Survival Coalition
of Wisconsin Disability Organizations

Recognizing the Need to Address the Caregiver Crisis and Supports to Families in State Budget

Caregiver Survey Shows People are Going Without Needed Care, Families are Reducing Work to Provide Care. Stress is High.

Survival Coalition of Wisconsin Disability Organizations members continue to see the impacts of the pandemic on family caregivers and direct care workers who are in crisis. These survey results share what is happening in Wisconsin communities and emphasize the need for increased resources. Specifically, Survival Coalition supports the proposals adopted by the Task Force on Caregiving which included:

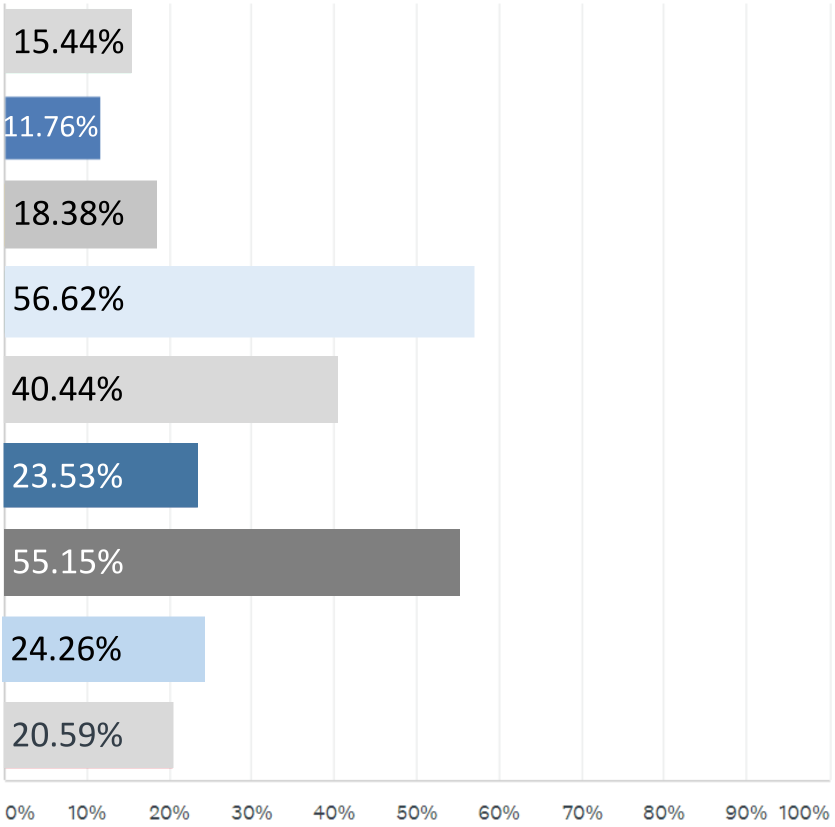
- increases for family caregivers provided through Aging and Disability Resource Centers (ADRCs),
- proposals to raise rates to providers that are tied to increases in direct care worker wages;
- efforts to ensure workers can afford and maintain essential benefits like health care and child care and other proposals that will alleviate stress – financial and otherwise – on family caregivers.

The average wage of a direct care worker in Wisconsin is approximately $12/hour with retention at less than 50% as employers compete with fast food and other area employers for applicants. Previous Survival Coalition statewide surveys of people with disabilities and families have showed that 95% of responding people with disabilities have difficulties finding home care workers; 85% said they didn't have enough workers to fully cover open shifts. Going without care puts people's health at risk; relying too heavily on family caregivers means people lose their jobs and compromise their own health and personal savings.

Caregiver Crisis at Risk of Being Ignored in State Budget

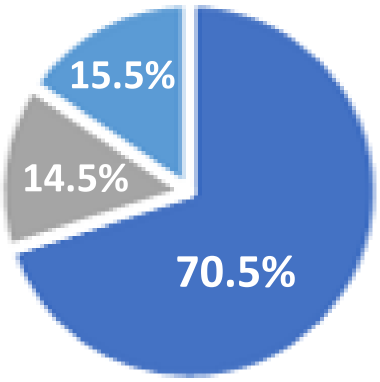
What impact has the lack of quality direct support workers had on people with disabilities and their families? (136 respondents)

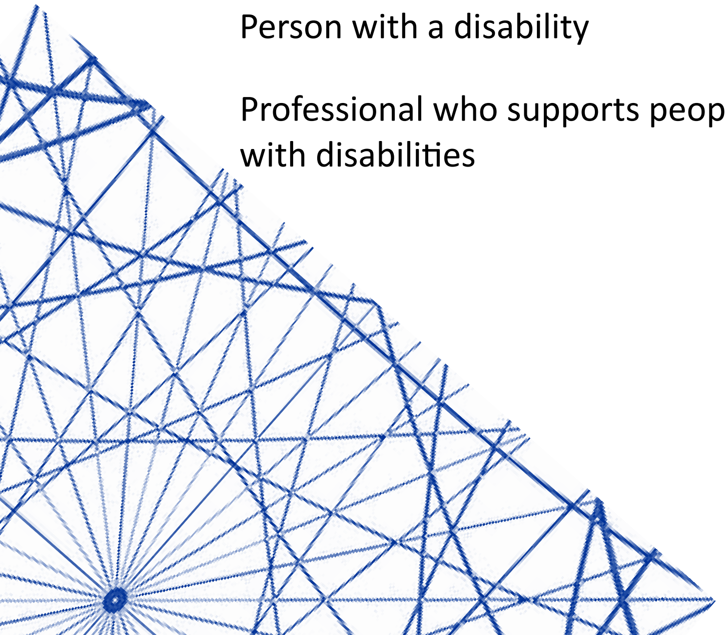
My health has suffered, resulting in more trips to the doctor/hospital	15.44%
I am less safe in my home	11.76%
I often go without the daily cares I need i.e. help with dressing, bathing, getting out of bed, other	18.38%
I cannot find enough workers to fill the shifts I need for my care	56.62%
I (or my family) have had to reduce work to provide care	40.44%
I (or my family) has had to quit paid employment to provide care	23.53%
I (or my family) are experiencing enough stress to affect physical health	55.15%
I (or my family) worry I may have to move to a facility or nursing home	24.26%
Other	20.59%



Here is who responded to the survey:

Family members	70.5%
Person with a disability	14.5%
Professional who supports people with disabilities	15.5%



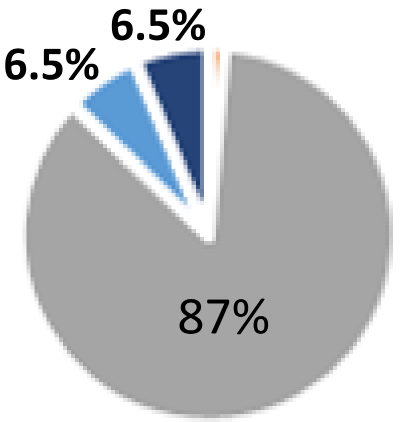


Families of Children and Youth with Disabilities

Survival Coalition of Wisconsin Disability Organizations asked member networks to provide feedback on funding priorities for the state budget and uses for federal COVID recovery funds. There is concern that children with disabilities will not be a priority. We asked how the provision of special education services and/or the lack of access to information and assistance has impacted your family. The COVID pandemic has only increased the strain on families in Wisconsin. We also asked what changes can improve special education and create a statewide Disability Resource Center for Children and Families.

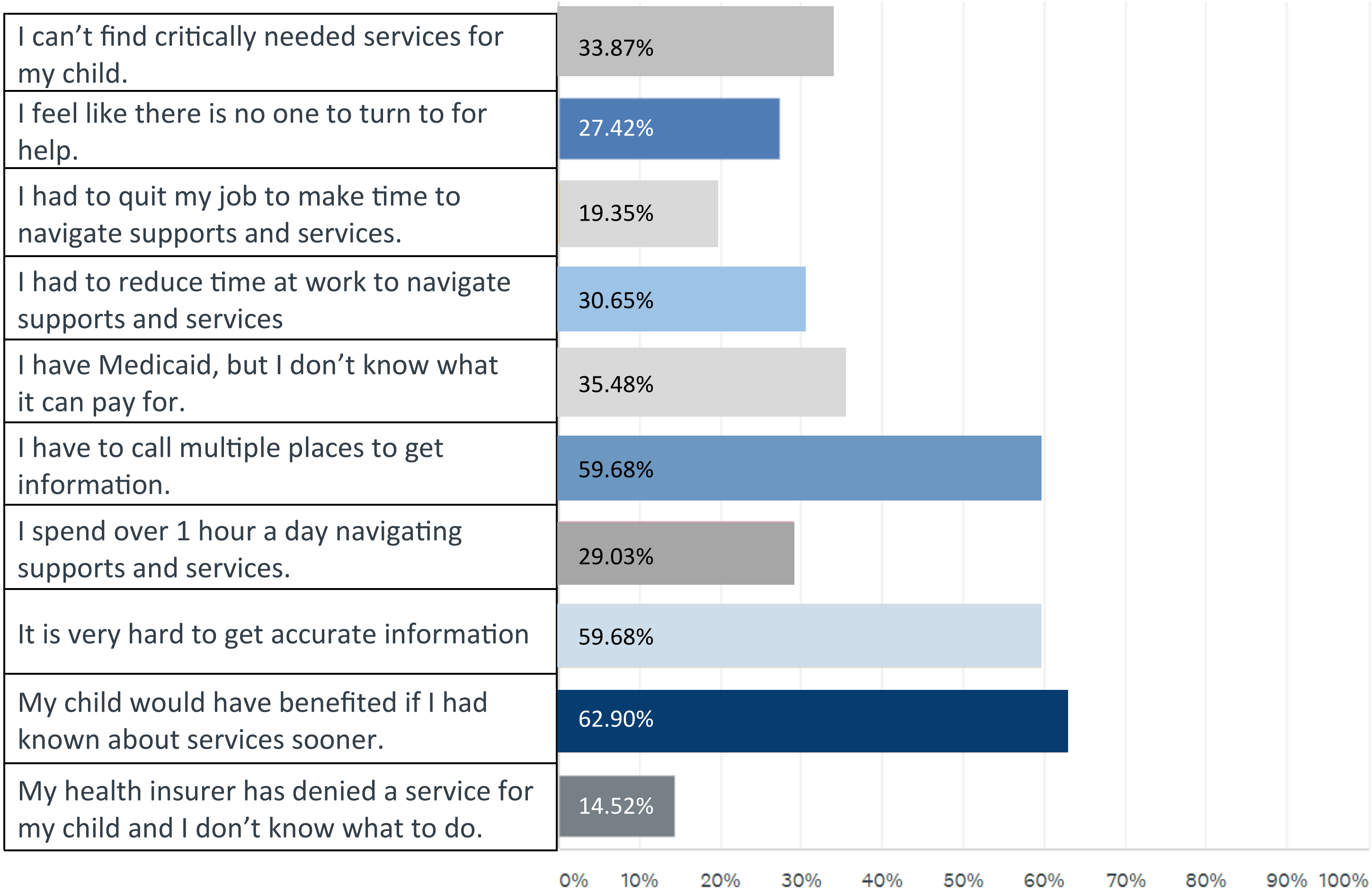
Here is who responded to the survey:

