What Medicaid Means to Wisconsin's 2nd Congressional District



www.survivalcoalitionwi.org survivalcoalitionwi@gmail.com

# Medicaid Provides Funding for More than 20 Wisconsin Programs

IRIS Legacy Waivers (COP/CIP) BadgerCare Nisconsin Chronic Disease Program Partnership Katie Beckett School-based SeniorCare School-based SeniorCare Brace <u>(Jell (Jonan</u>) HealthCheck (EPSDT) Community SSI Managed Care Support Birth-to-3, Family Care Children's Long Term Support Program Comprehensive Community Services Community Recovery Services

#### **Medicaid Enrollment in CD 2 includes:**

858 children with significant disabilities in the Children's Long-Term Supports waiver program
4,243 4,243 people with disabilities who are working in the Medicaid Purchase Plan (MAPP)
3,840 people with disabilities and older adults in Family Care and IRIS
2,222 older adults and people with disabilities are served by the Dane County legacy waivers (COP/CIP).
497 older adults and people with disabilities are on a waiting list for long-term care services in Dane County.

Medicaid Enrollment in Wisconsin's 2nd Congressional District Counties:

 Sauk:

 9,967

 Dane:

 64,658

 Iowa:

 3,568

 Lafayette:

 2,815

 Green:

 5,476

 Rock:

 35,759

Richland: **8,438** 

Total Medicaid Enrollment in CD 2 Counties: 130,681

Total: 11,660

## **Executive Summary**

Wisconsin's Medicaid program provides critical health and long-term care services to more than 1 million Wisconsinites. Nearly two-thirds of Wisconsin Medicaid participants are older adults, people with disabilities or children, many of whom have disabilities.

Wisconsin's investment in Medicaid is essential to the health and independence of people with disabilities. Adults with a disability are more likely to: be low-income, have less access to health care, report higher health risk factors and chronic conditions. Medicaid helps people with disabilities see primary care doctors, receive personal care services, go to the dentist, see therapists and obtain other needed medical services and equipment. Most people with disabilities cannot have all their needs met with private insurance.

## Survival Coalition surveyed 1,500 Wisconsinites who use Medicaid and found:



**60%** use Medicaid transportation to access the community.





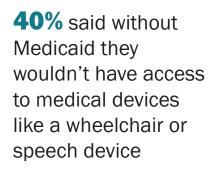
**80%** said without Medicaid they couldn't see their doctor, therapists or direct support providers.



33% use
Medicaid for
supports to be
able to work.
48% said changes
to Medicaid would
mean they
couldn't work.



**43%** said without Medicaid, they couldn't stay in their homes.





**32%** use Medicaid to access mental health services.

## Stories from People Living in Wisconsin's 2nd Congressional District

Survival Coalition received the following personal stories from people who use Medicaid and live in Wisconsin's 2nd Congressional District. They illustrate the different types of critical supports provided by Medicaid and the impact these services have on people's ability to lead independent and healthy lives in the community.

#### **BARABOO**

Without these services my sons quality of life would be horrible and our family would suffer greatly. I would not be able to hold down a full time job to help support our needs. Therefore becoming even more dependent. - Anne

My son is 22 and has Down Syndrome. He has hypothyroidism treated with prescription drugs. He also has celiac disease which must be continually monitored by a physician. - Sandra

#### BARNEVELD

It is very important to to keep my Sister in the Total Adult Family Home! As we family members! Are getting older! And we want her to be secure in the home! - Henrietta

#### BELLEVILLE



#### BELOIT

We are slowly going broke. high costs in general are outpacing our social security. I'm having difficulty caring for my wife, she has ms. we are scared of the future. - Randall and Patricia

#### **BLACK EARTH**

Many of my patients use these services to assist with daily tasks to meet basic needs. Also helps to pay for medication and medical appointments. - Tara

#### **COTTAGE GROVE**

provide the support so that we too can have time to meet our needs and the needs of our children - Jolene

Without these services he wouldn't be able to function. - Lisa

My great-grandmother (92) came to Wisconsin this summer with her husband for a family vacation and he passed away suddenly. After being diagnosed with Alzheimer's disease, left my family grieving while struggling on what to do next. She currently lives in a CBRF memory care unit. Her kids who were in the area were left to pay for funds until Medicaid was able to transfer states for her. This funding provides my great-grandmother to have a great quality of life surrounded my wonderful supports. Without this funding creates stress and barriers for her family to try and support when they are barely able to support themselves. - Kendall

#### **CROSS PLAINS**

We have support through ABA therapy to help our autistic child learn functional, communication and social skills to thrive in his home environment, community and school environment. The funds provided that help us provide ABA treatment, also help with growth hormone therapy prescription costs. - Katie

My son doesn't drive. The transition program in our school district has worked with him to find 20 hrs. per work of employment with transportation and a job coach. Without this support my son would be 21 yrs. with no means of income or a way finding employment as his writing and reading skills are at a 3 - 4 grade level. He would not be able to be at home all day unsupervised so I would have to quit my job from which we rely on income to help with our family living expenses. He would have to go on our family insurance (which I carry) but only until age 26 and at that time he would not be able to afford the multiple medications he takes and doctors visits. - Shelly

