Children and youth with significant disabilities can need unique supports to fully participate and benefit from community experiences that benefit all children. Added responsibilities beyond typical parenting for families include critical roles as advocates, care coordinators, benefits navigators and 24/7 caregivers. They must leverage supports, services, community connections, and employment opportunities for their children. Supporting families in these roles and ensuring full community inclusion is cost effective and needs to become a major focus in our system of supports and services. The impact of a child with disabilities can be profound.

- 28% of families live below the FPL compared to 16% without children with disabilities.
- 56% report financial hardship
- 24.5% of family members cut back or stop working.
- 23% of families report usually or always feeling stress compared to 5% of families without children with disabilities.
- Less than 48% of mothers report being in good health compared to 64% of mothers without children with special needs.

**WHAT END THE WAIT LIST**

In the 2017-2019 budget the Wisconsin legislature and Governor approved funding to serve 2600 children waiting for access to long-term supports and services. Since then an additional 1069 children have been identified as needing support. The long-term solution to ending the wait is to change the budget language to fund all eligible children rather than the current language based on a specific number. This change will finally end the wait, meet the legislative intent and bring equity between children and adult systems.

**RECOMMENDATION**

The Governor’s budget recommends “ensuring that any child who is eligible and who applies for the CLTS program receives CLTS program services.” Provide funding for all eligible children in the base Medicaid budget.

**WHAT HELP FAMILIES ACCESS AND NAVIGATE COMPLEX SYSTEMS**

Many families who have children with disabilities talk about how hard it is to find help. Yet we have not intentionally designed supports and services to accomplish this. 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 maximizes the use of existing “generic” community, health and school-based supports. This can reduce or even eliminate reliance on formal disability services.

**RECOMMENDATION**

Provide funding for *Family Support and Disability Resource Centers (FSDRC)* for Wisconsin children with disabilities and their families. The Governor’s budget recommends streamlining the intake, application and screening functions for children’s long-term care programs and providing for children’s services navigators, children’s disability resource specialists and advocacy services to help direct families towards available community resources, programs, and services. This is similar to ADRCs which only serve adults, but with expertise in the multiple systems that serve children and families.

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