Family members	87%
Person with a disability	6.5%
Professional who supports people with disabilities	6.5%



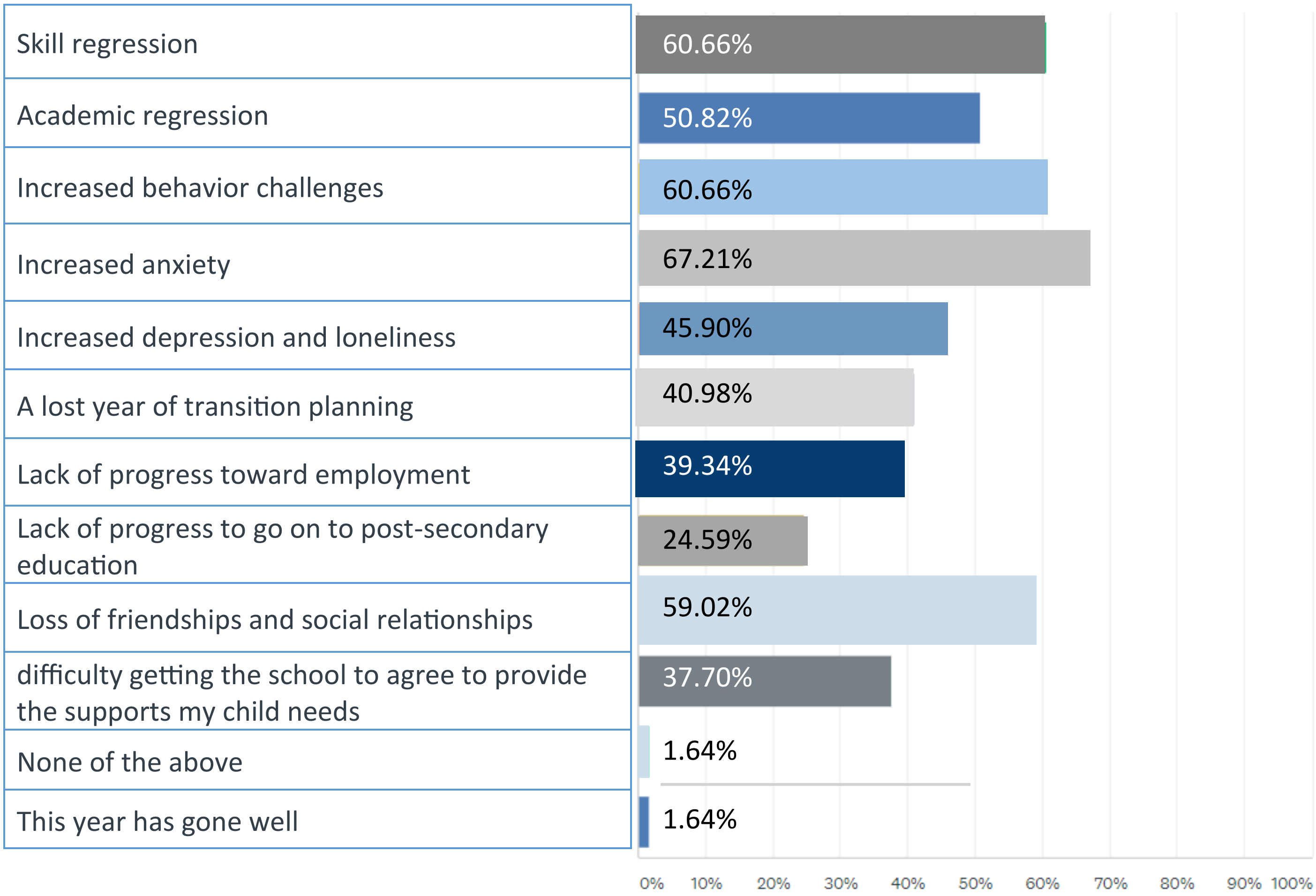
Families of Children and Youth with Disabilities

When it comes to health, community, and school supports and services, what impact has a lack of information assistance or advocacy support for you had on your child or family? (62 respondents)

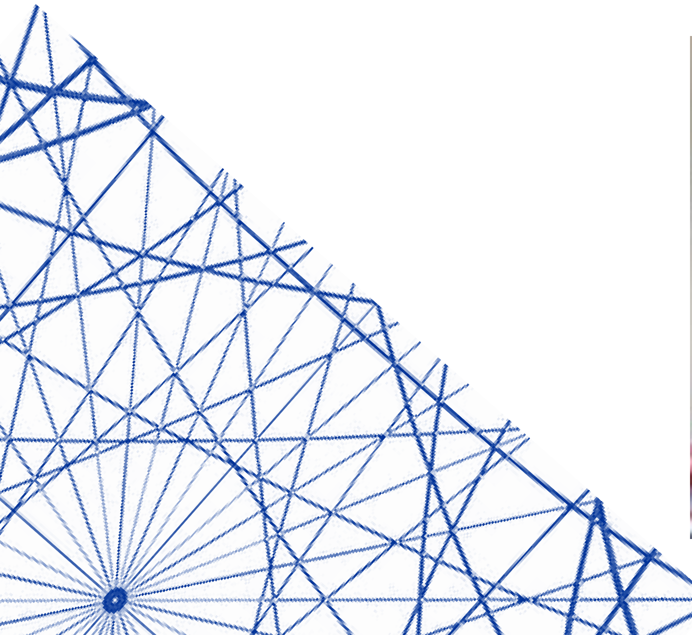


Families of Children and Youth with Disabilities

When it comes to health, community, and school supports and services, what impact has a lack of information assistance or advocacy support for you had on your child or family?



Skill regression	60.66%
Academic regression	50.82%
Increased behavior challenges	60.66%
Increased anxiety	67.21%
Increased depression and loneliness	45.90%
A lost year of transition planning	40.98%
Lack of progress toward employment	39.34%
Lack of progress to go on to post-secondary education	24.59%
Loss of friendships and social relationships	59.02%
difficulty getting the school to agree to provide the supports my child needs	37.70%
None of the above	1.64%
This year has gone well	1.64%



Here’s what people with disabilities and the families want you to know:

* Stories are in order of city, within each type

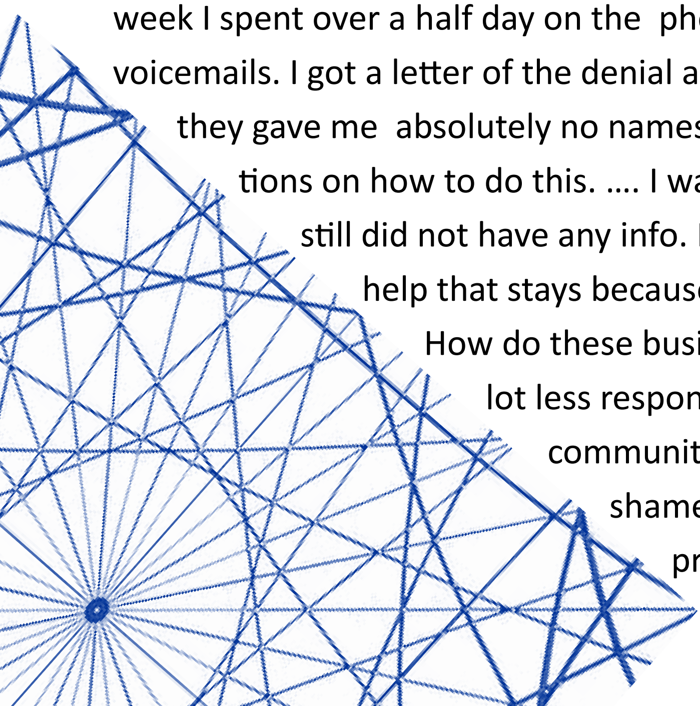
Stories from Families

Julie, Almena

Lack of skilled and dependable workers leave myself and husband to care for our disabled son. We have no outside help, no respite.