My mother was able to use the ride program to get to doctor appointments. - Teresa

We couldn't do it without a little help. Our son is a spastic quad and needs all assistance. We work full time and need help from caregivers between the time that Nick gets home from school and we get home from work. It's not like we can hire a high school kid from down the street to "babysit". We need competent care for our adult child. - Lisa

Helps me prepare for and engage in life's activities and employment.--Sara

I have a high special needs daughter with a very rare chromosome deletion disorder known as Phelan McDermid Syndrome in which is an umbrella to Epilepsy, Staticus Elipticus seizures, Autism, Non-verbal, severe cognitive delay, does not feel pain and does not generate her temperatures. There is only a few hundred studied cases in the world. She goes to therapy for her autism that has helped her immensely with learning how to use the toilet at age 11, has helped her learn how to somewhat appropriately ask for what she wants. She frequently goes to hospital by ambulance due to being immunocomoromised . Two years ago we almost lost her due to a severe colon infection known as Clostridium Difficele ( c-diff). That required a week in the ICU. Now we have to monitor any antibiotics she uses as some are more prone to causing this again for her. We also almost lost her to Noro virus. She recently was diagnosed with Staticus Elipticus which is a form of epilepsy where her brain constantly spike every second while sleeping and is at big risk for another Grand Mal Seizure. We almost lost her a few months ago to a grand mal seizure and had to have two ambulances at our house at 2am to get her out of the seizure with emergency medication. I don't know where I would be today without the Katie Beckett or Medicaid from the county for my high medical needs daughter. Actually I do know where my family of six would be, we would be living in a cardboard box, because this is not my whole story. - Deborahe

#### DANE

The services my son receives allows him to get the care he needs and allows him have the supplies / equipment necessary for him to live his daily life. My son is unable to do anything for himself, so these services are much needed and make it possible so we as parents do not have to be the sole caregivers to all of his many needs. The health care is also much needed as he sees several specialists on a regular basis and takes numerous prescription medications due to his disability. Without out these services we would not be able to afford everything needed for him to live his daily life.

#### DEFOREST

Allows me and partner to work same shift to be home as a family. Allows us to help with medications that private insurance doesn't cover. Quality of life would suffer. - Shannon

#### **FITCHBURG**

Allows parents to work, to care for sibling, and have quality interactions with our disabled child. Allows our daughter to have the opportunity to as much as possible go through the appropriate developmental stages of individuating so that she will be best prepared physically, psychologically. and developmentally prepared to live independently of us, particularly as we age and are unable to care for her. - Sandy

The services help my daughter get through her daily life with having someone to meet with and discuss things with as well as to get medication to deal with her mental illness. - Nichole Medicaid covers more than **1 Million** Wisconsinites. About **two-thirds of enrollees are kids, older adults and people with disabilities.**  Y 22 year old daughter has a number of developmental, health, and mental health issues that significantly impact her life. She is unable to work, so relies on the supports provided through Medicaid and SSI. Her life would be made even more challenging without the vital services she receives.

It is absolutely essential - Robert

Tom needs support managing medication, dietary needs, personal care, meals planning and preparation and being able to reside in a home and not institutional setting. He cannot be alone for more than an hour, needs prompting to complete tasks at work and to regulate his emotions. - Theresa

They help my mom stay active and administer her medication as at when due. Companionship will keep her from wondering and getting lost. Mom has been lost a couple of times but found by the police. - Chukwuemeka

#### LAKEVILLE

Our brother needs consistent oversight regarding work hours, any medical appointments, someone to schedule transportation, food shopping, and weekly follow-ups. - Pamela

#### MADISON

My son gets to keep a job - Chris

As a guardian of 2 adults having disabilities, Both gentlemen require 24 hour attendant supports from residential agencies to manage money, medical appointments, meal preparation, med administration, vocational agency supports to help accomplish working at various jobs, cues for health and hygiene etc... - Steph

y mother takes many medications. She would not be able to afford them on her very limited income. A difference of \$20 a month has a severe impact on her life. - Deb

live in my home of 40 years among friends in the 'hood whom I love. My son can come home and see Dad in a familiar, natural setting. Without help I can't even get up out of bed in the morning any more. I have a full, rich life in my retirement, and remain involved in community groups and affairs. - Carl

They help me with transportation to and from work - Rachel

My mother has Alzheimers, she can no longer care for herself, my brothers and I work full time and don't have the facilities or expertise to take care of her and provide her with what she needs. Medicaid has helped her receive meet her physical needs as well as allowed her to be in an environment where she can meet her social needs as well. - Jennifer

I wouldn't even be able to get out of bed if the changes go through. I wouldn't be able to meet friends to go out to eat, see a movie. Have a real job if I had one. I would get depressed to the point of maybe ending my life. - Betty

am not sure our son could live at home safely without the autism therapy and respite/long term care. Beforehand he was extremely aggressive, but he is now stabilized, thanks to these services. - Carol

