

What Medicaid Means to Wisconsin's 6th Congressional District



**Survival
Coalition**

of Wisconsin Disability Organizations



www.survivalcoalitionwi.org
survivalcoalitionwi@gmail.com

Medicaid Provides Funding for More than 20 Wisconsin Programs

IRIS Legacy Waivers (COP/CIP)
BadgerCare
 Wisconsin Chronic Disease Program
 Partnership *Katie Beckett*
School-based SeniorCare
services and supports ADRCs
PACE *Well Woman*
 HealthCheck (EPSDT) **Community**
SSI Managed Care Support
Birth-to-3 Program
Family Care
 Children's Long Term Support Program
 Comprehensive Community Services
 Community Recovery Services
Forward Health Card

Medicaid Enrollment in Wisconsin's 6th Congressional District Counties:

Columbia:	7,354
Dodge:	10,844
Fond du Lac:	15,440
Green Lake:	3,265
Manitowoc:	12,849
Marquette:	2,954
Ozaukee:	6,459
Sheboygan:	18,048
Waushara:	4,406
Winnebago:	26,156

Medicaid Enrollment in CD 6 includes:

811	811 children with significant disabilities in the Children's Long-Term Supports waiver program
3,622	3,622 people with disabilities who are working in the Medicaid Purchase Plan (MAPP)
7,366	7,366 people with disabilities and older adults in Family Care and IRIS

Total: 11,799

Total Medicaid Enrollment in CD 6 Counties: 107,775

Executive Summary

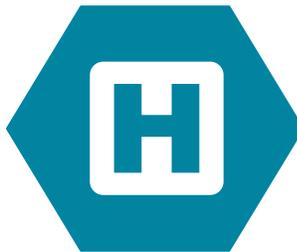
Wisconsin's Medicaid program provides critical health and long-term care services to more than 1 million Wisconsinites. Nearly two-thirds of Wisconsin Medicaid participants are older adults, people with disabilities or children, many of whom have disabilities.

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.

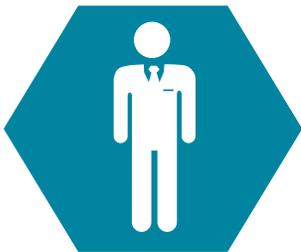
Survival Coalition surveyed 1,500 Wisconsinites who use Medicaid and found:



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.



40% said without Medicaid they wouldn't have access to medical devices like a wheelchair or speech device

Stories from People Living in Wisconsin's 6th Congressional District

Survival Coalition received the following personal stories from people who use Medicaid and live in Wisconsin's 6th 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.

BEAVER DAM

I am able to receive respite, support aids he needs that I wouldn't be able to afford. Such as his communication device \$300, his talking program \$250, sensory needs \$300 and more that he needs.—
Lisa

We adopted our special needs son when he was a baby. He is a survivor of extreme abuse and neglect. He has emotional and behavioral issues that keep him from participating in regular childhood social activities in school and the community. He has received help from Medicaid from the beginning, birth to 3, In-home Autism support, Therapy horse riding, a mentor from CCS program to take him into the community, and soon summer programs he can be with other kids to learn socialization and interaction with peers. He also receives in home psychotherapy and special education services at school-full time and medication support from a psychiatrist. Without these supports our son could not function in the home and we would not be able to manage him. The trauma he sustained will never go away but it can improve with professional help. Our insurance can't cover the total cost of all his medications and programs. We would be financially strapped with out Medicaid. I had to quit my job to stay home with our son, we are a one income family because of it.—Jennifer



BELGIUM

My son, age 52, was born with a defect condition known as Spina Bifida and hydrocephalus which back in the early 60's was not treated like it would be today. The knowledge for treatment was unknown; consequently, most of the patients with this disability died. The survivors had a long, painful, and difficult future to do and accomplish the things that a normal child could naturally do. He is paralyzed from the waist down which involves bladder and bowel incontinency and is confined to a wheelchair. This situation alone presents many physical and medical problems. He is in a shared apartment with support services thru Balance Inc. which help him in his daily living activities as well as the physical problems. The amount of services he receives are geared to his disability and needs. Taking or reducing these services, medications or support would be detrimental to his future. My husband, age 84, and myself, age 74, cannot do for him what these services are able to do. His future definitely depends on these people. –Nancy

BURNETT

Our daughter has significant disabilities, limiting her to a wheelchair. Without the necessary help, our family suffers many of the mental and physical challenges associated with it. It is extremely exhausting on a daily basis to care for our daughter. We are very desperate to keep all help available.—Tanya