Mary, Appleton

The stress is unbelievable at so many levels. It is hard enough taking care a special needs child not for 18-25 years but for the rest of their lives or our life….There is no way to tell you or for you to understand because unless you have experienced it yourself, you have no idea. However, if taking care of a special needs child isn’t enough, we have to deal with services, the government services and lack thereof, school services and issues, community issues, etc. etc. . My son is now thirty-six and in an adult family home for a year and a half now. My son has worn orthotics since he started walking. When I worked, they were covered under my insurance. I am retired now so I am on Medicare and so is my son. He has not had new orthotics in over 10 years. Without orthotics he will develop all kinds of problems with knees and hips. One of his orthotics is currently cracked. I have been working on this for over 6 months . Medicare and Medicaid are denying approval. I have turned to IRIS for help. Last week I spent over a half day on the phone. Last two weeks 4 calls to Forward health. Got all voicemails. I got a letter of the denial and that could ask for a hearing to appeal. However, they gave me absolutely no names or phone numbers of how or where to call with questions on how to do this. …. I was frustrated and angry and totally wasted 4 hours and still did not have any info. Finally, By the way I am 72 years old. Cannot find good help that stays because salaries are so terrible for what is expected of them. How do these businesses compete with places paying up to $15 with a lot less responsibility ? …. The most vulnerable of our society and communities and this is how they are cared for. ... Shame shame shame on all of you for how our country and states treat and provide for the most vulnerable!!! Disgusting!



Meghan, Appleton

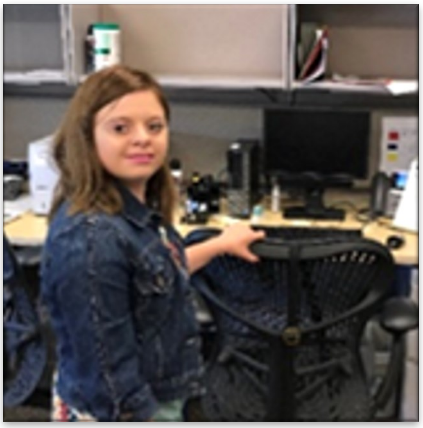
We are unable to find care for our severely disabled adult son after school, so I have had to reduce my work hours to make sure I am only working days my husband is off. We also have minimal caregivers to assist on nights/weekends, such that we only get one weekend away per year and rarely a date night.

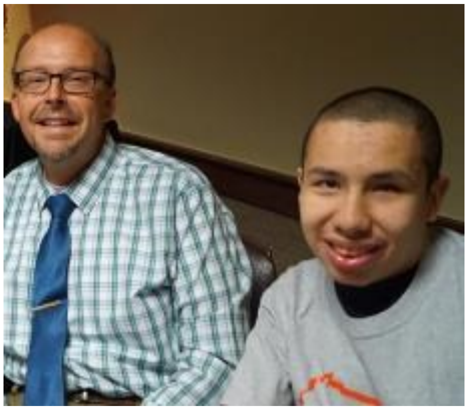
Juliet, Beloit

I can solely rely on very close and reliable people for my care because I cannot really make sure they are not infected. That reduces the possibilities of hiring people for the amount of funds that I have. I have to rely on family members to help me for free when I do not have enough budget to cover the amount of care that I need.

Julie, Brookfield

Within 3 weeks of the COVID lockdown our daughter lost every one of her care workers, her transportation to and from work and her job supports. She had to move from her beloved apartment in the community and we had to provide ALL of her support! If we hadn't been able to provide transportation every day to and from work, she would have lost her job!!! Her life basically fell completely apart in every way!





Julie, Brookfield, cont.

After over 1 year, we are just starting to rebuild the amazing life she has spent years building! Most of her workers left because they could get jobs at Target and Aldi for $19-20/hour, $5/hour more than we could pay them. And her life fell apart!!!

Penny, Cedarburg

My son requires one on one care and needs assistance with everything. Now that he has aged out of school, I have had to quit my former employment to stay home and care for him. After three years of advocating, he was finally accepted into a day program for ONE morning a week. After another year of advocating the day service finally had another morning opening so he went two mornings a week. Then Covid hit and he’s been home since then. It is difficult to find and retain caregivers to come into our home. It is even more difficult to find day service in our community that have enough staff to care for one-on-one individuals. Caregivers need to be paid much more! In today’s times people need to make a living and retail stores and even McDonald’s pays more than taking care of another human being. My son should have a life and opportunities in the community. In order for him to have that, he needs one on one. Please advocate higher pay with benefits for caregivers! This includes family caregivers!

Joy, Chippewa Falls

It’s extremely challenging to find appropriately aged caregivers to do the types of things our son enjoys. Hiking, biking, Xbox, and going places in his community that are age appropriate. We are fortunate that he has a older sister and younger brother however both will be moving this year and the roles they have been filling will be almost impossible to fill. Not just because they are brother and sister to him but mostly because they have intentionally considered his age found activities that are engaging both physically mentally and socially.

Phillip, Cudahy

With getting a caregiver that is available during the hours of need and the rate of pay is hard. The cares don't really get done. The timeline is too short, and the pay is below a livable wage that it doesn't pay to take the job because by the time I pay for gas to get here they are working for like $5.00 an hour. I don't know who can live on $5.00 an hour, can you?

Francis, Deforest

Sometimes the caregiver must work extra hours to cover for absences. Because caregivers are not adequately compensated for their work, there are vacant positions. This results in fatigue and stress for the staff who are working.

Deb, Franklin

My 3-year-old granddaughter needs round-the-clock care due to a disability. She has an in-home RN just over 20 hours a week. Her parents are always “on-duty”. My daughter has been forced to put her career on-hold indefinitely, so they need to rely on only one paycheck. Between monetary pressures and their daughter’s thrice-weekly medical/PT appointments, stress is taking its toll physically, mentally and emotionally.

Maria, Freedom

We experienced scheduling difficulties and high turnover of caregivers after we started home companionship care January 2021. Caregivers either didn't arrive on the expected date/time or arrived on an unexpected/date time.   There was a different care giver every week, or even a different caregiver for each of the two days of care each week.   This high turnover confused my family member who needs the care and created extra stress for me as each time I had to explain our needs and schedule.

Debra, Fond du Lac

My daughter hires university students as aides. During the Covid shutdown, she moved back home with us because aides were not available. Before going back, we had to post and hire new staff. People make more stacking shelves at Walmart than caretakers make, caring for our most needy.

Jayne, Glendale

As a single parent to a son who graduated high school in 2019, the pandemic has hit hard. I had worked tirelessly to create a schedule for him that involved a variety of people who kept him engaged and learning small steps to independence. We had just found a great combination of activities and people when the pandemic hit. Once fall hit I was so grateful for the ten hours a week I was getting in respite from a college student. After a few months, my son made it clear that he was bored with the lack of variety. His behaviors increased dramatically. I've been the victim of his aggression time and again. I had to let the one employee go as it wasn't fair to her to be greeted with aggressive behavior. It was not safe to keep her. I am exhausted and burned out of ideas. I have a major surgery coming up in a few weeks. I am frantically reaching out to find new caregivers and piece together some type of team. This pandemic has taken our crisis level to an all-time high. We need training and funds and better wages to provide safe, effective care for our family members. We must do better by families like mine.

Kim, Grafton

Lack of caregivers means that family members take on more of the care. This results in less work time for family members.

Cheri, Green Bay

I have hired family to do cares for my son due to being unable to find care providers. We are all now working for my son at very low wages and cannot afford many things due to loss of wages from jobs we needed to quit to provide his care. McDonald's workers make better money, serving fast food than those who provide care to the

Cheri, Green Bay, cont.

elderly and disabled. We cannot get the discounts afforded to other healthcare workers due to working in private homes. The IRIS program needs to provide identification to all workers .We work just as hard , if not harder than hospital, clinic and nursing home workers due to no backups. And have taken the same risks and not gotten pay for it. With unemployment what it is now, nobody will work for what we can pay them. We need a living wage(equal compensation) to those who work at facilities.

Cindi, Greenfield

A care worker contracted Covid in November. He exposed me, my family and both of my primary nurses. We were told we all had to quarantine for 14 days while the Covid + had to isolate for 14 days. so, during the 14 days, I had NO nursing services. Just one live in caretaker and myself. She is not able to bill any hours as it "exceeds my budget" There is a VERY real problem with the lack of flexibility and care coordination (especially with the pandemic) between Forward Health Private Duty Nursing and IRIS. PDN is FLEXIBLE in daily hours where IRIS plan is NOT. I require 24 hours a day full cares.   This lack of flexibility by the IRIS program is NOT acceptable. My staff has had to go without pay as hours exceed budget when nurses (different funding source) are not present.

Justin, Greenfield

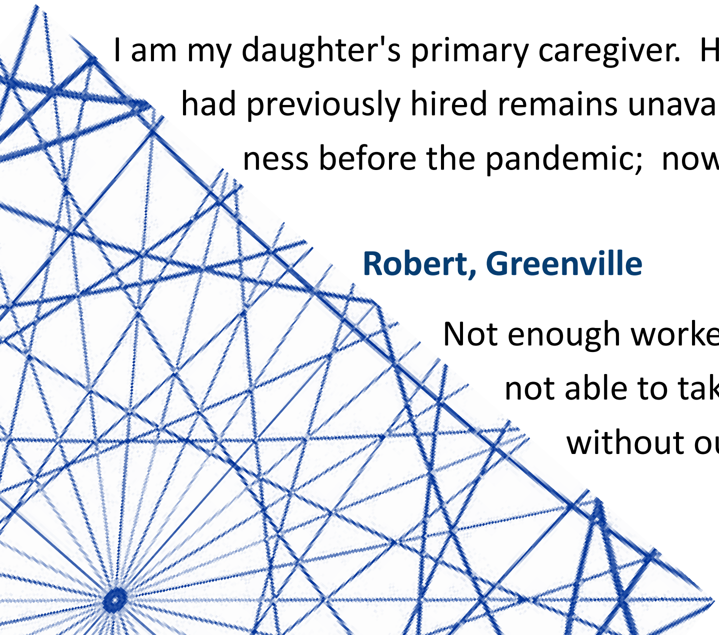
Long waits for in home therapies and the long waiting lists for other services.

