communities. With this information families can help their child be part of their neighborhood, 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 whether it be access to healthcare benefits, special education or other needed services. Family education is currently provided by a number of organizations, but is not always available across the state, is not always culturally effective or is not

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always in a family friendly language. We recommend DHS provide leadership and funding to assure family education strategies including information, skill building and navigation training are available to families statewide.

- **Family-to-Family Networks** – Connecting with other families who have “walked-the-walk” is often the best resource for another family both emotionally and socially as well as for problem solving. Family-to-family connections are also a good way to support siblings, non-traditional families, and extended families. Groups of families can also seek creative solutions, pool resources or try innovative ideas that are not available within service systems. Supporting an infrastructure to connect and support these types of family-to-family connections can generate community-based solutions that are otherwise invisible.
- **Eligibility Determination** – Many families report difficulty accessing and navigating the existing process to find out if their child is eligible for Wisconsin long-term supports and services. Because the process in most cases is currently county-based, there is not consistent statewide process to access eligibility. Counties vary in the documentation and information they request and the assistance they give families to compile this information. A *Family Support and Disability Resource Center* changes this state of affairs. Eligibility determination will then be consistent and predictable, no matter where a family lives, or their skills to navigate complex systems. Once a child is determined eligible they are referred to their county of residence to start the assessment and planning for supports and services. We recommend a uniform, statewide process to improve equitable access to eligibility determination.
- **Marketing and Outreach** – Families routinely report difficulty finding information and assistance when they need it, particularly when they are trying to understand and navigate multiple systems. An education and outreach campaign to launch the *Family Support and Disability Resource Center* is essential to impacting family access.
- **Technical assistance** - Support for front-line staff is essential to support high quality information and access to technical and legal expertise when needed. Personnel providing the various features will need a source of legal and informational backup for questions that require this level of support. For example, families may need assistance with appeals in an insurance denial, an IEP decision or placement, or an SSI eligibility determination. If the navigator does not have the necessary information they can contact the technical specialist or refer the family to that resource. Current Regional CYSHCN centers and ADRCs use this model with ABC for Health and Disability Rights Wisconsin providing technical assistance.
- **Funding:** In addition to state funding, some states are using Medicaid funding to cover the cost of some services provided through a “*No Wrong Door*”. We encourage DHS to explore this avenue of reimbursement for allowable services provided through the *Family Support and Disability Resource Center*.

<sup>ii</sup> Wingspread Report on Building a National Agenda on Supporting Families 2012 <https://waismanucedd.wiscweb.wisc.edu/wp-content/uploads/sites/74/2017/05/Wingspread.pdf> and National Community of Practice on Supporting Families <http://supportstofamilies.org/>