CEDARBURG

If it were not for these services my child would be in an institution.—Maribeth

Without these services, my brother would probably not have lived as long as he has. His group home living situation provides him with rehabilitation services and daily care that his family cannot provide.— Gwyn

My grandson, who I assist daily might loose his ot, pt, and speech therapist, as well as his oncology visits, he can not breath with out oxygen support, needs an o2 sensor, can't walk, working on regaining his speech...This is just the beginning....—Deb

My son is part of the Katy Beckett program. He has many sensory issues. His medication has to be in liquids form, because he will not take pills. He also cannot tolerate dental procedures. He has to go under general anesthesia in an OR. The dental procedures were not covered by my employer insurance. These were very expensive, Katy Beckett cover it in full. I could not afford these, I am a widow raising three boys. –Kay

The transportation provides my son with independence and socialization, which he values. It also affords him more opportunities to participate in activities than I could provide for him. –Joan

Our son, Adam is successfully living on his own due to the support he is receiving. He would not be able to live on his own without the help of the programs he currently has.—Gail

CEDAR GROVE

I receive excellent healthcare by staff of my choosing. I am in a pre-vocational program and recreation/activity program that I enjoy and gives me self-worth. I receive transportation services that enhance my mobility.—Leslie

ELKHART LAKE

Prescription drugs would be too costly if Medicaid were reduced. Respite care through Community Care is also essential.—Tim and Pat

FOND DU LAC

Supported home care to help me take care of myself and learn to live independently. Transportation to things I need and want to do like going to church, shopping and school. —Hunter

Without IRIS wouldn't have a job, a job coach, someone to eat or read or take me to store, couldn't have friends.—Joseph

Covers child's health care, transportation from sheltered workshop, respite services throughout the year as needs.—David

FREDONIA

Two adult daughters have autism. One attends Adult Daycare Services full time; the other has parttime jobs. These are all possible for them because of the Family Care program. Medicaid covers the medical care needed for them to stay as healthy as possible given their disabilities.—Donna

Three autistic teenage to adult sons. My wife died over a year ago. I can't care for them on my own so the support service help bath, feed, clothe, them. Not enough though because I'm still unable to return to work because we still have gaps in coverage to help them.—Tim

They make it possible for me to work and contribute to my community.—Mary

FRIESLAND

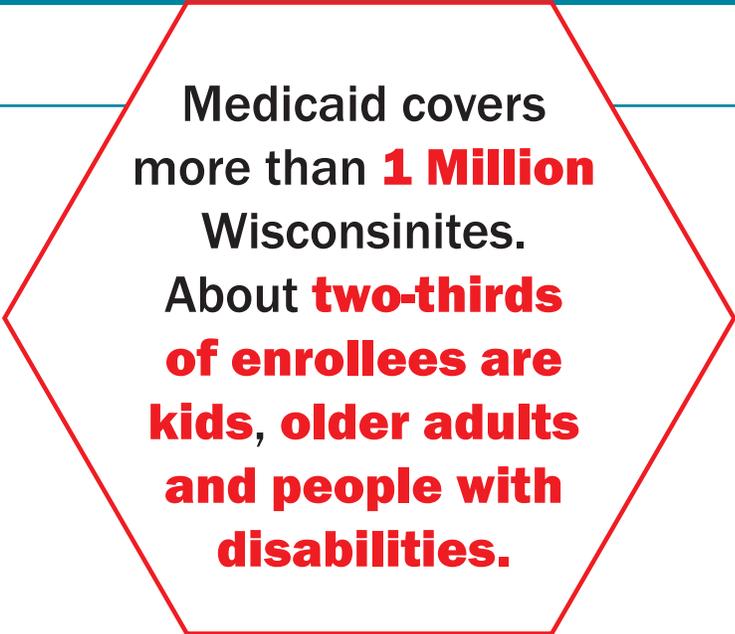
These services allow me to be a member of my community by providing me transportation to work and to other community based services. These services also provide the medical attention I need to stay healthy.—Ben

GRAFTON

Family member with MS requires expensive, specialized medical care. Cog display son with 2 chronic medical issues requires assistance to access programs to improve quality of life. Also, requires specialized healthcare.—Mary

It helps for our son to be less dependent on us when we will no longer be here.—Elizabeth

They allow us to continue to keep our daughter home with us and allow us to work full time.—Gabrielle



Medicaid covers more than 1 Million Wisconsinites. About two-thirds of enrollees are kids, older adults and people with disabilities.