Tamara, Greenfield

I am my daughter's primary caregiver. Her day program is now done by me, as the person I had previously hired remains unavailable due to Covid concerns. I had had my own business before the pandemic; now I care for my daughter full-time.

Robert, Greenville

Not enough workers available to help our daughter, therefore we are not able to take care of ourselves. We are supporting our daughter without outside help as none is available.



Dawn, Holmen

We are just getting started with services through the Children's waiver program for our son. He needs to develop a relationship with someone who will be consistent and able to meet his needs. Due to the low wages, and the intensity of the work, people are not interested in becoming caregivers. Who wants to deal with a child who has the potential to be physically aggressive when they are only getting paid $9/hr.? They could do better working at Walmart or McDonalds without the stress and physical injuries…. The caregivers live in poverty, and most are unable to afford the healthcare options their employers offer so they end up on Medicaid. They have no paid sick time or vacation time, and do not get any retirement benefits. Residential service and homecare agencies have a very difficult time recruiting quality employees. This results in people with disabilities going without and dealing with poor quality care…..

Linda, Jackson

First, there is a shortage of caregivers & workers DO NOT stay...they find other jobs that pay more. So, we are constantly advertising, hiring & then losing them.

Dawn, Janesville

I am a caregiver for my husband, he cannot be left alone for any length of time as he has a history of falling. He will only leave the house to go to the Doctor appointments he has. He does not want anyone to come and sit with him while I run errands, so I have to hurry and do it while he takes a nap.

Sharon, Lake Mills

I am an older caregiver of my adult son who has a developmental disability. It is very difficult to find respite services for my son in our area. There are limited choices.   It is difficult to leave my son in the care of some provider that I do not know anything about. I have not had a break for well over a year due to the pandemic. The last time I had a break in March of 2020, the provider called me in Florida to tell me my son had gotten ill, and I should probably return home from Florida ASAP. She did not know what to do with him. What a vacation that was!! My son usually never gets sick, and the respite person did not know what to do. Also, it was just when the pandemic started, and his doctor did not want him to go to the emergency room for observation. The doctor felt that the emergency room visit might cause other problems due to Covid-19 being so contagious.   Luckily, he got better the next day, and I had a couple more vacation days in Florida before heading home before the pandemic hit Wisconsin. I usually get one respite break a year.   Also, it is difficult to find quality adult family homes for future living placements. The caregivers and respite providers need to be paid a decent wage with some benefits. Thanks for helping the people with disabilities and trying to correct this caregiver crisis.

Carrie, Madison

This begins with Covid and assisted living program. We were told we could not provide care for our family member for one week, due to Covid situations. During that time, the staff were overburden, and the program was understaffed. This resulted in neglect of care. The unfortunate reality was the neglect was 7 days and caused enough trauma that was irreversible, and my family member died. We knew there was neglect because the food cartons were not opened for 7 days and upon our arrival, she had not been showered for several days and was in soiled clothes.

Janet, Madison

My nephew (nonverbal/low functioning/needs 24/7 care) has been at St. Coletta's for 15 years.   Finding nurses' aides/caregivers/direct support professionals to care for the disabled/ elderly has always been challenge but not it is near impossible due to Wisconsin's Medicaid hourly wage cap.   Nursing homes and disabled facilities have gone out of business due to the lack of state help.   Please remember the disabled/elderly in the state budget!

Patricia, Middleton

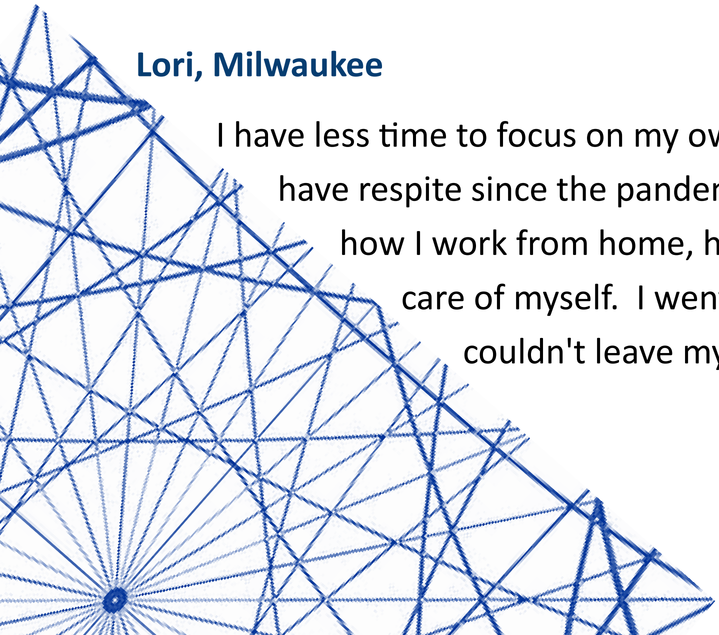
I am able to remain at home with a spouse--given assistance from caregivers---especially during the Pandemic or C-19 when there were so many restrictions for interaction--with the outside world--particularly if one were in NH/AL. Caregivers wore PPE and double masks and first to get vaccines--saved lots of money by being at home and not in hospital or formal care center. I am stressed that our Private PC workers are paid less than $15.00 an hr. and especially for eves., weekends, and during C-19 pandemic!

Beth, Middleton

The overall stress of our entire family has increased since the lock downs. I had to significantly cut my work hours to take care and teach my son. Respite workers stopped coming due to COVID. My son has shown significantly more difficult behaviors due to lack of school and a consistent schedule. I'm often exhausted due to having to work after my son goes to bed at night and waking up before he wakes up in the morning. Due to the low pay of respite workers, we have a hard time keeping them or even hiring them.

Lori, Milwaukee

I have less time to focus on my own health and priorities. I have rarely been able to have respite since the pandemic began (only 2 times in over a year). This impacts how I work from home, how I take care of my kids, and how I am able to take care of myself. I went a whole year before seeing a dentist, because I couldn't leave my kids alone by themselves as one has medical needs.



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Marie Isabel, Milwaukee

The crisis has not had a direct impact on us, but in our friends at CURATIVE adult program. Their salaries are too low for their responsibilities and hard work. It is hard to have quality day programs for adults because the pay is not appropriated.   Another problem of the crisis is the lack of consistency in support staff. My daughter had five coaches in her first year of work. That was frustrated for her because she needed to adjust to different personalities while working, as parents we never knew who to contact. Recently, it took four months to get a job coach approved by IRIS.

Pat, Milwaukee

My daughter who has severe Autism has a lot of difficulty when she cannot continue with her routine activity because there's no one to take her. It takes time away from us as parents to do our work because she is home and she needs a lot of support and hands on assistance, but no available caregivers.

Ashley, New Berlin

Our daughter is 3 years old. I left my job to care for her. We have tried to find PDN to help, but they are hard to find. The state is now sitting on our case renewal so our PDN is working without guaranteed pay. Our daughter uses a ventilator and is fed by g tube. She is completely reliant on caregiver help and needs full assistance for transfers.

Penny, Montford

Even in times of health crisis, there are all of these hoops to jump through to get the medical treatment, equipment, etc. that it is a full-time job just keeping up with all of that.

Candice, Neenah

Due to Covid and no respite or ability to have a break from caregiving having to provide care to my disabled special needs guy 24/7 has a very substantial effect on my own health that may preclude me from providing the services he needs. This will cost State more to move him into a Nursing facility...

Mary Ann, New Glarus

I have had to quit full time employment as an attorney to care for a child (and now adult) with autism. This was very disappointing to me, as I worked hard to obtain seven years of post-high school graduation and loved my job. Even at the age of 28 with my daughter now living in her own apartment, I still work 32 hours/week to provide her direct care. This would not be the case if there were adequately trained and paid direct support professionals in my area. This is especially problematic in rural Wisconsin.

Kerry, Oshkosh

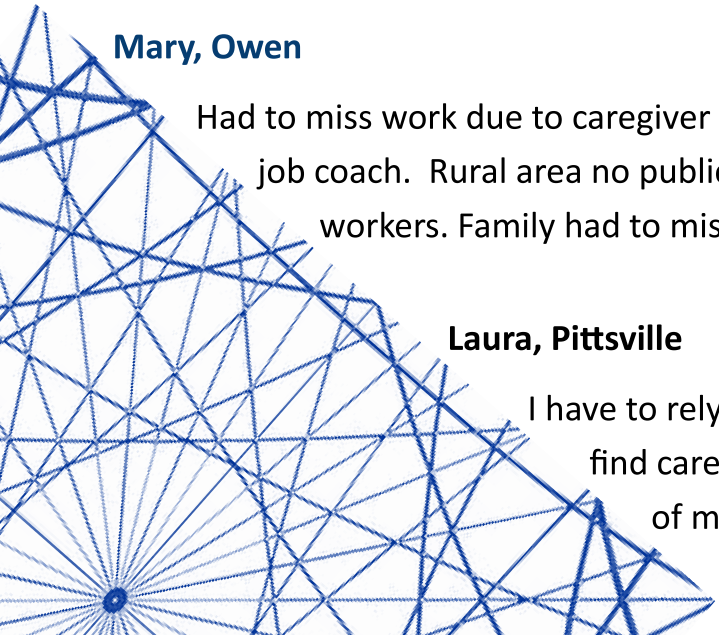
We supplement the rate provided by the CLTS program to attract quality workers to ensure consistent workers. However, it's still a struggle to find quality workers who we can entrust with our vulnerable son.