My brother and his family rely upon BadgerCare MA exclusively to meet health care needs. - Amy

Could not live without it - Mary

APP and support at his job are both essential for Sadler to be a productive member of his community. He works for the State of Wisconsin in the mail room where he has been for almost 10 years an makes more than \$11/hour. Sadler has Down Syndrome and while he is pretty independent, he would have most certainly lost his job on several occasions had it not been for a job coach assisting him to learn new equipment (it takes him longer) and understand subtle social cues that were impacting his relationship with co-workers and ability to do his work well. Because he works 20 hours per week at a good wage, he uses MAPP for his health insurance. Because he does not have access to insurance any other way he would be forced to leave his job if that program was not available. - Amanda

Job support and transportation allows my adult child to live independently in the community. - Theresa

Invaluable - Judy

Cole is able to maintain a healthy lifestyle - Vicki

These services allow clients to live in the community, rather than an institution/hospital. We keep people out of the hospital, and keep our clients and the community safe. - Christine

We rely on daily care to be able to work and provide for the rest of our family and stay off state assistance as an entire family. - Tonya

Wisconsin schools receive \$60 million per year in Medicaid funding for school-based services like speech therapy.

y 21 year old son is supported by 2 separate vocational agencies for his employment at 3 different employers. He also receives transportation to and from his job sites. Given that both his parents work, we would not be able to work if his vocation and transportation needs were not supported with the services he receives. If he were to lose this support we would have no other options available and I would have to quit my job to care for him and additionally we would lose not only my income but also healthcare benefits through my employer, as my husband is self- employed. Not too mention the devastating affect on my son if he were to lose his employment due to loss of job coaching support. His work has made him feel like a person of value and ability.

Medicaid brings about \$5 billion to Wisconsin which supports hospitals, providers, and jobs through 20 Medicaid-funded programs as well as program participants.

Every person has the right to utilize their God given abilities and feel like a valued member of society. When you take away the necessary supports to help that ability become a reality, you not only diminish a person's self worth, but send a message to others that these individuals are disposable. - Krisit

Amber has to have care during the day while her mother/sole care provider, is working. So she is transported by bus to the MARC Center for disabled adults where she stays for the day. - Amber

A llows my son to live an independent as possible. He is able to live in his own home with the support of residential care providers. He is able do work because of vocational support he receives. My son is very proud of himself and the job he does. My son has autism, epilepsy and type I insulin dependent diabetes. Without the intense medical support he receives, he would not be able to live in and be an active participating member of his community. - Carrie

Helps me stay healthy, independent in my home and my full time work life. - Kelly

My child is only 2 right now. His services aren't extensive, but will be in the future. Right now he's receiving therapies to help him speak and learn to walk. We are on the waiting list for family care & hopefully will be able to use future funding for a fence and safety devices in our home. And hopefully a tablet or other device to help him communicate in the future at school. - Nanette

Our son relied on 8 of the above services. He would have died without them. Our family would have fallen apart. - Leslie

Allows our daughter to live and work more independently - Anne

My clients express their choice to live in the community rather than in an institution. Flexibility in long term care currently allows one to live where they choose and create a service plan that values their independence and individual needs. - Erika

work to support many people with different needs, and they only receive the care I and my agency provides through the county's funding and through Medicaid and medicare. Without the funding and structure that we have now, the people I and my agency support would be losing out on medication they need because they will not be able to afford it, home support that keeps them as independent as possible, the social interaction that is impairative for their mental wellbeing and health, and the connection to a community that without it, would leave them isolated and without any hope. They would possibly have to enter a facility that would cost the county exponentially more money and would only serve their "basic needs" rather than providing autonomy and self directed care. This would literally be devastating to an already oppressed and ignored entire population of people. - Miryam

Matt is in a group home with two other men. This was necessary years ago at the time of his fathers death as he refused to return to an empty house and at the time I was working full time. This all began prior during his fathers illness. I was unable to be in two places at once and requested the change for Matt. He is in a good place and comfortable with his living and working arrangements in the community. - Anita

I could not do any of these without help. - Guinevere

they help me with keeping my job and transportation to go food shopping - Brian

I could not deal with early cancer without assistance/ I need to exercise, go to therapy and support groups and upon diagnosis my husband up and walked out - Sandra

They help my disabled adult sibling. If not for the help, I would not be able to work being that I am the only primary family who is able. - Davun

We adopted our daughter at age 4 1/2 from China. She had an undiagnosed genetic syndrome. Without the financial help for doctor visits, therapies and hearing aids, we would not be able to afford helping her towards independence. She now has access to hearing/language and physical mobility.

With our CLA support I'm able to care for my other child, attend to household duties while my disabled child is well cared for. My husband's employer does not offer health insurance and I stay home to care for our disable child, we have private insurance for my husband, me and our other child, if we didn't have Katie Beckett MA I don't know what we would do for health insurance for him. - Trina

basic medical/mental health needs and LIMITED dental services - Hannah

My son has a disability that impacts his speech, physical strength, coordination, swallowing, etc. The health care and services he receives help him afford to live at home. - Satiya

Some medications for my sons ADHD are not covered by our insurance but through the Katie Beckett program my son can get those medications for a lot less or sometimes free which is a great help to our family.