My 32 year old daughter is blind, disabled, developmentally delayed, has a chronic, progressive disease with no cure, needs 24/7 assistance with all ADL's. I am with her at all times and need the respite I receive from home health agencies to get out and run errands, appts for self, and to try to have an enjoyable much needed break. I am a single parent with no "family members help", concerned about my own aging needs and ability to continue taking care of her. Having these support programs have allowed me to stay home and take care of her.
—Mary



MANITOWOC

My son has autism and regularly sees a therapist to help him succeed. Without the Forward Card we could not afford this care.—Paul

My daughter has multiple disabilities. Our family would not be able to function at all if we did not have the supports we have. It reduces the stress level I have being her case manager. I don't have to put my daughter in front of the TV while I deal with physicians, home care companies, day services, and the rest. I work as a Family Engagement Coordinator for the Wisconsin Statewide Parent-Educator Initiative, a DPI grant. I help parents with children with disabilities understand special education. I am working with the same population that is effected by the services being talked about here. I would not be able to work with these families if it wasn't for what I receive from the state and federal governments.— Deena

MAYVILLE

My son is severely autistic, is nonverbal, has seizures and other medical issues. He lives in a supported apartment and needs round the clock care and supervision. —Deenette

MENASHA

With my daughter's Medicaid benefits, I know that my she is getting the medical and developmental care she needs without having to worry about if we can afford to have her seen by her medical providers and therapists. If we did not have Forward Health for her, I'm not sure how we would be able to pay the bills we would get from her providers since we have a High Deductible Health Plan from a private insurance company through my husbands employer. We would be in debt with medical bills since I am only working on a very part-time basis in order to be home to care for my daughter to make sure her needs are met. Without Forward Health, we may have to take her only when absolutely necessary and health and development would suffer greatly if we were not getting assistance from Medicaid for her.—Ann

My 13 yr old son is profoundly disabled requiring 24/7 care for all his needs. He is on numerous medications that primary insurance does not always cover 100%. He requires diapers that MA funds. I, his mother, provide all his care but am able to use respite money for a caregiver 20 hours a month so I can leave the house.—Connie

MEQUON

Without the health and community supports my 91 year old parents receive they would need to leave their own home and move into a nursing home.—Michelle

Employed 16 years Panera, 10 years Willowbrook, (senior apt. complex for elderly), various activities offered at Portal Inc.1 day/week. Transportation via OZ. Taxi helps maximize independence.—Joyce

My son has been able to participate in a number of social, leadership and mentor programs which has definitely had an impact on his ability to navigate his environment. He now is able to continue a job that he loves with a part time coach paid from his long term care money.—Kathleen

they are literally a life saver. I wouldn't be able to pay for my meds, no transportation, no emotional support. I wouldn't eat well, no help with my seizures. I get medical care at 5 different hospital systems and wouldn't have that if it were not for my mom. I don't think I would survive.—Name not provided

If Kelsey didn't have the services that I provide to her on a daily basis, she would have to live in a care facility. She will never be independent, so living at home with the family is dependent on her being able to receive these services.—Tammy

NEENAH

The medical care my disabled son receives inpatient and at home due to Children's Long Term Support waiver(s) / Katie Beckett program helps our family defray costs for things including: • Prescription medications • Skilled Nursing home visits • Office visits with primary doctors and specialists • Physical Therapy, Occupational Therapy and Speech Therapy • Durable Medical Equipment Rental and Medical Supplies • Emergency Department visits • Local Ambulance and Life Flights • Surgical Procedures • Hospitalization for both Acute and Intensive Care Our son's health and well being depend on the affordability of these items and my ability to stay home to care for him.—Andrea

Senior care helps to provide insulin for my family member who requires it. Another family was able to receive treatment for opioid addiction and my son, when we were eligible, was able to receive care and equipment for his disability. —Jennifer



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

My son sees many specialists and has had many medical procedures. If he did not qualify for Katie Beckett we would not be able to afford his medical bills.—Jill

These medical supplies are expensive and we would not be able to make ends meet. And the respite provided for our family helps alot for shopping and piece of mind.—Brenda

My friend/co-workers son is 4 years old and has down syndrome. I have seen the struggles that have come to them after he was 3 and not old enough to receive help from public schools. They've had to look for several daycare solutions after he was becoming a challenge in the day to day setting. They've been in contact with daycares that just aren't that accepting of children with disabilities. They've finally found a daycare that has welcomed him with open arms and these programs have helped them pay for daycare, a state aide worker, and much more. I hear from his mother every day how much improvement she's seen in him with the extra attention where he had previously been regressing. Daycare aside, the programs assist in the every day health struggles associated with Down Syndrome. Between doctors, therapists and hospital visits, they rely heavily on these programs for financial support.—Name not provided