Mary, Owen

Had to miss work due to caregiver issues. Could not work due to no transportation and job coach. Rural area no public transportation. Pay is too low. No healthcare for workers. Family had to miss work too.

Laura, Pittsville

I have to rely on my family to care for me. Extremely difficult to find caregivers that I can trust and that can lift me in and out of my wheelchair.



Virginia, Pleasant Prairie

We have been unable to find enough supportive home care workers. Our son is required to have a 1:1 at his day program and is unable to attend if we do not have a worker. He has missed many days there resulting in reduced physical activity.

Amanda, Prairie Du Chein

I was and still am unable to find available nursing or even respite care assistance for my toddler Son/Myself. I resigned from my full time/ great benefits employer to be a fulltime in-home caregiver when he was diagnosed so he could stay at home. We live off of state assistance. It has impacted our ability to receive necessary items for him due to denials. We live on very little money each month and I am not provided any caretaker funds because of his age. Simple things like new furniture or a new bed for him, car repairs or even taking him on a small vacation are virtually impossible.

Linda, Racine

My disabled son lives in an adult residential group home. He needs trained staff to properly care for his needs. At times the care is a problem because of untrained staff. There is a need for higher pay for these workers so that the care my son gets is appropriate and professional.

Beth, Rhinelander

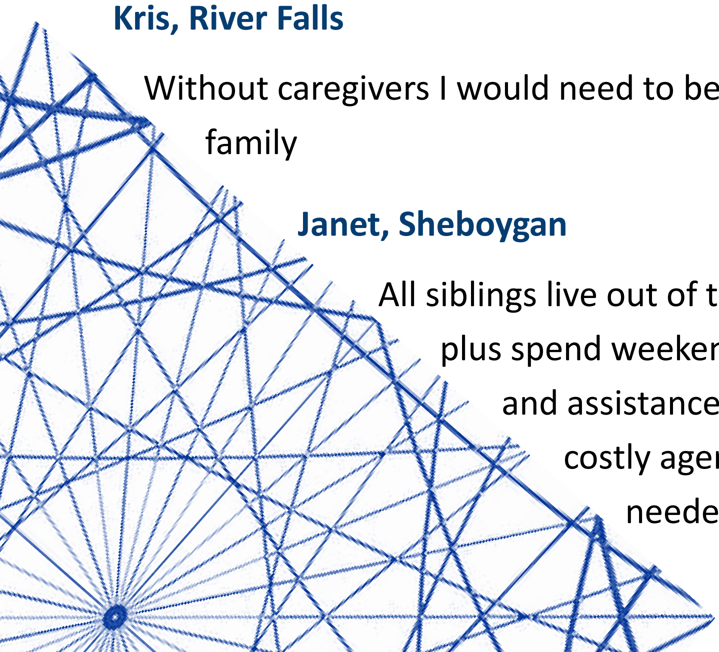
There are no care givers in our area.

Kris, River Falls

Without caregivers I would need to be in a group home and want to stay in home with family

Janet, Sheboygan

All siblings live out of town. Have had to use PTO and FML time from work plus spend weekend time splitting staying up at night to ensure safety and assistance for elderly parent after stroke. Have hired some costly agency staff but there is not enough agency staff to cover needed 3rd shift hours so family must do so in addition



Janet, Sheboygan, cont.

to the day shift hours we cover. Too costly to use agency then, plus unsure they have the staffing to do so anyway. Providing this ongoing coverage is stressful for all.

Jane, St. Francis

Family needs to closely monitor caregivers hired to ensure my son is safe and not abused.

Nancy, Shawano

My home is funded by Family Care. Because the funding is low my caregivers are paid very little. This makes it extremely difficult to find and retain good caregivers.

Nanette, Sturgeon Bay

We are senior citizens (70s) and Guardians of our 30 yr. old daughter. As our own health starts to fail, we've been concerned about keeping her in her apartment when we can't continue to help her. We've tried to make her less dependent on us and provide supports she'll need for when we are gone or incapacitated. She had 3 providers and we mainly had to take her home on the weekends while looking for more workers. We esp. can't find workers for Sundays. When Covid hit, 2 of our workers decided to stay home and we have had to provide even more hour for her in spite of being told we should stay home and have our own groceries delivered, due to our age. We simply cannot find enough providers and have been running to town even more than ever. Agencies do not have workers to provide, and we were told if she needs that much supervision, she'd probably end up in a group home. There is none in our community, so she'd be uprooted from everyone she knows and need to be in a strange town away from any friends and relatives. She'd also hate having to live with other people . Besides the need to fill in for the lost providers, when the only provider she has left ends up sick or has car trouble etc. we have to drop everything to run into town by my daughter. I don't know how much longer we can continue, but we have no other options.

Deb, Stoughton

During Covid restrictions I have had to let my son’s caregivers go to keep him safe. As the sole income in our home, I needed to reduce my employment hours in order to keep up with his care. We sold his business which means his employment support was canceled. When investigating supported care, we found many supported care agencies will not care for individuals with a g-tube and g-tube feeding. Now that we are both vaccinated caregivers are extremely hard to find. I need to go back to work in order manage our household expenses.

Danielle, Stoughton

very very difficult to find people to take on respite for a very medically complex child, same with private duty nurses because the pay is just not enough.

Kristen, South Milwaukee

My daughter has had difficulty finding transportation, so it impacts her ability to arrive at work on time.

Kathleen, Verona

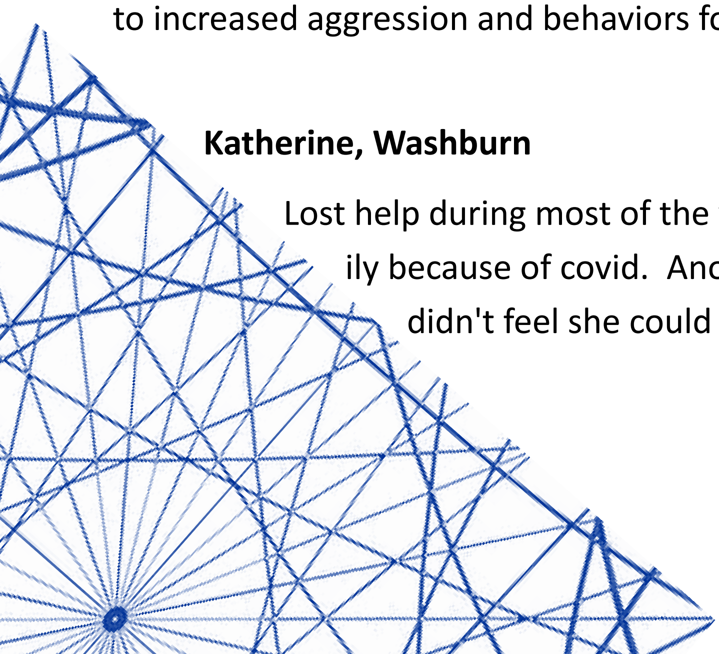
I am not able to work because I cannot leave my son 19 yrs. old alone all day.

Sheila, Verona

Lack of quality care givers has really affected the quality of life for my loved one. This has led to increased aggression and behaviors for my child.

Katherine, Washburn

Lost help during most of the year. One caregiver felt the need to isolate with family because of covid. Another's partner is a long-distance trucker and so she didn't feel she could provide safe care.



Sheryl, Waukesha

We felt a move into a group home was necessary. We ended up with only one choice of provider homes with one spot open, as most all were filled due to a lack of homes and openings because if fewer residents moving out due to COVID19. The home has violations of a bedroom window that was painted shut and does not open. They are also not conducting the 30 day individual services plan meeting within the legal 30 day timeframe. The staff that were offered to come to our home last summer we're driving without drivers car insurance and the agency was supposed to assign employees who could drive my family member in the community.   The pay is so low that the quality of employees is very low.

Emily, Wauwatosa

I have two boys that require significant care. I cannot find qualified caregivers that are willing to stay for a long period of time. Also, they do not really understand the impact of them not showing up to work on time, doing quality work, etc.

Barb, West Bend

Not having staff to cover daily needs of my son.

Kathy, WI Rapids

I am looking for a home for my sister Joyce (age 54) and struggling to find one with the appropriate cares she needs. It is difficult to find an AFH in our area. And many homes have to few trained staff and her cares have increased as she ages due to her Cerebral Palsy.   I also work at a PreVoc facility in central Wisconsin, and I see how understaff the homes in the area are. And those that do stay at a job because they care are very overworked due to under staffing and under pay.   It truly is at crisis levels!!

Stoies from People with a Disabilities

Jordan, Auburndale

Hello, it’s important to me because I need help with all my cares, and I am just really worried.

Christi, Green Bay

Have to have a lesser quality of life and use more emotional, mental and physical energy on trying to get basics dine so can't get other things moving forward.

that in a couple years so. that’s why it’s important to support personal care in the budget.

Neil, Janesville

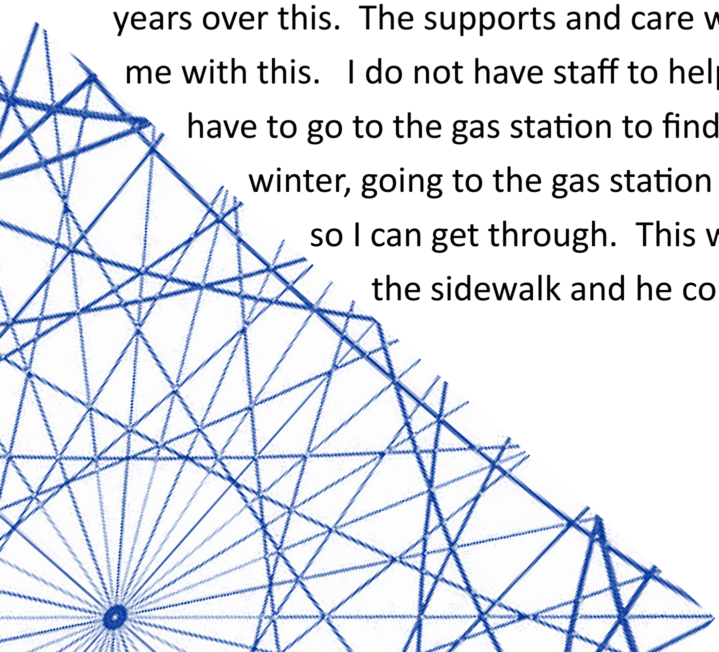
My aging parents have had to take over some of the tasks I need to have done by a care giver.

