



of Wisconsin Disability Organizations

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Media advisory: Legislature’s State Budget Falls Short for People with Disabilities, Family Caregivers

Disability advocates are deeply disappointed with the lack of investment and cuts to key programs contained in the Legislature’s state budget. People with disabilities and their families across Wisconsin are really struggling. Many were struggling before the pandemic, and COVID-19 made existing problems worse.

Many important low-cost, critically needed investments are missing from the currently-proposed budget—including removing lead pipes and paint that are a 100% preventable cause of intellectual and developmental disabilities in babies and toddlers and funding to guarantee poisoned children can get help. Family caregivers are leaving the workforce, sacrificing family income, and burning out trying to fill the gaps left by the caregiver crisis. This budget does not help those struggling daily to meet care needs. Students receiving special education services have lost ground both academically and socially because of the pandemic and may need years to rebuild and recover skills. Cuts to Wisconsin’s largest transit systems will make it more difficult for low-income people with disabilities and the caregiver workforce that rely on it to commute to client homes to return to work and live independently.

The state budget is Wisconsin’s opportunity to help people now and commit to ongoing investments that will support people in the future. Our folks can’t wait.

- **Press Packet:**
 - **Survival Coalition 2021 [Family Caregiver Survey](#)**
 - **Survival Coalition 2021 [Special Education Survey](#)**
 - **Survival Coalition 2018 [Non-Driver Transportation Survey](#)**
 - **Lead poisoning in Wisconsin**
 - [DHS warns about lead poisoning risk for Wisconsin children](#) (2020)
 - [Wisconsin rate of lead poisoning worse than flint Michigan’s](#) (2018)
- **Who:** People with Disabilities from across Wisconsin share how the state budget does not address the family caregiver, special education, health disparities, and transportation challenges they face. The Media may contact the following individuals directly for their experiences:

Lisa Schneider, Appleton WI (Family Caregiver Crisis); 920.540.1094,
lschneider@respitecarewi.org



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“Because there are not enough workers available, I am a family caregiver that is providing care for my daughter much longer than I initially planned. There is no confidence on my end that Kelsey could move out of my home, knowing there is not enough direct care worker staff anywhere to support her. This greatly affects my ability to do my job, tend to my health, and quality of life for my daughter. I am currently stressing out planning wise for me to have an outpatient surgery that will take ten days of doing nothing to recover; I am having to ask family members from Arizona, Upper Michigan, and Minnesota to come to Appleton to help care for my daughter as I need someone to transport my daughter to and from adult daycare, feed her, dress her, bathe her, get her to sleep, and being able to tend to her 24/7. I have to align the sun, moon, and stars to take care of my health. I also know many family caregivers who have had to cancel their much-needed planned vacations due to agencies contacting family caregivers and advising them they will not have the staff on hand to care for their loved ones.” **Lisa Schneider also directs the Respite Care Association of Wisconsin which works to help family caregivers statewide find support.**

Jessica Nell, Green Bay, WI (Family Caregiver Crisis) – [920-360-2169](tel:920-360-2169)

Jessica Nell is 33 years old and has a physical disability. Jessica uses a wheelchair and has complex medical issues that require daily direct care and personal care supports. Just over a year ago Jessica was forced to move from her apartment in Madison and give up her dog and her freedom because she wasn't able to find enough direct care workers to fill her shifts and provide her with appropriate care. She has been living in a nursing home ever since. Over the last year Jessica got COVID in the facility and is still dealing with related health issues. Recently she was moved from a nursing facility in Clinton to Green Bay and has been begging and dreaming of going “home” again. Jessica says, “What 33-year-old belongs in a nursing home?” Jessica also says there are others in the facility she is in now that could also live in a home/community-setting much more independently and at less cost to the state if they could just find direct care workers.

Stacy Ellingen, Oshkosh, Wisconsin (Family Caregiver Crisis); stacyellingen@gmail.com

Stacy Ellingen from Oshkosh had major challenges finding caregivers before the pandemic, but had to relocate to live with family during COVID-19 because the shortage became more acute. Stacy also lives with CP, and uses a communication device.

Milwaukee resident (Lead exposure); info@orangebutterflypersonalservices.com

Milwaukee mom lives in an older neighborhood. She and her neighbors have had lead exposure. “I live in a 4 unit apartment building. To my knowledge the city has never replaced the pipes leading to the building where I live, nor has my landlord ever been offered money to replace the lead pipes on the property. There are entire neighborhoods exposures to lead. My neighborhood is diverse, not wealthy, but diverse. White, Black, Asian, LatinX, engineers, educators, realtors, stay at home moms, artists, personal care workers, retirees; people of all backgrounds. I buy bottled water every week to drink



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every day for years now and I have known neighbors to do the same. We still shower, wash dishes, clothes, etc in the lead water."

**Edward Ruffalo, Appleton, WI (Special Education); 920-851-4127,
edward.ruffolo.wi@gmail.com**



My daughter Erin is a person with significant disabilities and her educators went above and beyond in helping Erin reach her full potential and has made a profound difference in her life. My family experience has led me to work to ensure that students with intellectual disabilities, physical disabilities, or emotional or mental health issues receive the support and education needed to reach their full potential. For someone with a disability, the educational experience is life-altering and affirming, and can be the critical difference necessary to achieve their full potential. I was recently elected to my local school board to further my advocacy for people with disabilities.

Jenny Smith, Verona WI (Special Education); 608-239-2339



When our school closed due to COVID-19 in Spring 2020, my son was left without the significant special education supports he needs to be a successful learner. Despite the efforts of his special ed team to help via email and phone, my husband and I had to become his teachers while we continued to work full time. Our son was able to return to in-person learning this year, but he has lost ground in some academic areas, which is a huge concern and worry for us as he heads into middle school this fall. The special education staff in our school was stretched thin even prior to the pandemic, and the inadequate level of funding in this budget means that situation will continue to get much worse.

Denise Jess (Non-driver transportation) Executive Director of the Wisconsin Council of the Blind & Visually Impaired; 608-237-8103



Denise Jess advocates for the rights of Wisconsin's nearly 2 million non-drivers. Denise, who is legally blind, knows the everyday challenges faced by those who cannot or choose not to drive. She advocates at the national, state and local levels, including serving as co-chair on the WI Non-Driver Advisory Committee, the City of Madison Transportation Commission and the Madison Metro Re-Design Taskforce. "When we invest precious public resources into transit and specialized transportation, we open the doors of opportunity, create greater equity and enhance our economic development."

Survival Coalition is comprised of more than 30 statewide disability organizations that advocate and support policies and practices that lead to the full inclusion, participation, and contribution of people living with disability.