

WHAT PEOPLE WITH DISABILITIES & THEIR FAMILIES WANT YOU TO KNOW

STORIES FROM *PRESERVING DISABILITY SUPPORTS ACROSS THE LIFESPAN AFTER COVID SURVEY*

Kirk, Kim & Vanessa, Lake Mills

Our daughter, Vanessa, and our entire family has been profoundly devastated by the pandemic. In March, we lost ALL of our supports overnight (in-person school, autism therapists, nanny, and respite care providers) - wonderful supports that we had worked so hard to put into place. We struggle to explain it to Vanessa, and we don't know for sure how much of it she understands - likely much more than she is able to communicate to us. Vanessa started 4K in Fall 2019, and she was doing FANTASTIC. Our family had begun to see much hope for the future – Vanessa taking huge strides toward being able to achieve her potential, as well as the possibility of getting ourselves organized and achieving so many things that had been long-relegated to the back-burner. This all ended with the pandemic shutdown - but we don't blame any of the necessary measures that have been taken to slow the spread of COVID-19. Vanessa's school and teachers have done an AMAZING job at providing virtual instruction! But it has been incredibly difficult for us to manage home-schooling for Vanessa, and her development has certainly been greatly harmed.



Amber Bricco, Milwaukee

We are a family of 4. My son has autism and was making so much progress in 2019. We were so proud of him. Once schools shut down, we started to see a change in behavior immediately. His routine and day to day schedules were shattered. Since then, there has been a huge decline in his behaviors and functions. He has regressed. He cannot focus. He has started experiencing symptoms of psychosis, talking to himself and delusions. Every service we have reached out to has had incredible wait times and hoops to jump through. Most services are limited to virtual care. No one should have to wait months to receive care simply because there is not enough people power behind providers. Providing additional funding to train experts on next steps and how to work with these children is needed. Our schools need training on how to provide specialized, individual care for their special education students. My son is difficult. My son is autistic. He is also brilliant when the right education and practices are applied. He deserves support, education and Healthcare that doesn't push him aside when it becomes hard to understand.



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Jessica, Chippewa Falls

We have often had to make choices which protect and preserve our son's health and-not to be dramatic, but his very life-over other very valuable things like his education, his therapies, and even his support staff. Given his multiple risk factors and combined with polarized opinions on matters of public health and safety, he has been unable to leave our home since March 5th, 2020. The only exceptions have been for medically necessary appointments with providers who couldn't accommodate Telehealth appointments. As a special needs family, our family is no stranger to isolation and have worked very hard to create meaningful connections for our child within his community over the past few years; over the course of this past year all of those connections have been completely severed. We are deeply concerned with what the future holds for him, as well as for us when we consider all that has been sacrificed-necessary sacrifice to protect his health-but losses just the same. We have always struggled to staff his support care hours fully and this year alone we lost a long term provider and friend when she was unable to justify the exposure risks to herself and her family by being a direct care worker when the job offers no benefits and pays so poorly compared to other types of employment opportunities available to her. As parents we are providing all of those un-filled service hours AND filling in the gaps where virtual learning makes the education environment completely inaccessible. It is exhausting and we need funding to provide the support and assistance that is necessary to help people with disabilities thrive in their communities.



Tiffany, Madison

Our son has multiple disabilities and requires electronic AT-AAC (technology) devices and services in order to communicate. Prior to COVID-19 he routinely encountered barriers to the supports and services he needed in order to communicate, especially in the public schools. Because of these barriers he has been forced to change elementary schools several times and his educational progress has been nil. Currently, COVID-19 has necessitated the majority of general education to be delivered remotely which has been particularly devastating for us due to the pre-existing barriers preventing our son from gaining accommodations involving technology. In the past few months, we have been encountering more episodes of discrimination against our disabilities in our community. Our experience is that COVID-19 is accelerating the systemic inequities that prevent us from participating in community life, and this situation is establishing new social norms of more severe exclusion and segregation for our son due to his disabilities. With each passing school day, his classmates and his school are becoming more and more accustomed to regarding his exclusion and segregation as normal and expected. I am worried that this will have a chilling effect on our participation in community life for years to come.



