



of Wisconsin Disability Organizations

Who are the people impacted by this issue?

Approximately 56,000 children in Wisconsin have a significant physical, developmental, or behavioral disability such as cerebral palsy, autism, or Down syndrome that results in eligibility for home and community-based services. Of these, about 14,000 participate in one or more healthcare coverage or long-term support programs such as BadgerCare, Katie Beckett Medicaid, the Children’s “Waiver” and Children’s Community Options Program (COP). These programs provide primary healthcare coverage such as autism treatment and therapies and long-term supports that help prepare children for school, participation in their communities, preparation for adult living and employment. These programs also support participating families with information, assistance with care and resources. For example, home modifications make it possible for families take care of their child with disabilities and go to work. For many families, Medicaid coverage is in addition to their private insurance, which often does not cover many of the medical and long-term care services needed for children with disabilities.

Families of children with disabilities in Wisconsin face unique challenges and the impact of a child with disabilities can be profound.

- ⇒ 28% of families live below the Federal Poverty Level (FPL) compared to 16% without children with disabilities
- ⇒ 56% of families report financial hardship
- ⇒ 25% of family members have to cut back or stop working to care for their child
- ⇒ 23% of families report usually or always feeling stress compared to 5% of families without children with disabilities.
- ⇒ Nationally, less than 48% of mothers who have a child with a disability report being in good health compared to 64% of mothers without children with special needs.

Why is this issue important?

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. The families of children with disabilities are the most important resource to ensure their child is healthy and included and connected with their community. Added responsibilities beyond typical parenting include critical roles as advocates, care coordinators, benefits navigators and 24/7 caregivers. Supports and services for families in these roles lead to full community inclusion, is cost effective and needs to become a major focus in our public systems.

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 “generic” community, health, and school-based supports.



SUPPORTING CHILDREN WITH DISABILITIES AND THEIR FAMILIES

How are supports for this issue funded?

Children with the most significant disabilities in Wisconsin are eligible for Medicaid funded acute, primary, and long-term supports and services. In many cases this is in addition to a family's private insurance. Medicaid is a state and federal funding partnership. The federal medical assistance percentage (FMAP) is the portion of total Medicaid spending supported by federal matching funds. The typical federal match for child disability programs is 40% state and 60% federal.

The Children's COP program is funded with state General Purpose Revenue (GPR) and is used to pay for those things families may need that are not Medicaid allowable such as care of a sibling while parents are with the child with a disability in the hospital.

What are major concerns related to this issue?

Unlike the adult long-term care programs, home and community-based supports for children has a statewide wait list. Eligible children with the most significant disabilities are the only Medicaid population in Wisconsin on a wait list due to lack of funding. While the Wisconsin legislature has approved funding to serve a specific number of children, they have not changed the funding mechanism to serve all eligible children as they did for adults with disabilities in Family Care and IRIS Medicaid waiver programs. 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 and create equity between children and adult systems.

Another major concern is lack of access to information and assistance that can help families navigate and coordinate complex systems such as special education, healthcare, employment, and the coordination between public and private benefits. Many families who have children with disabilities talk about how hard it is to find help. Supporting families can reduce or even eliminate reliance on formal disability services. Like ADRCs which serve adults and seniors, Wisconsin can create a statewide access network of *Child Disability Resources (CDRs)* that specialize in information, assistance, and benefits counseling for children with disabilities and their families.

How has this issue been impacted by the COVID-19 pandemic?

Like many families during COVID-19, families of children with disabilities have to make decisions about keeping their family safe and healthy, when and how to return to work, when and how their child participates in school and engages with the larger community. Unlike typical families, families with a child with disabilities may have additional considerations. The child may have to stay home due to additional health risks from contracting COVID-19; they may be unable to practice social distancing or wear a mask due to their disability or need for care; childcare settings may be unwilling to take a child needing these additional cares; consequently families may be unable to return to work or be faced with trying to work from home if allowed by their employer and take care of their child at the same time. With children home all day, many families have had to take on additional roles during COVID-19, becoming the teacher, nurse, 24/7 caregiver, while at the same time working and taking care of all family members.

For many this is not sustainable without assistance.

Additionally, Wisconsin's family medical leave policies do not offer paid leave options, nor do they allow for leave for the types of intermittent care responsibilities, meetings and coordination duties required of parents. This can force families to choose between work which is essential for the entire family and the care needs of the child with disabilities.