I born with spina bifida use a wheelchair with the changes that are happening with Medicare I will be with out the things that have made my life manageable. - Betty

It allows me to live at home, work and be a productive member of my community. - Nick

If I didn't have services, it would compare to driving a car without streets or a steering wheel. - Thomas

Services make it possible for my son to be employed. Maintaining successful employment for nearly five years is a crucial part of my son's self-worth. - Nancy

just help me get by - Kristin

he services allow me to live in my home. i receive personal care services in both the mornings and evenings every day. without this i would stay in bed all day or in my wheelchair all day. i'm able to live in my own house with my husband, socialize, work, go to meetings, do advocacy, and much much more. - Barbara

I regularly see a psychiatrist and psychologist and use medications.

I don't have to take off work because he gets transportation. He has a life threatening illness and will eventually need a transplant. He has terrible anxiety and depression due to his prospects and gets mental health services. - Ellen

My son is 24 and has Down Syndrome, he needs a lot of support. - Jennifer

Eric would not be living in the communiy at this time , with his increased health needs without all of the supports he currently receives. We anticipate his need for assistance will increase - Peg

I would not be able to live as independently in my community without supports. - Lisa

The therapies have changed my son's life, had he not received any therapies, I KNOW he would be on medication for all sorts of disorders!! - Laureen

We would not survive without them. I am the brother and guardian of an individual with developmental disabilities. I became her guardian out of necessity. I was not prepared for the extra time and money it would take to provide the proper care for my sister. If we do not have this care it will likely be a trickle down affect that will not only affect her but will affect my child, wife and myself. We will likely lose our home, cars and not be able to pay for our own insurance. - Ryan

It allows my son to live @ home& work in the community. - Jane

able to have health care lead a more productive life - James

My husband has been a Quadriplegic for more than 53 years, we adopted 6 children with special needs. He works and has insurance, for now, that helps our dependents get better services than on MA alone. He has been unable to retire because he would not be eligible for Long Term Support services but unable to pay the out of pocket costs at the same time. Being in the COP program has helped him get the services he needs but prevented him from saving for the future. - Kathleen

Our son couldn't live in the community without significant help with personal cares, employment support and respite funding we use to get breaks from 24/7 care we provide to him - Catherine

### THESE SERVICES HELP MY SON GET THE MEDICATION HE NEEDS TO MANAGE HIS WEEKLY SEIZURES AND ALSO ALLOWS FOR EQUIPMENT HE NEEDS TO BE SAFE AND COMFORTABLE - Sylvia

Monthly medication is expensive. Additionally, this is secondary to our family insurance, however, should we lose that plan, our child would still be covered, which is necessary, as he is autistic. - Teresa

#### Life-saving. Son is suicidal and so anxious he can't perform basic self-care. CCS is our last hope - Mara

My sister with developmental disabilities gets her medications delivered in a pill box provided by medicaid. This helps her take her medication correctly, becase she has developmental and mental disabilities. She also gets transportation to medical appointments, also vital for her care. - Tracy

Our daughter has had epilepsy since infancy. Many medications have been tried and she has a VNS implant, which required surgery. Yet nothing has provided complete control. Over the years the seizures have taken a toll on her brain and she isn't capable of living independently. Medicaid pays for her doctor visits, dentist, counselor and medication. She isn't currently working but when she has had a job it was very part-time and could not begin to pay for the services she needs. - Mary

to continue to survive and to thrive as an independent adult. - Fred

support at work - job coach respite to help me get to training for the USA paralympic swim team - Beth

Helps our son to have a place to go during day for work/activities and helps with his medical needs. - Jean

As a parent of a medically-complex child, we depend on good medical care and respite for ourselves so that we are better equipped to support our child. - Lynne

with out the help from family my son would never be able to do anything he is totally dependent on someone 24/7. I lost my job after 10 years of working because of the care my son needs and I still am not able to work outside the home. - Sue

My brother is unable to care for himself. He lives in an Adult Family Home that is staffed 24/7 to care for him. He attends a day program for which he needs transportation as well as to multiple medical appointments. - Amanada

I'm a mental health counselor and a substance abuse counselor. I have also been a supervisor for a mental health case management program. The Comprehensive Community Services Program is a true asset to clients who have Medicaid and need a variety of services to address their mental health and substance use treatment needs. Many clients struggle with housing, employment and social skill development, which directly impacts their mental health and substance use recovery efforts. With the team approach that CCS provides, clients have had reduced need for impatient stays, which can be very costly to taxpayers and health care premiums.