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Anna, Madison

I am a single parent to three children with disabilities. Before COVID we struggled but felt like we were making progress and had opportunities to rest. Since COVID it has been nonstop with stress and we have been in a holding pattern with no progress. We are concerned about if we will have housing, if we will have food, and we are all on edge. All four of us are suffering from depression and there is no break in sight. It has been hard to watch families like ours get discounted as unimportant casualties to this virus. My oldest child has cerebral palsy and is in high school, I was already concerned that he would not be properly supported and reaching goals before graduation I am now even more concerned. I home-school one of my children to provide them the needed respite from public education and I am concerned because there has been little to no support for my other children meaning it falls on me and that means that I as a human being who has finite stores energy am less capable of providing them with proper education. It's a butterfly effect. My youngest child is eight and already struggles with anxiety as well as an immunodeficiency that causes her to miss a lot of school— her inability to get past the anxiety of working with strangers to get educational supports that she desperately needs, is causing her to fall further behind and lose hope for herself as a person who can learn. All of this is not to say that I believe that my children should've been in school--their lives and their survival come first. But I worry about the impact on our future and what it will take to come back from where we have gone. I know that we are not alone in this and I think it's imperative that there are steps taken to help families like ours to thrive.



Kathrine, Kenosha

COVID resulted in my partner/primary caretaker leaving both his jobs to avoid endangering myself and his immunocompromised elderly mother. The IRIS program has helped immeasurably because having him as my caretaker has allowed us to continue living in our current home, and has allowed him to care for me during my declining health. I need help nearly 24/7 and could not function without his assistance. Without the IRIS program, I may have succumbed to suicidal depression, and it's highly likely that we would have lost our home. These programs are literal lifesavers and should be prioritized.



Person with a disability- unknown

I am in a wheelchair. My support company changed because the first can't provide enough staff. The new company doesn't have a wheelchair accessible van. I can roll to the grocery store, but the snow isn't plowed enough on the sidewalks. Grocery delivery is too expensive. The bus service I take won't wait even if I am to pick up groceries that have been ordered. So, I have to sit at the grocery store for a minimum of 45 minutes waiting for my bus. But because I'm in a wheelchair, I can't get many groceries because I can't carry them.

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Joclyn, Milwaukee

We have lacked having service when care workers had to quarantine on their other jobs and for the safety of our child even if they later tested negative. If my child is hospitalized, quarantined, or ill, the worker does not get paid, have sick pay, or vacation options. They don't have access to benefits that other employees have. I've been trying to contact state and county program directors about options, but they say the state won't offer any benefits because of the employment/pay structure. However, I lose workers every year to steadier jobs and jobs with benefits even if they have to purchase them. I lost two workers because she thought she was getting paid more only to find out there was a \$2 discrepancy in her pay rate (last year).

Dona, Horicon

Has a great adult family home but may lose that too with lack of day services.



Janet, Madison

Alex is a hard-working man who had 4 jobs (only 1 during COVID) and lives with a roommate who is his best friend, with staff who come in to provide support as needed. I am his volunteer guardian and care about Alex's life. Employment services are critical as they provide needed income, social connections, being productive in our society, and giving Alex a sense of pride to have jobs in the community. These services mean that he is an employee of local businesses that need workers, he pays taxes, and contributes to his community. He lives in his own apartment with a roommate and come-in staff. This is called Supported Living and means he has a life with a job, in his own home with friends. Isn't that what we all want? Funding for Supported Living and Supported Employment is cost-effective in the long run as people with disabilities being a part of their community is good for ALL! The Managed Care Organizations have not held up to their promises to cover the cost of services needed to live in the community. The law requires this under Medicaid Home and Community Based Services (HCBS), and it is the best outcome for people with disabilities and elders who receive these services. Supporting these outcomes is both the right thing to do and is required under HCBS. Great combination! But funding is desperately needed to support these outcomes. Supporting Home and Community Based Medicaid funded services is the best outcome for everyone in our great state of Wisconsin. We must support community services vs. institutional and facility-based services, please keep this funding in place as the need continues to grow for older adults as well! Matching federal Medicaid dollars isn't a political choice, it is a human choice for your parents, grandparents, children, and adults with disabilities. It makes a difference for Alex and his life and the thousands of others in our state!!

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Holly, Eagle River

My son is 49 years old & lives independently. He is employed by McDonald's but on layoff due to COVID-19 as McDonald's has no in store dining. He depends on the minimal amount he makes to allow him to live. He attempted to collect unemployment in Wisconsin but called & called & called with no success. I was not allowed to act in his behalf as he is emancipated & DWD of Wisconsin will not speak to me. My son is used to talking to people in person. No one called him back when leaves a message. The DWD has done a true disservice to him & others like him. He does quite well under normal situation but this last almost 9 months has taken a toll on him. His work is a source of his social life as well. When we pick him up to come to visit at our house, I can see that his social skills have slipped dramatically—much due to the fact he is alone a lot. He is a very independent man so coming to live with us is not what he wants or would be good. His independence is what has made him strong.

