



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 resulting in eligibility for home and community-based services. Of these, about 14,000 currently participate in one or more healthcare coverage or long-term support programs such as BadgerCare, Katie Beckett Medicaid, the Children’s “Medicaid Waiver” and Children’s Community Options Program (CCOP). For many families, Medicaid coverage supplements their private insurance, which often does not cover many of the medical and long-term care services needed for children with disabilities.

Why is this issue important?

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 must 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.

Children and youth with significant disabilities may need unique supports to fully participate and benefit from school, work and community experiences. The programs that pay for these supports and services, like Medicaid and Medicaid Waivers, are essential to child development and family health and wellness.

When families have access to meaningful information, training, and navigation assistance, their success increases. These supports can prevent crises like lost jobs, lost opportunities for child development, dependence upon public services and lost economic stability for families. 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, which is both traumatizing and expensive.

How are supports for this issue funded?

Children with the most significant disabilities in Wisconsin are eligible for Medicaid based on the severity of a child’s disability. In many cases Medicaid is in addition to a family’s private insurance. Medicaid is a state and federal funding partnership. The typical federal match for child disability programs is 40% state and 60% federal.

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



SUPPORTING CHILDREN WITH DISABILITIES AND THEIR FAMILIES

What are major concerns related to this issue?

Children and their families continue to wait for funding. Unlike the adult long-term care programs, children eligible for long-term supports may be put on a wait list for the program due to a 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. The permanent solution to ending the wait is to change the budget language to fund all eligible children. This change will finally end the wait and create equity between children and adult systems.

A statewide disability resource center will offer critical information. Families who have children with disabilities struggle to navigate systems like health care, long-term supports, education, and Medicaid. Wisconsin has no statewide, coordinated effort to connect children with disabilities and their families to information, assistance, and services, but is currently using ARPA funding to develop a limited resource for families. A sustainable source of funding is needed to offer a comprehensive Disability Resource Center for Children and Families that would offer:

- Information, assistance, and resource navigators to help families find available community resources, programs, and services.
- Children's disability benefits specialists.
- Advocacy services for children.
- A front door to eligibility determination for CLTS programs including Katie Beckett and CCS.

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

Unlike many other families, families of 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; or 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. For many this is not sustainable without assistance.

It will help families in Wisconsin to implement a family caregiver tax credit and expand who can use Family and Medical Leave (FMLA) to include grandparents, grandchildren, and siblings. Additionally, Wisconsin's family medical leave policies should be expanded to offer paid leave options, and allow leave for intermittent care responsibilities, such as when a child can not be in school.