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

OSHKOSH

We have used the Long term waiver for supplemental services to help teach skills not covered in the school district that need to be implicitly taught. These services work with family and child with autism. My son needs much more repetitive education to function independently successfully at school, in the community and at home. The intense focus we spend with these interventions have affected our entire family. We use respite funds to allow for a break from parents as well as for us as parents.—Pam

My daughter works part-time and cannot do her job without a job coach. She has epilepsy and is developmentally delayed, thus she needs supervision. She also needs the medical services and medication.— Deanna

Having support from medical assistance allows us to obtain equipment/supplies/medications/care needed to improve our daughter's quality of life and prevents us from using a disproportionate amount of resources on our disabled child (we have two other school-aged children).—Amy

My son has therapy for his autism, physical, occupational, speech and behavioral.—Laura

Prior to these services our son was not able to do anything independently. The help from several services has not only given our son some independence but it has also helped our family tremendously financially. Without these services we would not be able to afford medication or doctors visits. Prior to these services our son was not getting all the medical care he needed because we were drowning in medical debt. These services have given my son a voice by providing him with speech devices that we could not have afforded on our own.— Cassy

Without the team of therapists, Teddy would not be walking. He has made tremendous progress with his gross and fine motor skills yet still has tremendous work to do. —Kerry

Medicaid pays for my sons ABA Therapy, he is 4, and in the passed 3 months he has gained words, is almost potty trained, has been making strides in learning colors, letters, and using sentences.— Amanda



My grandson is a 4 year old with Down Syndrome. After using the Birth to Three Program my son and daughter in law realized there is a gap in between services for children who are 3 years old and not in school yet to receive the public school's help. Their in home daycare provider was unable to keep him there any longer as he grew more challenging in a day to day setting. While my son and daughter in law were looking for a new day care they found that day care providers are not very accepting of children with disabilities in their area. Thankfully after many searches they found a compassionate director at Kyria Day Care who was willing to take on my grandson and his needs. She also informed my son and daughter in law that they could look to see if they were eligible for a state one on one aide to help my grandson with his daily needs and routines as he needs much more repetition than most children in order to learn. They are now very fortunate to have been

approved for a state aide. Because of that our grandson is no longer regressing and is incorporated into daily class routines with all the other children and is now thriving. Just because of that small change. It is truly amazing for them! The Forward Health Card also helps them out financially! He has been hospitalized 3 times in a 4 year period for respiratory issues as pneumonia and dehydration. All of the bills for those stays on top of his regular and specialty doctors that he needs to see (therapists) would not be able to be covered by them had they not had the financial assistance that they have. –Debbie

My husband and I just brought our third child into the world. Our eldest child is severely dependent and we would not have been able to give him siblings without the nursing help that Katie Beckett and Respite care provide.—Name not provided

They help so that we both can still can continue to work our jobs on a daily basis with a child with severe mental health issues. They also help give us a well needed break from the daily frustrations of raising a child like this by providing some respite. –Lisa

My son is totally dependent on others for care. He receives day services so that my husband and I can work. Iris allows us to fund his day program and we also use the funds for personal cares and mileage. –Wendy

I would not be able to work and getting anything done would be impossible as a single parent.—Sonita

Simply put, I couldn't live without these services.—Stacy

I would not be able to live independently if I was not receiving these services. They assist me with meal prep and seeing up appointments and becoming more organized. They assist with keeping my apartment clean and motivating me to do it also.—Allan

I'm only getting started with ADRC, but the MAPP program and other programs we're looking to get me involved in will help me be more independent and reduce the strain on my 74-yr old mother, who is my caregiver.—Lisa

My husband needs IRIS due to a physical Disability, I need home care due to a severe chronic illness and one of my sons needs Mental health services and CLTS.—Wendy



They enable us to live as “normal” of a life as possible. I have two typical children and if I couldn’t get help with my disabled child, I couldn’t support them the same way. –Rachael

Our son requires assistance to maintain a healthy living environment.—Sara

PARDEEVILLE

We would have no financial means to pay for the services my son receives now.—Kimberly

Trained job coach helps my daughter work in the community where she earns minimum wage. Trained staff at facility based facility help her learn new tasks and maintain current skills. Helps her work on her “soft skills” in a safe environment. Enables her to work and interact with her peers who have become her friends. She earns a paycheck via the sub minimum wage commensurate with her productivity. Transportation helps her get to/from work. Time to volunteer in the community with trained staff.—Dallas



