

Use the following talking points to describe the problem you want your elected official to understand. Share part of your family story that best illustrates your family's experience with the problem, including what *solving* the issue would mean to your family. Be sure to include **YOUR ASK**—This is what you want your elected official to do.

Support Families by Addressing the Ongoing Caregiver Crisis

PROBLEM

Families take on many roles as they care for their children with complex needs. As workforce shortages continue to impact all parts of our economy, families of children with special health care needs are disproportionately affected. They are unable to offer a livable wage to their caregivers, and systems developed to provide care are crumbling because of the very low reimbursement rate. These issues make filling positions in caregiving very difficult, and too often, the workers are not available. Families are then forced to fill those gaps by providing care coordination and direct care, themselves. Many family caregivers leave their jobs or must cut work hours because there are no other options. The constant stress is affecting the mental and physical health of the entire family.

Facts

- Half of surveyed families cannot find workers to provide needed services.¹
- Over 18,000 Wisconsinites were denied or delayed receiving services due to staffing shortages.¹
- Before Covid, 1 in 4 families had to cut back or stop working to care for their children. It is much worse now.
- 60% of surveyed families have had a parent leave the workforce or reduce their work hours to provide care.
- Half of families reported that if they did not intervene and become a caregiver themselves, their loved one would be placed in a residential facility.¹
- Over one-half of surveyed families report their ability to provide constant care is not sustainable.¹

Talking Points

- The Caregiver Crisis effects families every day, in every community throughout Wisconsin.
- Medicaid approved services go unfilled because of a lack of staff.
- The rate caregiver positions are paid cannot compete with other vacancies.
- The rate organizations are paid to provide caregivers does not cover their direct expenses for this work.
- In the absence of qualified staff, the responsibility falls on families, who often leave jobs (impacting livable wages, retirement, and benefits) to care for their child with special health care needs.
- Wisconsin children with disabilities wait every day for services they need because there are no workers.
- Families need local support to make community life possible for their kids.

SOLUTION

Ask your legislator to recognize the importance of caregiving with competitive wages and value the role of families as essential caregivers.

This can be accomplished through:

- Increasing the payrate for Direct Care and Personal Care Workers by 25% in all long-term care programs.
- Increasing Medicaid Personal Care (MAPC) rates by 39%, reflecting the actual cost of providing these services.
- Supporting the Governor's proposed \$500 Family Caregiver Tax Credit for direct caregiving expenses.

PROBLEM

Wisconsin has under-funded special education for years and the pandemic has added to these challenges. Wisconsin only reimburses about 30% of local costs for special education, despite small percentage increases in the state budget the last two cycles. Public schools have an obligation to meet the needs of all students (including special education), but are not funded sufficiently to do so.

Facts

- Just under 120,000 Wisconsin students (14.5%) have disabilities.³
- Students with disabilities lag significantly behind their peers in academics. The percentage of students with disabilities who score proficient or better on the Forward exam is three times less than their peers without disabilities.^{3,4}
- The rate of out of school suspension is over four times higher for Wisconsin students with disabilities than for their non-disabled peers.

Talking Points

- Investing in students with disabilities improves their future success in the community and workforce.
- Youth with disabilities, who leave school unprepared for adult life, are more likely to live in poverty and rely on public benefits.
- The portion of special education funding that is not covered by federal or state budgets must come from local tax dollars, which puts great pressure on communities. Districts currently cover \$1.25 billion annually in special education costs, statewide.
- Since the year 2000, special education costs have doubled.⁵
- Wisconsin reimburses 90% of expenses for students attending private schools in the Special Needs Scholarship Program.

SOLUTION

Ask your legislator to increase special education funding to cover at least 60% of costs, to provide the quality education that students with disabilities need.

Support Children's Mental Health

PROBLEM

Wisconsin falls far short of recommended school staffing for services like school counselors, psychologists, social workers, and nurses who help students with mental health needs. Students with emotional and/or behavioral disabilities have the highest suspension rate and the second-lowest graduation rate of any disability group, which could be improved by increased access to school-based mental health services.

Facts

- Thirty-four percent of students in 9th- 12th grades reported feeling sad or hopeless every day in 2021, up from 29% in 2019.⁶
- Twenty-five percent of female high school students and 48% of lesbian, gay, or bisexual high school students seriously considered attempting suicide in 2021.⁷
- Students dealing with mental-health issues miss more days of school than their peers.

Talking Points

- Tell your legislator that increased access to school-based social workers, counselors, psychologists, and nurses would help children and their schools.

SOLUTION

Ask your legislator to support sustainable funding for pupil services staff and for school mental health service systems overall.

PROBLEM

The Children's Long Term Care Support (CLTS) program is designed to serve children needing an institutional level of care. Despite small funding increases over the years and a departmental change in terminology to avoid using the words 'wait list', the experience of families in many areas continues to be one of lengthy delays to access services, with families still waiting more than 6 months to as long as two years. Comparable adult services are 'sum sufficient' (assuring funding is available to meet the need), but children's services are 'sum-certain' (having a fixed maximum budget each year). This results in continued waits, increasing stress upon families and preventable delays in addressing developmental milestones. These postponements effect the stability, mental and physical health of the entire family.

Facts

- As of January 2023 data, 1,599 Wisconsin children are waiting to access CLTS resources and supports.²
- The average wait is just over three months, with the longest current wait being more than 2 years.²
- While the term 'waitlist' has been removed from departmental materials, the experience of families and children continues to be that of waiting.

Talking Points

- Changing the terminology and not using the term 'waitlist' has not changed the experience of families.
- A change in statutory language would make the program sum-sufficient, so that when a child is found eligible they can begin services right away.

SOLUTION

Ask your legislator to support changing the statutory language for the Children's Long-Term Support Waiver (CLTS) to be sum sufficient, making it equitable to similar adult long-term care programs.

Footnotes:

¹Survival Coalition Survey, 2022 http://www.survivalcoalitionwi.org/wp-content/uploads/2022/11/SurvivalCoalition2022FamilyCaregiverSurvey-Summary_100422-.pdf

²CLTS DHS Dashboard, 3/9/2023

³DPI WiseDash, 2021/22 school year

⁴Education Week, 2016 article <https://www.edweek.org/teaching-learning/why-are-students-with-disabilities-failing-standardized-tests/2016/05>

⁵Education Law Center Report, "Wisconsin's Special Education Funding Crunch: How State Underfunding Disproportionately Harms Students in High Poverty Districts", 10/2022 https://edlawcenter.org/assets/files/pdfs/publications/2022_ELC_WisconsinReport_Final.pdf

⁶OCMH 2022 annual report

⁷DPI 2021 Youth Risk Behavior Survey, <https://dpi.wi.gov/sites/default/files/imce/sspw/pdf/yrbs-preliminary-release.pdf>