Ben, Madison

I have no personal care on the weekend so I need to go back to my parent’s home so they can support me.

Kristina, Madison

I have not had the care to allow me to do the things that would give me better health. I would like to go to swim therapy and have been trying to work with my support people for 2 years over this. The supports and care workers do not have enough time or people to help me with this. I do not have staff to help me prep for mealtimes at all meals. These meals, I have to go to the gas station to find something to eat. But I'm in a wheelchair- so in the winter, going to the gas station is almost impossible if the sidewalks aren't shoveled so I can get through. This winter, I got hit by a car because I couldn't get onto the sidewalk and he couldn't see me.



Steven, Madison

I'm an author with severe cerebral palsy living in a group home. My care agency can't find enough care attendants to cover all of the shifts for my two roommates and me. At times we are left alone. My case manager has to work a double often. I don't get a shower sometimes. I'm writing my tenth manuscript about a boy with CP, during the pandemic for my literary agent. I write a newsletter for my agency. I need a staff to write. If I can't write, I will commit suicide. I'm an asset for society who deserves the best care.

Teresa, Madison

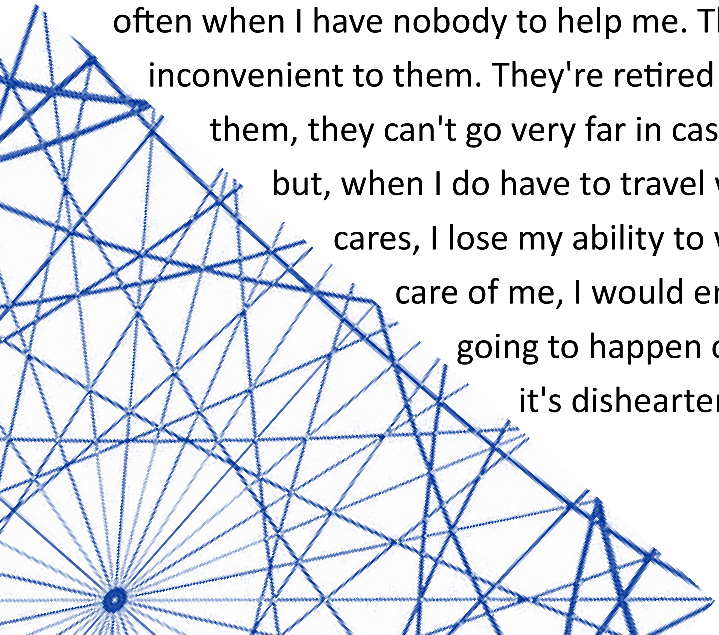
I have been assaulted 2 times by 2 different caregivers from the same agency in a 5-week period of time. I found out later that there is no clear path of protection for us, the person with the disability. It’s criminal that out state is providing funding and multiple contract opportunities to just about anyone.

Timothy, Madison

I am 33 and need 24/7 care. My 65-year-old mom had to quit her job to work for me full time. I don't know what will happen when she no longer is able to be here for me.

Stacy, Oshkosh

Well, I'll share it again. It's the same story. I'm always struggling to fill my shifts. I've slept in my chair, not been able to use the restroom, and skipped meals multiple times because I couldn't find workers. I'm fortunate that my parents are still able to take care of me and do so often when I have nobody to help me. This not only is an inconvenience to me, but it's also inconvenient to them. They're retired and want and deserve to travel, but, unless I'm with them, they can't go very far in case I need help. And, not to add another layer to this, but, when I do have to travel with them or go to their house because I don't have cares, I lose my ability to work. That said, I know if they weren't able to take care of me, I would end up in a facility (I'm fully aware that it's probably going to happen one day when they're no longer able to care for me--it's disheartening, but that's the reality I live with).



Stacy, Oshkosh, cont.

For me, being able to work gives me purpose in life. It's good for my mental health. When I have caregivers problems, it truly affects everything in my life!

Colleen, Racine

It has impacted me terribly. Finding good quality workers is very hard. The ones I'm dealing with currently come when they feel like it. I've had to cancel drs appointments cancel grocery pick up orders I could keep going but this will do.

Gary, Racine

There were several times over the past year when I was unable to find workers to come into my home and assist me with daily living. This worries me for future.

Erica, Milwaukee

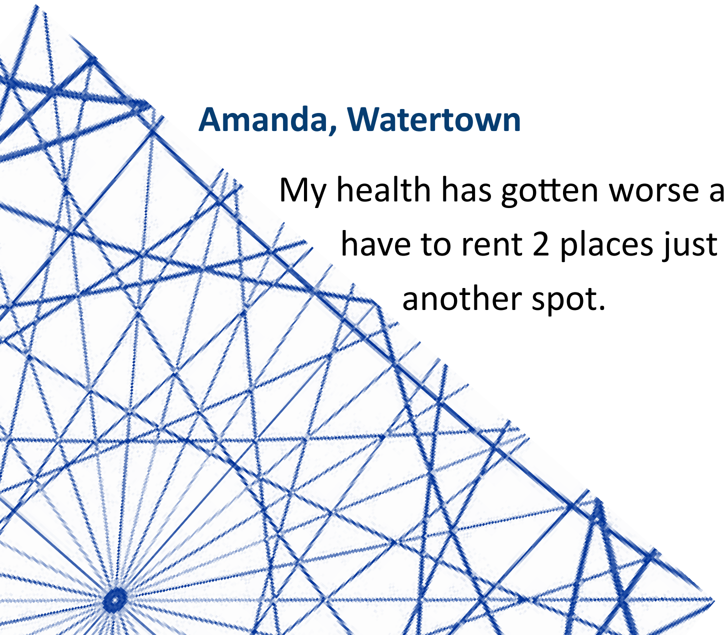
With COVID, I stopped having outside caregivers coming in. My boyfriend that I live with was my only caregiver. I get 24/7 care. I am now trying to bring back caregivers, but I am struggling to find applicants. There are very few people out there. Because of the low wages and no health insurance, the few people looking for work don't want this job. My boyfriend would like a break, but he isn't getting much of one, since I can't find workers.

Jeff, Plover

It got so hard to find good help, and I had to move back with my parents, and it is difficult for them to help me too, do their ages.

Amanda, Watertown

My health has gotten worse and lack of accessible housing in rural areas is bad. I have to rent 2 places just to get what I need for cares and my family in another spot.



Emily, Wauwatosa

Transition from an educational institution to work or further education has been very stressful due to lack of resources, especially with COVID19 related limitations. Our student functioned well with support & in person learning, struggled during virtual learning and is now struggling to find their way after graduation... We have another student with a physical disability, who has encountered different but equally stressful challenges, which has been very overwhelming for them and the parents. It has caused stress in our family. Parents are health care professionals/have health care background, so are supporting and caring for many, but there is much increased stress from work and supporting family with disabilities during COVID19 without all of the usual support. It has taken a toll on physical and mental health.

Stories from Providers of In-Home Supports

Ann, Sturdevant

Two of my newest referrals had a very difficult time finding caregivers, which slows the enrollment process for IRIS. One is still looking for a caregiver which puts his health and safety at risk.

Becky, Brookfield

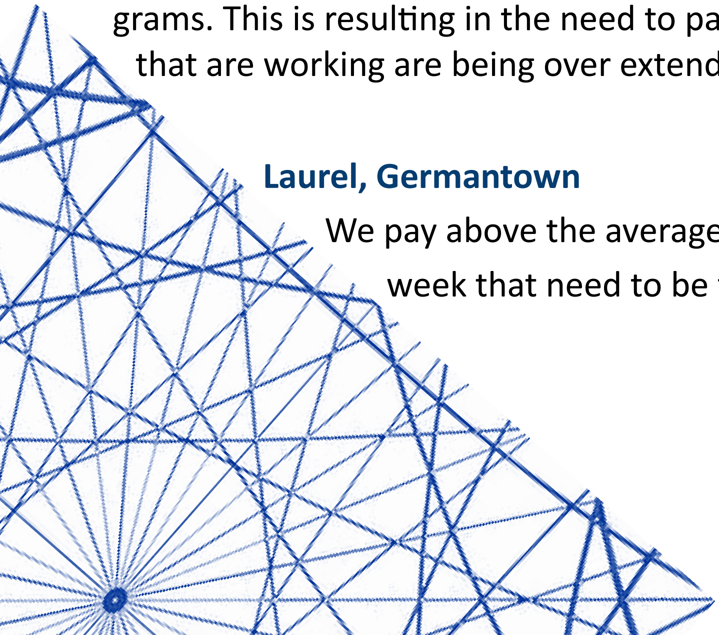
The ability to maintain caregivers and find qualified caregivers have had an impact on Iris participants mental health.

Kris, Germantown

Our current employees are needing to pick up many extra shifts to be able to staff our programs. This is resulting in the need to pay an usual and difficult amount of overtime. Staff that are working are being over extended due to the lack of staff available.

Laurel, Germantown

We pay above the average starting pay but still have 100+ hours open every week that need to be filled, resulting in high overtime costs.