Our son is able to have a part time job and has increased self esteem. He also can afford his medications, dental care and medical care and with this help. - Denise

I am able to pay for doctor visits, therapy prescriptions and surgeries that are vital to my health. I would not be able to function without these things. - Lori

The services help my autistic son to learn daily self-help skills, social skills and work skills. - Anna

My son is receiving intensive home therapy for his autism. It has been a huge help for him. - Jiandong



The personal care, supportive homecare, meal preparation, feeding, toileting, bathing, dressing, transferring, provided through the Community Options Program have allowed me to maintain my employment with the state for the last 35 years. My wife and I adopted six children, five with special health care needs. They have all graduated from high school, to have graduated from college and all living independently. They depend on SSI and Medicaid for the health care coverage and mental health support. - Dan

Many of our clients would be homeless, in jail or the hospital without our services. - Mary-Jo

they help me take care of myself - Lori

My father(97) receives Medicaid and lives at a Memory Care facility. His Medicaid allows him to do this and he pays a portion of his housing which takes up all his income. - Bonita

He wouldn't be in a community setting without the services. He needs 24 hour supervision and care. - Mary

they help to be a better employee to my job I have several heath issues to deal with I also need assistance to help me go grocery shop - Brian

I COULD NOT LIVE WITHOUT ANY OF THEM

Allow those the remain in the community to achieve fulfillment in everyday life. - Erin

I could not live on my own or work without these services .-- Tyler

I need help in getting to appointments and in understanding how my treatment real help me.--Catherine

#### MARSHALL

My daughter gets cab vouchers to work & back, which then I am able to work. She has a job coach, we have the help of her support broker - Carol

Helps me socialize in my day program and live with home health care - Bonnie

#### MAZOMANIE

It allows for David to have a level of independence. - David

#### **MC FARLAND**

Birth to 3 in home therapy services covered with our forward card. So much less stressful to have services at home especially in the winter -

I have a brother and sister with autism. Their support in the community is vital. Their brokers are necessary in order to keep everything functioning properly (paperwork, funding, ect.) and to give them a voice on issues regarding their quality of life. - Maria



Moderate Down Syndrome, needs help learning tasks, then can do on own. Likes to work & case manager makes sure he has good skills to keep his job and pursue other's that he can enjoy. Trying to find good safe housing. - James

PCW's provide COMPLETE daily living supports to our adult daughter with a disability, including dressing, bathing, food prep, eating, exercise/range of motion, basically all daily living areas. Our disabled adult daughter is totally dependent on others and is unable to live independently. She's nonverbal. Uses eye gaze, gestures, vocalizations, to communicate her needs. As older parents we worry about the day when we are no longer able to physically help our daughter in our family home. - Jeanne

#### **MERRIMAC**

he medical services (doctor, psychiatrist, dentist) and medications have made an incredible difference. Without all of that my grandson would most likely have had run-ins with the law, be unemployed as well as having declining physical health. As it is, he is well, employed part time, is able to drive. - Kit

#### **MIDDLETON**

It helps a lot..My son is Autistic,he is getting therapy from WEAP.He is not potty trained completely..so all his prescriptions , diapers, therapy all covered through medicaid. - Lavanya

Our respite care worker through UCP, paid for by the Waiver, has been invaluable in allowing my wife and I to continue to work at our desired jobs. It also have given us a chance for respite now and then when in the past we had our daughter at Easter Seals Respite Camp. - Don

They are essential. As the primary wage earner who has to work full time, I have to have the services & the supplemental support in order to provide a healthy environment for my daughter who has complicated needs. She has epilepsy, autism, and an intellectual disability. Because of her complicated health issues, we use Medicaid to supplement Unity for health needs. We use Medicaid for autism services, services billed by the school district, incontinence products, and personal care help in the home, as well as respite. Because my husband also has a disability, I cannot imagine how we would get by without the services, products, and support that Medicaid helps us afford. - Kirsten

The services my son receives (medication, therapy, and case management) help him to function and go to work. He struggles with emotional dysregulation, poor executive functioning, and at times, uses substances to cope with his disabilities. - June

ntensive Autism therapy has made ALL the difference in my child's progress towards being ready for school and gaining function and independence.He not only has autism but a brain abnormality and chromosomal deletion. At 6 weeks they said he may never walk, talk, eat orally or see. He is doing ALL of those things thanks to the medical and therapy care he gets.

It allows me to hold a job and offset those medical costs. We can participate in community activities. Learning essential skills as a child that are not taught in schools will help my child be more independent as an adult and will lead to less services required over his lifetime. - Christine

My father is able to live with basic care assistance at age 99, but has no income or savings (left) other than Social Security. Without the rent assistance he receives that allows him to stay at an assisted living facility I don't know what we would do. In addition, my 8 yr old son receives autism support services that allow him to attend school and also receives supplemental therapies. This support is critical to his development and growth. - Lisa

can not do my own personal cares or get into or out of bed without help. I need help preparing my meals. I need transportation. I basically could not live without the supports that Medicaid provides - Stacy

Both of my adult sons are on SSI. That isn't a lot of money to pay for living expenses, food, etc. Having Medicaid pay their Medicare premium & medical copay is a big help with living expenses. - Janis

Gives parents a break from the extensive caregiving for our child. - Kayla

#### MONONA

Drastically improved/improves his quality of life, he can get the ongoing therapy he needs to help him develop and function in society.i also receive help for respite and medical bills (single mother), which relieves a lot of stress for me. Without this help, we would have no support for him and his future would be severely impacted. - Sarah