Joy, Racine

My son has CP from a stroke at birth. I run an accounting firm and my husband is a cop. He's also started a safety training business this year. Because of our son's issues with any virus and how that sends him to the ER and how the hospital access is now limited, we've had to change how we work so we don't have anyone coming into our home. (We used to pay for his childcare ourselves). We're managing and our son has actually been healthier this year than he has his entire life. I've not taken a paycheck all year so I'm not sure how long this is sustainable. My concerns are mostly two-fold. How long is it going to take to open up hospital care?

Taking my son to the doctor really takes 2 people. One to care for him and one to talk to the doctor. If he's in the hospital, having family come to relieve me for a short time is necessary. All of this affects the quality of care he gets. Second is if we can qualify for services such as respite care once it's safer to have people back in our home? The money we used to use for childcare has been reallocated into renting office space for my staff to use for working as they used to work out of my home. We've had to change how we operate but have been able to keep everyone except childcare workers employed.



Karen, Mequon

I'm a single mom. My son sees his dad normally but during peak COVID times, we don't risk it. I'm working full time and when daycare is closed due to cases, it's incredibly difficult to maintain a level of work with a 3.5-year-old at my feet. It's impossible to find respite workers I can trust to minimize COVID exposure and find workers willing to come right now. It's exhausting to manage work, kid, several therapy appointments, doctor appointments, etc. on top of it all. I'm missing out on income at work due to COVID so that's stressful. When we've needed to test for COVID, it's been very difficult to find a place to test children under 5. We had to try 3 different places. Toting a kid with disabilities around like that is torture.

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Terri, Milwaukee

My daughter Eleanor has Down syndrome and aged out of Birth to 3 in September. We are just now in December getting her assessment for school completed. Due to COVID there was no enrolling in school on her birthday, and all therapies were virtual since March anyway. This means that not just mine, but MANY kids are just not receiving the early intervention services they're legally entitled to. It's a setback that we will live with, but we need adequate funding for additional early childhood special ed hours going forward. We have a generation of kids like mine who will be making up for this lost year during the most crucial stage in their development. It hurts to even think about all the catching up our kids will have to do after losing some to all services for a year.



Carie, Oshkosh

I have a daughter who is 19 years old and medically complex/fragile. She has a trach, g-tube, is ventilator dependent, central line power port, VP shunt and is physically and developmentally disabled. We need to see her 12 specialists often to be able to manage her healthcare and keep her at home and out of the hospital. Since COVID, our daughter has had obstacles to accessible healthcare due to COVID restrictions and requirements. We live in Oshkosh and have primary care there but all the rest of her specialists are in Madison at UW Health. Since we are two hours away from Madison, we have to rely on primary care for some chronic issues. Since COVID hit we have had a hard time accessing her primary care since Aurora physicians will not see any "ill" patients so that means our daughter who has chronic complex UTI's now needs to see an "on call" Doc in the "sick" immediate care setting. Anytime she is ill she now has to go to the ED or IC setting with other very sick people. This is not easy or appropriate when you have a loved one who is HIGH Risk due to their trach and lung disease. If she is ill with a UTI after hours she has to go to the ED. She does not have access to primary care now when she is ill with anything. Since we don't go anywhere and our daughter hasn't left the house except to see a Madison Doctor less than a handful of times, the likelihood of our daughter having COVID is none. Yet she can't see any of her healthcare providers without getting COVID tested first or going through an ED or IC setting. This is putting children and adults with medical complexity at risk of morbidity. We cannot forget that our most vulnerable population are suffering the consequences of COVID restrictions and requirements making already inaccessible healthcare even harder to obtain. A lot of the clinical healthcare workers are working from home and are not providing quality care by doing so. The patients that are medically complex need to have direct access to healthcare and not have obstacles in the way of accessible healthcare. We have also experienced medical supply shortages of ventilator circuits and related medical supplies that our daughter needs to survive and thrive at home. Since COVID hit instead of receiving 4 vent circuits a month (we need to change them weekly to keep germs and bacteria from forming in the circuits) we would receive zero to one and the sterile water that she needs to humidify her lungs while on the vent. It is terrible. As parents my husband and I are feeling anxious and isolated. I have this dreadful feeling that COVID will end up taking the lives of our most vulnerable and they won't even have COVID. This State needs to step up and protect our most vulnerable.