Peg, Hudson

As a leader of a direct care agency it is really difficult to hire workers to help assist people in their homes. The reimbursement rate is so low that we can’t attract applicants.

Russell, Little Saumico

As a manager of direct care, less home time with the lack of workers. I had moved the first weekend in October and finally finished the move in mid January. Know it is the end of April and nothing really has been put away as i fill shift and trying to stay on top of my own job duties also.

Thomas, New Berlin

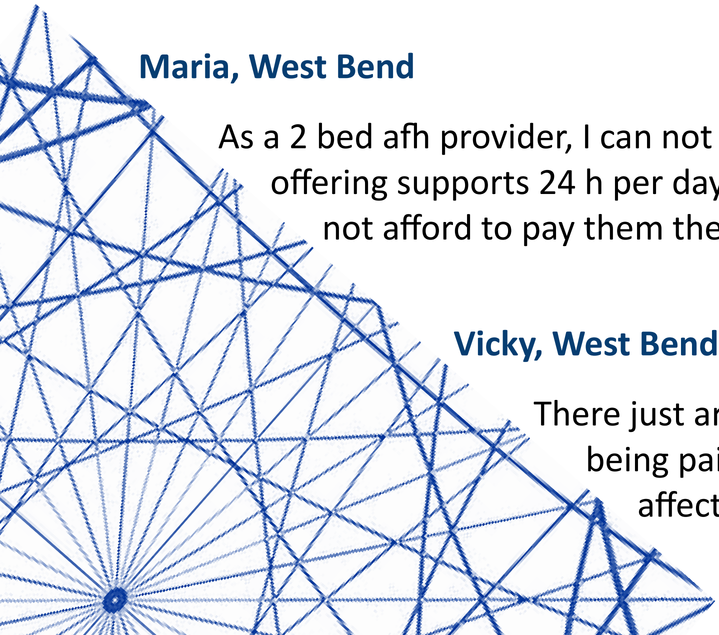
We have not been able to attract, retain and train competent caregivers. This creates more stress on the system as few caregivers are working more hours/OT to cover the vacancies. Folks have had to tolerate less the adequate care staff for fear that if they terminate staff, they will not be able to fill the vacancy. Our vulnerable population deserves quality caregivers, not just any willing person to work with them.

Lindsey, Waukesha

If we have a managed care organization they pay very little leaving the family short handed. Care giver shortage is because of managed care organizations being greedy.

Alisa, Wauwatosa

Because we are not able to find enough caregivers, the individuals I support are not able to access all of the community activities they have previously participated in.



Maria, West Bend

As a 2 bed afh provider, I can not find anyone to provide respite care for me. I am offering supports 24 h per day, 365 days per year. Even if I can find someone, I can not afford to pay them the hourly rate they want.

Vicky, West Bend

There just aren’t enough caregivers willing to work for the wages being paid. Those that are working, are overworked. It is affecting their families and their mental health.

Here’s what families with children with disabilities want you to know:

From Family Members Supporting Somebody with a Disability

Shannon, Appleton

My daughter Trinity has Down syndrome. She receives a total of 60 minutes a week for speech. Which is not enough considering how significant her speech delay is. Only option is to have her see a private speech therapist outside of business hours. Going to school is tiring enough for her. I feel part of her curriculum should include extra speech. Yet it can not be written into her IEP. The max is 60 minutes. Takes her more attempts to remember things. Budget does not have money for this. Yet children with other disabilities get more help. I feel this is because as adults they are contributing more to society. My daughter is not give an equal education. This cycle keeps continuing. Down syndrome is at the awareness stage. There is much more to be learned about her disability. Yes I understand that she will go to school past the age of eighteen. At 18 her brain will be more developed. New things will be harder to learn.

Juliet, Beloit

It takes sometimes a very long time to have accurate answers about specific things when teh law should be applied. It also takes asking too many people because they say that is not their department.

Sara, Cambridge

I can’t answer this in the 3 minutes mentioned. I can say that without my own knowledge of services from working in the field we would be much worse off. I can go to the county CLTS worker for help but I have to call for any doctor or therapist to assess or change treatment goals. Many providers have no clue the life we live.

Joy, Chippewa Falls

We were not aware of a children’s waiver in our area until my son was nearly 18 years of age. This service could have provided much needed respite, support, and financial help.

Connie, Deerfield

Speech is the area where my daughter has the most delays. She needs weekly therapy. Insurance would only approve a few sessions at a time and because of how far out her therapist was booked, we could get a few sessions and then have to wait 2 months until the next one. Now insurance has denied any speech referral bc they are saying she isn’t making progress despite her therapists letter of support that had numeric measurements of progress. We just lost the appeal so now what? Coverage by MA also is not a given bc of the areas she needs help w are also covered by school. Not sure what to do next

Gracie, Eau Claire

You can't use services and programs if you don't know about them.

John, Fennimore

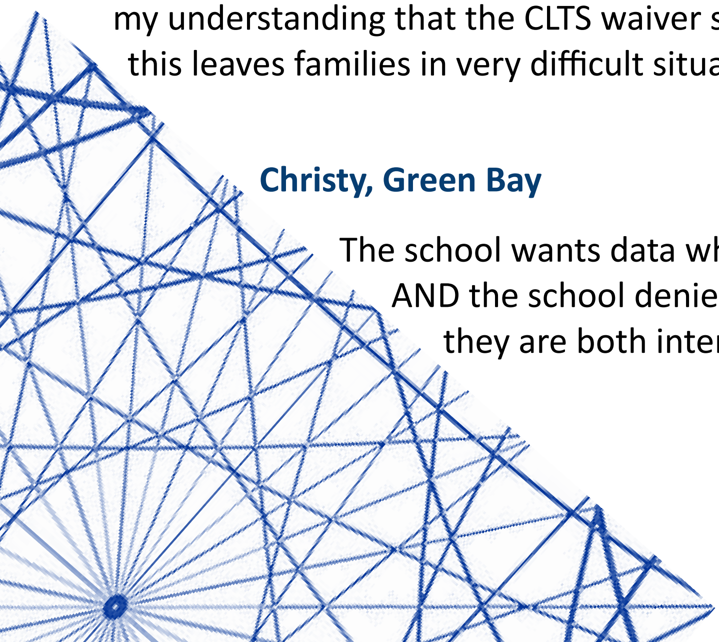
My son’s academic progress was slowed or stopped when schools were closed. Special education was extremely difficult to do with the virtual learning format.

Nancy, Glendale

We applied for the CLTS waiver and the Katie Beckett program for our son in October 2020. It was not until March 2021 that he was found eligible for Katie Beckett and April to begin on the CLTS waiver. His Long-term care screen showed functional eligibility back in October at the time of the screening. I have been unable to work outside the home because of our son's support needs and the pandemic/virtual learning needs. One of our son's 5 medications cost $275 per month even with my husband's insurance from work and a coupon. We had a psychologist that we wanted to increase services with who is in the Medicaid provider network for CLTS but these supports were delayed and limited while we waited for the waiver. It is my understanding that the CLTS waiver should not have a waiting list but kids are waiting and this leaves families in very difficult situations.

Christy, Green Bay

The school wants data which is nearly impossible to obtain wjhile she is virtual AND the school denies connection between home and school to see how they are both intertwined in her mind and that affects her behavior



Denice, Greenfield

When our visually impaired child was in 3rd grade, there was lack of an Orientation and Mobility Teacher for 5-6months. There was none available through CESA 1 at the time. We ended up sending her to a short-term, week-long, program at the WI School for the Blind to work extensively with an Orientation and Mobility teacher there to "make up" for loss of services. This was fine, but our daughter was missing out on the training in her own community where she traveled daily. When our special needs daughter was in 10th grade, we started the job development process with DVR. We worked with Curative for several months and then they stopped doing job development. We then started over with with Easter Seals job development. Then Easter Seals stopped doing job development. Then we started over with a very small company. This job developer was very inexperienced and did not do much for our daughter. Then that person quit and we started over with another small company for job development. Because of the turn over in job development providers, our daughter lost a lot of opportunities for temporary work experiences over a 2-3 year period.

Robert, Greenville

My child was hospitalized for suicide thoughts. Hospital called us and said insurance was not going to pay anymore however when we called insurance it turns out the hospital did not request more time. Insurance was not the problem the hospital was.

Dawn, Holmen

Starting the process to access services for Children is very difficult because there is no central location to get information. The Aging and Disability Resource Center only serves adults with disabilities and the elderly. It would be incredibly beneficial to have a similar resource for children. In order to get my son access to the Children's Waiver and Medicaid, we had to call multiple agencies (The Parenting Place, Compass Wisconsin, La Crosse County, WREA) numerous times before we were able to get things moving. We started the process in December, 2020 and we first met with the case manager last week (4/23/21). I'm a social worker with a lot of familiarity of the systems, so I believe our case went much more quickly and smoothly than others might. We are still waiting on Katie Beckett eligibility and Medicaid through the waiver program. I anticipate it will take a few more months before we get an answer. For families with children needing intensive services as soon as possible, this process takes too long. I have heard over and over again from families who are desperate for help but don't know what is available or how to access services. They will frequently go without because they don't know what to do. Medical providers are not helpful because they basically know nothing about how to help families get services. I know this because I work in a

Dawn, Holmen, cont.

large medical center and hear providers say they don't know what to do, or they tell families incorrect information, sometimes giving them false hope. This is incredibly unfortunate and unnecessary.

Christina, Janesville

Took time away from work to find options for my son

Ela, Lancaster

I was not talking my son to in patient therapies because I was not aware that I could with different goal and my son has been only receiving 20 minutes session of PT once a week.