Our daughter needs constant care which is provided by me, her mother, so respite care is essential for a break every once in awhile. - Laura

#### MONROE

Without BadgerCare helping to cover costs that our insurance didn't cover, our family of 6 would be in the kind of debt that we'd never be able to recover from. Now, up until recently only our kids were covered, but now my husband and I are also on BadgerCare since he has left his dead-end job (and crappy insurance) to better himself by being self-employed. Once our business gets going and we no longer qualify for BadgerCare, we were hoping to buy insurance, but I'm very worried that there won't be anything affordable available, and we'll end up back where we started. - Amanda

#### MONTICELLO

My daughter requires assistance with everything. Nurses do personal cares, dressing, feeding, exercises, position changes, transfers from bed to wheelchair, take her to school, first aid, administer medicine. All medical equipment, feeding supplies, incontinence supplies, medicines, doctor and hospital fees are paid. Her medicine alone for one month costs more than \$1000. There is no way we could afford any of the necessary items and medicines she needs. - Angie

#### **MOUNT HOREB**

Required for survival. - Dennis

Without these supports, I wouldn't have my own business and a safe place to work. I wouldn't be able to care for myself and would be completely dependent on my aging parents and home bound. - Franke

#### **NEW GLARUS**

elps my daughter stay in her home. Helps teach skills and independent living that will help her in her future. Vocational supports allow her to live a meaningful and productive life. - Mary Anne

#### OREGON

My son's supports allow him to grow and achieve skills that will prepare him for full community life. - Patti

Y 10 year old niece has severe epilepsy. She needs constant physical support for safety. The services she receives allows her to remain living at home with her parents and two younger brothers. The services she receives allows her parents time to work, care for their other children and run their household. - Julia

work, transportation, medication, counseling - Dillon and Dustin

#### PLATTEVILLE

help care for two adult children with disabilities who rely on medicaid, SSI and IRIS to allow them to live, work, attend school etc. in their community. Our family is also facing challenges with needing in home care and supports for an aging adult with MS. Home modifications and mobility equipment are expensive. Access to in home care supports will allow for remaining in the home and community rather than moving to a skilled nursing facility to be safe and receive medical care needed. - Brenda

#### **PRAIRIE DU SAC**

The hardest to access is mental health services, but when services are accessed, they help the families and can keep the individual in the community. - Liz

#### **SAUK CITY**

Without therapy and CCS I would be in a really, really bad place. They help me get through every day. - Patrick

#### **STOUGHTON**

Having respite care helps out immensely. She needs a buddy and it seems to work out because we try to get someone around Kayla's age. - Cindy

The services that my daughter receives are a life saver. Her meds alone would add up very quickly every month.

Without the help that our daughter gets from outside she could not live a quality life. Plus if she loses those support systems either my husband or i would need to quit our jobs and stay home. - Linda

The supports for my child allow me to work full-time. Medical assistance provides healthcare coverage to maintain my child's health and keep our family from bankruptcy. - Lynn

My daughter is not be able to be on her own so she has 24/7 caregivers. She is cognitively disabled and has mental health issues. - Nancy

My son needs 24/7 care so he would rely solely on family members. I as the sole income provider would have to quit my job to take care of Adam. The consequences from this would dramatically affect everyone in the family. - Deb

I am disabled, unable to perform a lot of tasks. She helps me to maintain a clean living environment, helps in mobilizations that I am unable to perform. Laundry is also a necessity. Eases my stress and anxiety of everything that my disabilities won't allow, she is my total support. - Kaylar



Provides medical grade pull ups, impacts financial payments for services - Stacie

Manage diagnosises for our special needs children (twins) - Jim

My work support helps me keep a job. It's hard for me to stay on task, so the support helps me find ways to be productive and successful at my job. I need to have my food locked up at my apartment because I want to eat all of the time. I need the staff to fix my meals and give me my medicines twice a day. I need direction and support especially when my anxiety is way up! - Emily

am a single parent of a child/young adult who has life threatening issues heart/kidney/seizures. He needs daily assistance in all aspects of his life. I would not be able to work if I didn't receive help. He also always needs someone that is cpr/defibulator trained. He has a quality of life and is a happy person because of the life he has now. - Cathy Peace of mind knowing that our daughter/s heath care needs are possible. Without the Katie Beckette program (Adult Services soon to follow) we would be struggling far more than we are currently. - Brandon

#### **SUN PRAIRIE**

My son is a 10 year old with extreme global developmental delays, autism, thyroid disorder, epilepsy, and extreme hyper kinetic disorder. He needs constant 1 on 1 care to insure his safety. - Beverly

Y daughter has autism as well as a sensory processing disorder. my son has significant developmental delays and we rely on therapy to give them a chance at a normal healthy life. without therapy my daughter will never learn to communicate and will have a hard time learning any basic life skills - Kari

our totally disabled son is 20, we are in our 60s,father has bad heart, and we need the help to keep him in our care - John

