

Suggested Issue Talking Points

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

The workforce shortages that continue to impact our economy have disproportionately affected families of children with special health care needs. 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 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 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.
- Sixty percent 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 reported their ability to provide constant care is not sustainable.¹

Talking Points

- The caregiver crisis affects 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 employment 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 to care for their child with special health care needs. This impacts wages, retirement and benefits.
- Wisconsin children with disabilities wait every day for needed services 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:

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

Support Special Education

PROBLEM

Wisconsin has under-funded special education for years and the pandemic has added to these challenges. Wisconsin only reimburses about 33% of local costs for special education, despite small percentage increases in the state budget the last three cycles. Public schools have an obligation to meet the needs of all students, including students with disabilities, but are not funded sufficiently to do this.

Facts

- Over 122,000 Wisconsin students (14.9%) 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 and a half 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 90% 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 counselors, psychologists, social workers and nurses who support 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 high-school aged students 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 are needed to support children's mental health and their schools.

SOLUTION

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

Support Improvements to Healthcare Access

PROBLEM

Multiple factors contribute to the difficulty families have accessing healthcare through Medicaid, but at the root of many access problems are low Medicaid service rates for healthcare providers. For example, Private Duty Nurses serve kids with medical complexity in their homes. When nurses are not available, parents must fill this role, which often means a parent must quit their job to provide nursing-level care. In addition, accessing dental care for children with Medicaid is extremely difficult due to the limited number of providers willing to accept low Medicaid rates. Adult dentists are even more difficult to find. This means many adults on Medicaid go without preventative dental visits, requiring more aggressive treatment later at a far higher cost. For families who have a child with autism spectrum disorder, many have therapy providers who either limit the number of Medicaid patients or have stopped serving these patients entirely, pointing to very low Medicaid rates as their reason.

Facts

- More than 1 million Wisconsin residents are enrolled in Medicaid.
- Not long ago, hospitals wouldn't discharge children with significant medical complexity without professional home care in place. They have eliminated this requirement, not because it's no longer needed, but because nursing care cannot be found. When asked, many point to the pay rate, including requirement of non-compensated planning time, as the reason.

Talking Points

- Explain the impact of access problems upon your child and your family.
- A comparison study of Medicaid rates and private insurance rates could verify what families are experiencing.

SOLUTION

Ask your legislator to support a comparative study of rates, and support any DHS requested increases to current Medicaid rates for critical childhood special health care need services, which will support current providers to continue serving families and may increase the number of providers to an adequate level.

Footnotes:

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

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>