Amy, Madison

There are many resources in the Madison area but connecting to them has been difficult or knowing what the differences or similarities are to figure out how to make choices is time consuming and confusing. The different organizations don't seem to know about one another to help point us to what will be a good fit. Our son turned 18 last June. We were directed to start searching for services to start transitioning to adult services last spring. It took 9 months to get an official diagnosis, to go through all the assessments and interviews and start working with new adult services. During that time our son's mental health deteriorated and he ended up being hospitalized inpatient 3 times and in jail 3 times. He was "helped" by multiple doctors and therapists and social workers who rarely consulted with each other and all tried different things with medications and programs. They kept him safe, but it also felt like such a waste of time and money. Collaborating with his primary doctors could have made things go much smoother and possibly he could have found relief sooner. When schools closed because of covid I had to quit my part time job, which was all I could work due to the strain of my son's need for shortened school days and multiple appointments with therapists and doctors. I had to quit that job to stay home with him. I tried to work more evenings, but that was too hard. A coworker mentioned a friend who was able to receive caregiver wages through the county, so I asked my son's caseworker about this. Again it took several months before I was approved and couple more months before I actually received the first payments. It has made a big difference in our ability to have some stability and less stress as a family, not to have to work so hard to keep a tight budget. We are great full.

Loretta, Marshfield

Our son has a genetic disorder, autism, and severe intellectual disabilities and needs one on-one therapy. In person school is not safe, virtual education does not work and is not even an option. Only one therapist consulted with us throughout the last year. Either my husband or I need to be home with him since we do not have a child care option and we have had to miss work and care for him without any outside support.

Lori, Milwaukee

When my child had a very serious breakdown and needed a crisis stabilizer, the service was overwhelmed and we were not able to have someone respond. It is now May and we are still on the wait list for a crisis stabilizer-her breakdown was in January 2021. If my child can not cope with daily stressors, she can not be receptive to learning in the classroom.

Mary, Milwaukee

Confusion about whether Medicaid services would be continued during COVID due to loss of job etc.

Rachel, Milwaukee

We've had our severely disabled daughter home for most of the past school year. It has greatly affected the functioning of our family as having a respite care worker is ineffective in our home due to lack of space. It was exhausting and cumbersome to care for her 24/7 without a break.

Dan. Mukwonago

Systems to apply for resources are so complicated. So much paperwork- lots of social workers-few actual services/resources

Ashley, New Belin

We have spent the better part of three years "getting by". I have left my career and my husband uses every moment of vacation and leave for my daughter's needs. We have very little community support and any equipment we need (other than big insurance items like a power chair) have been funded through family's help.

Tracey, New Berlin

My son has struggled for years with ADHD, Anxiety and we just received a diagnosis of Autism. In school, due to lack of understanding of mental health issues my son became withdrawn, angry and depressed. School has dismissed our requests for assistance for years until the pandemic. During the pandemic, the stress of school was off of him and he became the child he used to be, however, academically he really struggled. He failed all of his classes, our school was open so we sent him back on an amended schedule. We have finally advocated enough where the school is helping him and that is being reflected in his IEP. At 14,He still does not have the skills that would be required for a job, but he is working on that little by little. Schools need a better understanding of mental health issues and ways to support students instead of punishing them for things they cannot help. I truly believe that if we had not fought as hard as we did, we would have not received the support for our son that he needed. As terrible as the pandemic is, it has got others thinking about alternative ways to educate students.

Heather, Oak Creek

My child did not have services to access healthcare, therapies, special services to help socialization, cost of services may have been covered as we have private insurance and may qualify for more. I would never know if financial help was available as I don't know what I am missing for a mother of a child with a disability. Financial burden is high, burnout is high, respite is not available, work is unmanageable with all the extra needs and therapies. We have stopped going due to cost and time constraints. There is no one to help. It's just me alone all the time and can't meet all of my child's needs all the time. It effects me personally and my other children as I have to prioritize one child's needs over another. Physically. academically, financially, emotionally, and behaviorally. It is difficult to sustain the family but was worse this last year due to the pandemic. The quarantines have been challenging too! I am concerned with my child's safety in returning as there is a medical disability too!

Kerry, Oshkosh

Our child would have qualified for birth to three sooner, if we had known. Also, we could have been using our CLTS waiver program could have supported childcare needs earlier, had we known. It's about not knowing the questions that we don't know to ask.

Scott, St. Croix Falls

Our 3 year old has significant needs across a broad area - we are very good advocates for her, but it is still difficult. without the knowledge we already had it would have been more difficult to make the progress our 3 year has made

Kristen, South Milwaukee

My daughter's school stated over and over they did not know what to do with my daughter. What does that mean?

Wendy, South Milwaukee

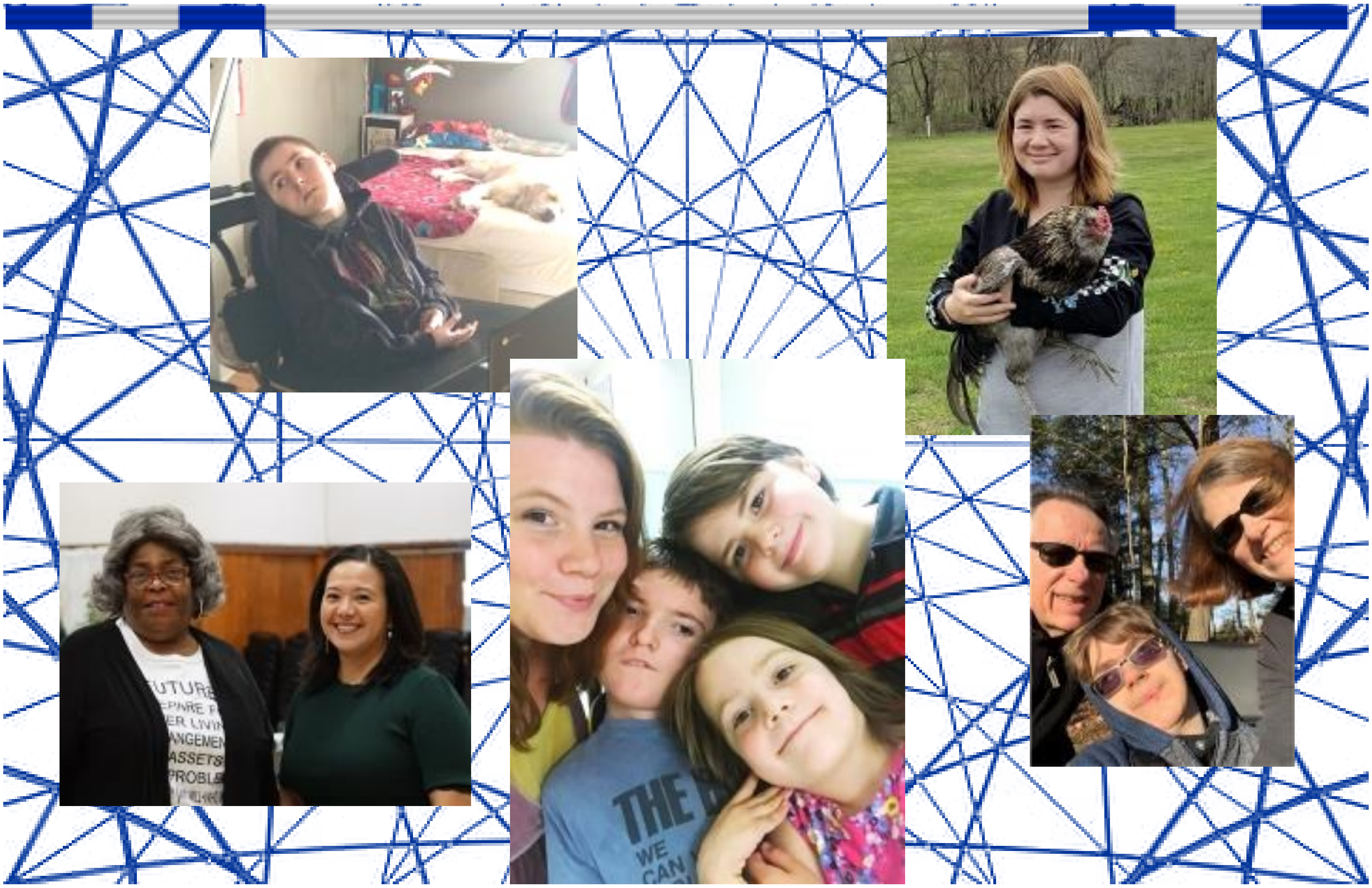
I was told that my son qualified for incontinence supplies and when I finally found a place that would work with me they said he only qualified for diapers even though he's required to be in a pull up for school. He is 7 will and there are other kids his age younger and older that do get provided pull ups. Also our district was virtual from March 2020 until January 2021. I did the best I could trying to help him learn things at home from activities his teacher and therapists gave me during virtual learning but I'm not a trained professional so there is very much regression. Now that he is back in school I believe there needs to be more staffing to help him but admin is resistant. My son qualifies for a one on one aide but the district doesn't allow that language in his IEP'.

Amanda, Watertown

My daughter had to change schools due to lack of support and now is struggling even more.

Emily, Wauwatosa

Transition from an educational institution to work or further education has been very stressful due to lack of resources, especially with COVID19 related limitations. Our student functioned well with support & in person learning, struggled during virtual learning and is now struggling to find their way after graduation. It has been very stressful for the entire family, especially the student & main support person/mother. We have another student with a physical disability, who has encountered different but equally stressful challenges, which has been very overwhelming for them and the parents. It has caused stress in our family. Parents are health care professionals/ have health care background, so are supporting and caring for many, but there is much increased stress from work and supporting family with disabilities during COVID19 without all of the usual support. It has taken a toll on physical and mental health.



This summary was prepared by:

Survival Coalition

of Wisconsin Disability Organizations

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.

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