My mother is elderly and I am physically disabled. I am lucky in that I have been able to work a 40 hr a week job but if I wasn't able to do that any longer I would have to rely on one of the programs you had listed. We both pay for in home chore and home care because we cant manage doing the heavy cleaning/ chores like vacuuming, laundry, deep house cleaning. - LeeAnn

Helps my mom pay for prescriptions on her limited Social Security income while the expenses of living at home strains the monthly budget (utilities, food, etc) - Jim

> Brain injured, need supportive living care in order to live. -Florence

My daughter is a non-verbal Autistic. She needs 24 hour supervision and care. A simple dentist visit requires a hospital visit to be placed under anesthesia to do simple dental work. This would become a major expense. We also receive pull-ups monthly for her, she is 16 years old and this would be another large expense every month. In order for my husband and I to go out we have to have respite care help to stay with her, we have no family in the area so having respite help is a huge deal to us. - Lisa

It helps both children with their lives. - Lorrie

Work in the community, contribute to increased self esteem, increase mental health, increase physical health, be with peers, socialize, be a contributing member of society.--Name not provided

#### VERONA

My daughter is healthy and happy, her vocational support allows my husband and I to go to our other jobs. - Leslie Allow us the ability to maintain our son's health & quality of life. Respite affords us the ability to maintain our jobs that provide primary Heath care & dental coverage and the ability to maintain care for our son in our home environment. - Dave

Well, being on disability income and diabetic my Medicare and Medicaid are my health insurance and I would have none then to pay for doctor's visits, prescription co pays. - Rick

They allow us to keep some sense of normalcy, and not go into major financial debt. We are provided some assistance with incontinence products, daily formula for her g-tube and assistance with other copays that are not covered by our primary insurance. Periodic assistance with her daily cares also allows us to provide our other child the attention they deserve. - Wendy

My son is 21 with severe autism/seizure disorder. he is supported in long term care through Dane county. He is 100% dependent on staff for all of his needs including 2 on 1 for his own safety as well as others. - Shelia

We use Katie Beckett for therapies and other medications/ nutrition support not covered by our regular insurance - Rachita

I am receiving treatment for a hormonal imbalance. Without this treatment, I become fatigued and have low mood, irritability and generally function at a lower capacity. - Karen

there isn;t enough help!!! we get about 6-9 hours of help /week. Help is next to non-existent. Luke is allowed 9.25 hours /day via personal care billed to MA. Minimal/No help means it all falls on us, Luke's parents as he lives with us. - Jo Ellen

They help our family run more smoothly and take some of the stress out of worrying about doctor visits and costs. - Becky

services allow me to prepare meals, to go to work limited hours, - Susan

he services help my son to live a more normal life. They help with all basic daily living needs i.e.: eating, dressing, toileting, bathing, mental health care (to manage aggression and self injurious behaviors) - Elizabeth

Staying in my home with caregiver support I am able to be a viable member of society. - JoAnn

Since taking care of my son Services provided like respite care helps us to recoup energy and provide sometime to take of personal work. Music and swimming clases help my son to lead a quality life. - Rama

My son has severe autism and lot of health issues. We depend on forward health for medical needs. He gets aba therapy through Medicaid which is very crucial for learning daily living skills. - Aditya

Services provided assist our two disabled grandchildren receive the medical care they need. - Janet

Atie Beckett supports our need for services for our son who was born with a genetic deletion which causes physical and cognitive challenges. Our employer-provided insurance is a grandfathered plan under the ACA and excludes therapies and other services relating to or resulting from a developmental delay and won't cover habilitative services. Katie Beckett gives us access to essential health services, the cost of which would otherwise be insurmountable. - Christianne

My son is totally dependent on others to provide help with daily living skills. Without constant support from others, he would not survive. - Gina

We have two children with disabilities one with autism and mental illness and another with down syndrome both of them use Medicaid services in different ways they are both adults . - Patricia

Zach needs constant supervision by trained staff throughout the day when parents are working and frequently during nighttime due to challenging behavior and inability to do own personal cares/hygiene. He needs direct assistance in his paid jobs and while in the community due to significant intellectual disability, limited communication and poor reasoning/safety skills. Supported employment job coach provides safe transport and job support to maintain employment. Day supervision is provided by vocational agency between jobs and until parents can pick up at end of day. Autism causes motor issues and limited communication requiring extra transition time and visual support to complete grooming, personal cares, preparing special dietary meals, extra laundry due to incontinebce and all ADLs. Although limited available funds, respite provides support in the community and on overnights when parents travel to visit daughter in MN. Zach rents room and board from parents who provide groceries and currently provide overnight supervision. Currently parents volunteer as Rep. Payee and file all SSA required paper work. MA waiver covers specialized transportation needed to get work because home is not on Paratransit route. Although he qualified for paratransit between jobs it is more cost effective to reimburse job coach mileage (covered in vocational services rate). - Zach

Allows my mother in law to live. The level of care with meds, support etc. we simply do not have the skills to provide. - Brad

