

Wisconsin Children's Long -Term Support Council

FAMILY SUPPORT AND DISABILITY RESOURCE CENTER - CONCEPT PAPER (7/18)

May 2018. 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 someone who helps her navigate resources. Recently, Hope's doctor recommended continuous glucose monitoring to help fine tune her diabetes management, but offered no help about how to pay for the device. The provider of this equipment told her this was not covered by Wisconsin Medicaid and did not pursue a prior authorization. Kelly already had to pay private insurance copays and deductibles for the insulin pump Hope received previously and was not able to cover these additional costs for the monitoring equipment. Desperate for information about how to help her daughter Kelly attended a community training offered by Family Voices of Wisconsin which provided an overview of health and community supports and services for children with disabilities or 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 on the steps to try and the language she needed to use to get help. Following a series of conversations with this parent trainer, Kelly was able to get approval for the glucose monitoring device and get reimbursed from the pump provider for the copays and deductibles they should have billed to Medicaid.

Kelly's story is one small slice from one family's experienced. Multiply Kelly's story for thousands of families every day who have a critical need for an easy to find front door to information, assistance, advocacy skills and services for children with disabilities in Wisconsin.

Recommendation

Develop and implement a statewide network of *Family Support and Disability Resource Centers* for Wisconsin children with disabilities and their families that provides:

- 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
- Seamless access to eligibility determination for Wisconsin long-term supports and services for children.

Need

It is estimated that approximately 56,000¹ children in Wisconsin have a disability such as cerebral palsy, autism, or Down Syndrome 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., Children's Long-Term Support Waivers, Katie Beckett Program or the Children's Community Options Program).

¹ DHS/Program Access and Benchmark Project, 1/2018

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. The right supports at the right time can be the difference between children thriving with their families as opposed to families making agonizing decisions to place their child out of the home, to quit their job or to forgo critical needs for other family members. 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 even more costly services, and to maximize use of “generic” community, health and school-based supports while reducing reliance on formal disability services. Families are the most important workforces to accomplish these goals when they have access to appropriate information, training and navigation assistance.

Strategies to support and strengthen families need to address all facets of life. Evidence shows that several key features result in effective family support. (National Community of Practice on Supporting Families and Wingspread Report²). We propose a “*Family Support and Disability Resource Center*” approach to giving families the tools they need to take care of their child with disabilities.

Key Features of a Wisconsin *Family Support and Disability Resource Center* for families.

- **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 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. Consider funding family navigators similar to those supported by the Promise grant. Navigators could be co-located in the Regional CYSHCN center or ADRCs. An

² Wingspread Report 2012 <https://waismanucedd.wiscweb.wisc.edu/wp-content/uploads/sites/74/2017/05/Wingspread.pdf>
Supporting Families CoP <http://supportstofamilies.org/>

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 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.

Structure:

- A handful of information resources currently exist in Wisconsin that might serve as the basis for the *Family Support and Disability Resource Center* services. None of these have a primary focus on supporting families nor provide all the elements recommended but could be expanded to include these additional elements. While geographic units based on county lines might be ideal, a regional system also has efficiencies. We recommend a combination of statewide features such as eligibility determination and regional features such as comprehensive information, family education and navigation with local service coordination and CLTS program administration.

We recommend a process that includes all the features proposed above and includes family serving organizations including family run organizations as providers for at least (based on funding) 10 local, regional and statewide (culturally responsive) *Disability Family Support and Resource Center* for children. We recommend a seamless eligibility determination process such as that currently offered through CompassWisconsin. *Family Support and Disability Resource Center* providers must have a track record of working with families of children with disabilities using principles of family-centered planning; understand cultural responsiveness and effectiveness; and have a comprehensive working knowledge of national, statewide and local supports and services.

- **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 new 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*.