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April, Mauston

I am a mother to a child with Spina bifida and numerous other degenerative complications that stem from his primary diagnosis. I am currently in process since he is getting older and bigger, wants Independence and dignity to have our family home modified accessible based on his disability needs. As a single mother limited to a low income to maintain and continue to receive his SSI funds and ensure he never loses his medical since it is of dire necessity to maintaining his optimal level of health and well-being I am unable without assistance programs or state funding to afford these accommodations that just make his basic daily living worthwhile and safe. I dread the day that funds will not be available for individuals living at poverty level or low income yet want to have their civil rights and liberties to ensure their pursuit to happiness and independence as individuals regardless of the limitations on their bodies or minds when they are trying to be active incorporated citizens and do what they are able to achieve and accomplish.

Andy, Thorp

I rely heavily on my family to provide paid and unpaid support to me during a time when employee turnover is high. The higher-level of turnover means that more staff members are required to provide support I need increasing the risk of exposure to both me and my family. In addition, when I'm not able to cover shifts that are required for me to live independently it creates extra stress on my family members and loved ones.



Beth, Milwaukee

My 24 yr. old son with ASD quit his part time job at Kwik Trip due to immune dysfunction and anxiety on March 15. I had to the quit my full-time job on May 17th to care for him as he was pacing the house and talking to himself for much of the day. I had to put together a home program for him that kept him busy. I found 3 UWM students to come over for workouts, college online tutor and executive functioning planning his work. He takes online theater classes through Pink Umbrella and is training to do voiceover work. Issues at hand are that neither of us received unemployment because we quit our jobs. I am just getting by. There is no extra money for care through IRIS. His budget went down \$4000 with no explanation. I am now on Badger Care. My son takes many meds and supplements. He doesn't sleep many nights since birth. I have to care for him. I left a \$50,000 a year job with nothing afterwards to help me. I fear isolation and anxiety and depression. I am my son's guardian.

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Jennifer, South Milwaukee

Both of my young children have autism. Our family relies on assistance from state, county, and City programs to keep our kids safe, healthy, and progressing. They are both in the early intervention window, and it is terrifying to see the regression and increases in maladaptive behaviors this year with decreased services per COVID-19 has caused. Everyone on our team works so hard for every gain we make, so hard. To see so much skipping away and to know that our early intervention window is closing is truly heartbreaking. We just want to do everything we can to give our kids every opportunity to be thriving adults who can live in society and hopefully be independent someday. We have lost therapy hours, respite providers, all community interaction, educational opportunities, and most types of social interaction this year due to COVID-19. My children have become markedly more violent, more destructive, and less communicative. These are truly brilliant individuals whose minds may solve all the problems in our future, but they will never have those opportunities without tremendous services and supports to assist with maladaptive behaviors and communication delays. Someday I will be gone but my adult children will remain here. We all want them to be strong, contributing members of Wisconsin Society. Please don't squash all the hope for the future now. Providing services to people with disabilities during COVID costs more. We need budget increases to help these people! COVID has been incalculably difficult for everyone, but so much more so for people with disabilities. Their lives are turned upside down and the world without supports is unlivable. My children have been home since March because we need supports to be in the community. We have experienced significant delays or complete lack of services. Please be compassionate and pragmatic when reviewing the budget. Ignoring the needs of those with disabilities today only increases your burden in the future. It also causes tremendous and unnecessary suffering and challenges for those with disabilities and their families.



Julie, Brookfield

My daughter has been able to keep her job but we lost her transportation person right away so we have had to provide it, which is very difficult. Her job is not ideal, and we would love to find a new one but are worried that companies are not going to be ready to hire workers with disabilities as quickly as other workers and I fear that the employment providers are going to be SO overwhelmed that we won't have the right access to job development or support as necessary. I believe that all the years that we've spent building a great independent life for our daughter is now going to have to begin all over again and that all the systems and providers are going to be too overwhelmed to meet everyone's needs.



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Karen. *Pleasant Prairie*

Due to COVID, we have not had care workers in home or have attended day services for fear of my daughter catching it. I fear she has regressed socially because of this and won't be able to go back to our day service provide. Care workers need a living wage with benefits to keep them in this field we cannot compete with Amazon.

Margaret, *Wauwatosa*

Speaking for our 26-year-old son: my parents are aging and won't be able to take care of me forever. I need to be able to know I can rely on state funding to help pay my Caregiver's adequately for so I can keep them for the long-haul. I require 24/7 care so this is very very important to me. I don't want to end up in a nursing home at age 26.