Helps fill in the gaps left by our primary insurance. - Sallie

Without these supports we would be devastated. I am the only person my minor son has to care for him and when he is an adult and I am gone, we are counting on these supports to ensure he is a contributing member of society with some quality of life. - Rebecca

Allows my son to work in the Community, and live a fulfilling meaningful life. - Bob

My son needs help with the use of therapy programs for speech, OT and food. He is 11 years old and still cannot communicate much of his feelings or needs. - Rachel

#### WAUNAKEE

If we didn't have the services, my child would be in the hospital for suicide threats, possibly be in trouble with the police, because he wouldn't be able to have learned to deal with his behaviors, he has come a long way with the help of therapies and medication, we also would have to choose what to pay and what not to treat, with out the help we are receiving - Becky

ob coaches and transportation for my daughter with Cerebral Palsy make it possible for me to work and care for elderly parents. My mother-in-law relies on Medicaid for a place to live as she needs Assisted living due to her severe Parkinson's disease. - Lynn

having someone to help care for Kainen when we are not available has been a huge relief for our family. As he has grown it has become too difficult for our extended family to assist in his transfers, toileting, etc. and has been extremely difficult for my husband and I to juggle his care. - Tracie

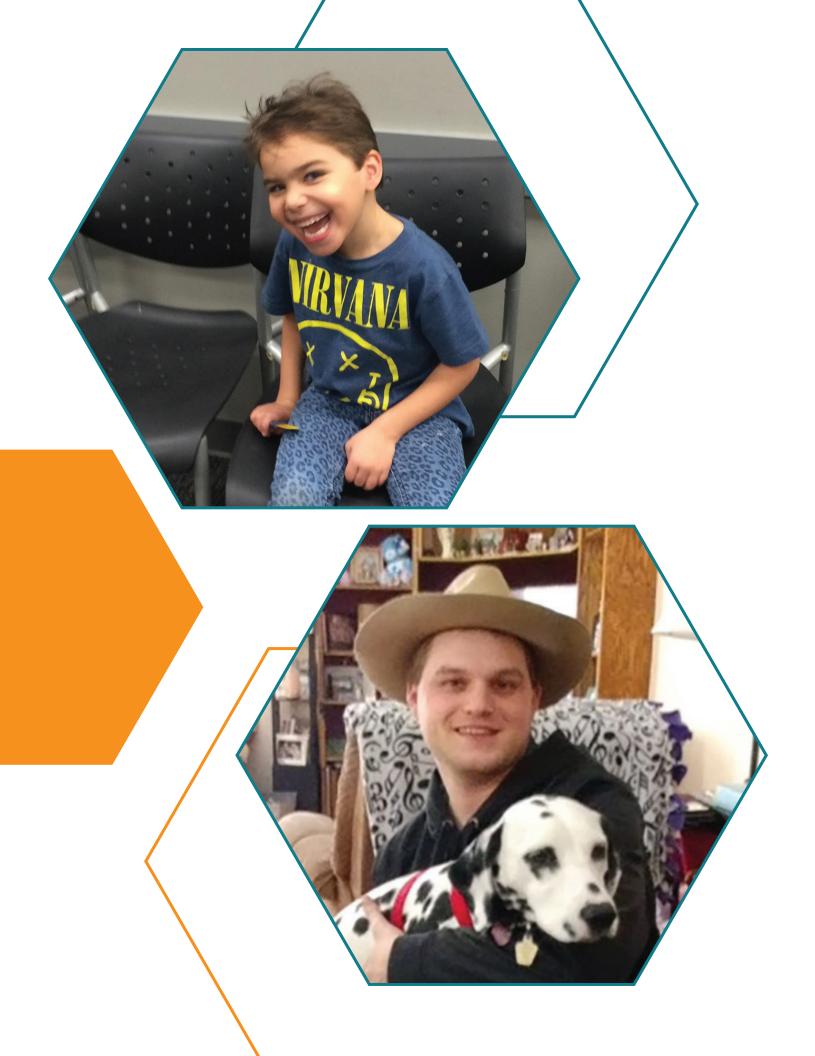
enables us to work full-time jobs, although husband recently retired. Gives us a break from caring for our son. Also enables or son to have job coaches so he can work. - Jan

Provides food and medical care - Larry WINDSOR

The care i provide my elderly disabled mother and my down syndrome sister allows them to continue to live in their own apt. Without my help, they would need to be in a nursing home. - Barb

to be able to live and work more independently - Stephanie





Wisconsin's Medicaid long-term care programs make it possible for more than 6,000 children with disabilities and more than 60,000 seniors and adults with disabilities to live in the community instead of institutions.

Wisconsin is set to become one of the first states in the nation to end longterm care waiting lists for both kids and adults with disabilities.

4VF

RIS





The Survival Coalition of Wisconsin Disability Organizations is a cross-disability coalition of more than 40 state and local organizations and groups. For more than 20 years, Survival has been focused on changing and improving policies and practices that support people with disabilities of all ages to be full participants in community life.

> www.survivalcoalitionwi.org survivalcoalitionwi@gmail.com