

Medicaid and Families: A Critically Important Resource

Medicaid is a lifeline for many children and adults with disabilities. Medicaid covers more than visits to the doctor and is more than Badgercare Plus. Without Medicaid coverage for therapies and long-term support programs, families won't be able to access services and supports their children with disabilities need to grow and thrive. Medicaid waiver programs, like the Children's Long-Term Support (CLTS), Family Care and IRIS, provide coverage for critical equipment, home modifications, respite and many other services that keep people out of institutions, and allow their family members to stay employed, pay taxes and care for their family.

What can you do:

Protect and preserve current Medicaid programming to maintain existing services

Support Families by Addressing the Ongoing Direct Caregiver Crisis

Families who have children with disabilities want to live together at home and be active in the community. Wisconsin's ongoing long-term care workforce shortage is impacting families' ability to do this. Provider networks are shrinking due to low payment rates. Often direct care workers find higher paying jobs in other fields. When these direct workers cannot be hired, parents must become the primary caregivers 24/7. Many parents or other family caregivers leave the workforce completely, or greatly reduce their work hours, which leads to a dramatic decrease in a family's finances. The constant stress also affects the mental and physical health of entire families.

What can you do:

Support laws and policy that invests in Wisconsin's community-based child and adult long-term care workforce and provide pay and benefits to the in-home care workforce equal to what workers in facilities and healthcare settings receive. Same work = Same pay.

Medicaid Payment Equity for Private Duty Nursing (PDN) Services

Children with complex medical needs want to live at home with their families but may need nursing services to stay out of the hospital and maintain their health. Wisconsin Medicaid covers Private Duty Nursing (PDN) for a limited number of children across the state. Finding a nurse to provide PDN is *nearly impossible* for many families. To improve access, the 2025-2027 state budget increased payment rates but **ONLY** for nurses who work for an agency. This was an oversight in the final budget language and urgently needs to be corrected. Nurses in independent practice were excluded – their payment rates have not increased since 2018 and they provide 90% of all PDN services. Agencies who offer these professional services only serve a limited number of counties and families in many areas only have the option of hiring a nurse in independent practice. Without access to this care, discharge from the hospital gets delayed, costing Medicaid hundreds of thousands of dollars each year. It adds an overwhelming demand upon parents who must take on complex nursing responsibilities. These families are not just parenting—they're acting as nurses for their child.

What can you do:

Support a 30% increase in the Medicaid payment rate for Nurses in Independent Practice who provide private duty nursing services.



Paid Parent Caregiving for Children with Complex Needs

The critical shortage of direct care workers means that many parents cannot work outside the home and instead provide skilled care for their child with a disability or complex medical need. While 38 states provide compensation for parents who care for a child under age 18 as part of their Children's Medicaid Home and Community-Based Services waiver, Wisconsin does not. Note that for those who have a child age 18 and older, parents and other family members can be paid to provide this same skilled direct care to their loved one.

What can you do:

Support the addition of paid parent caregiving for children with complex needs as part of Wisconsin's Children's Long-Term Support (CLTS) Program waiver renewal.



Support Special Education

Students with disabilities deserve public education that meets their needs, and school districts deserve the state funding to make that education possible. For years, Wisconsin has deeply under-funded special education at the state level. School districts across the state spend over \$1.25 billion in property taxes each year toward filling the gap. The insufficient funding means that schools and families feel pressure to meet complex needs with inadequate resources. This year, Wisconsin promised to reimburse 42% of special education costs but did not allocate enough funding to meet that promise.

What can you do:

Support using the current budget surplus to keep the promise of at least 42% funding for special education.

In the next state budget, increase special education funding to cover at least 90% of costs, equivalent to the reimbursement provided to private schools, to ensure the quality education that students with disabilities need.

Family Voices of Wisconsin is a non-profit 501(c)3 organization serving the entire state. We are part of the Wisconsin Title V Children and Youth with Special Health Care Needs Network, and serve as Wisconsin's federally-recognized Family-to-Family (F2F) Health Information Center.

Family Voices supports and empowers families who have children and youth with disabilities and special health care needs. Visit familyvoiceswi.org or call **608-512-0217**.

To learn more about our policy and budget priorities, contact Danielle Tolzmann, Executive Director, at Danielle@fvofwi.org