I received help to be dressed and groomed and seated in my wheelchair. My meals are prepared and served to me. When I need help with anything during the day that my disability won’t allow me to accomplish, the help is there. That can be getting set up to read a digital book, look up something on the internet, choose a channel on the TV etc. I need help with just about everything including transportation. –Dawn

PLYMOUTH

My daughter is my daughters PCW which then gives me that break that is sometimes needed. My son also uses Paragon services which is support for disabled adult and teen day program it is another RESPITE service for parents for the SOCIAL part of there day so they can be around people with the same or worse but not be bullied but excepted. There people too give them a break.—Lisa



PORTAGE

I’m a single mother. I work outside the home. MA helps us to cover Rx copays; Dr an treatment copays all for my son. He sees a multitude of specialists and is on 14 different medications to help with the effects of his autism and the epilepsy he deals with. I would not be able to work or carry private insurance or pay for any of this help without Medicaid.—Holly

Without the health care supports my child has received, we may have lost our home for example. BUT... The stress from constantly worrying about losing healthcare coverage for my child, has undoubtedly contributed to my current health problems. This has in turn affected my ability to care for her, my family and myself. Healthcare coverage is very literally a matter of life and death for my child and myself. Without medical care and coverage we would both not be alive. I recently applied for disability coverage for myself and was denied without even a review, because of my husband's income level and the fact that I have worked only in an extremely limited capacity since my child was born due to her severe disabilities and mine. I have several life threatening and physically disabling diseases which should undoubtedly qualify me for supports. This has greatly discouraged me in many ways. Supports would matter in so many ways. I could care for myself, my family and child better. I believe my health could improve. My husband would be less desperate about having so much of the burden. A system that makes qualification so difficult for people with legitimate and severe health problems, contributes to struggles that are already overwhelming. Sometimes people who have the least capability of standing up, are those who have the greatest need.
-Rebecca

PORT WASHINGTON

The services and supports assist my family members to maintain their skills, improve their personal and social well being, sustain a basic level of quality of live and provide respite to re-energize care givers. Our most vulnerable citizens should not be forgotten in great country. – Carole

I have had some health problems and I would not have been able to take care of our child.– Geraldine
I'm blind and I need transportation to my job and to Dr. Appt. and grocery shopping. I also use a cpap machine.—James

The support our daughter receives allows us to breathe more easily knowing that she is being mentored through many tasks of daily living.—Name not provided

It helps to keep her at home and healthy.– Michele

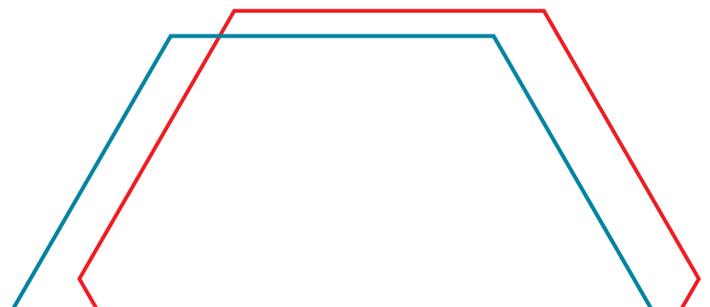
I am able to be an active participant in society, Caring for elderly by supporting meals on wheels. – Jacob

RIO

My granddaughter is covered by Badger Care and is autistic. She is in therapy to learn social skills and would not be able to afford this without Badger Care.—Mary Ann

RIPON

It keeps me out of a nursing home, as I am bed bound. My home care aides get me out of bed and into my wheelchair.—Name not provided



SAUKVILLE

This service allows me to keep my young adult man at home and to have help with daily hygiene care, allows me to get him to his day services programs and to see his primary care physician, neurologist, and psychologist. He is a challenge as he is non-verbal, autistic and has epilepsy. He is a large young man of 39 years of age and weighs in at 287lbs. At our age any help is well received and has allowed us to keep him in our home and the care he deserves. –Diane

My son has spina bifida. He has many medical needs including a wheelchair, AFOs, monthly urinary catheter and bladder irrigation supplies, multiple medications. He also receives physical therapy services and special help through school. He has a VP shunt to manage hydrocephalus and has had many orthopedic surgeries in his 12 years. He requires assistance with many activities of daily living, especially bowel and bladder management. –Jenni



SHEBOYGAN

Knowing that she has health care for her medical, transportation, prescriptions, and support for her daily living- If we didn't have this I don't know what we would do!—Michelle

SHEBOYGAN FALLS

With these services my son has at least a chance at continuing to develop and live a fulfilling life. He requires constant 7 x 24 hour supervision and care.—Kathy

These services allow me to maintain my full-time job, and help my son stay at home during the day.—Patti

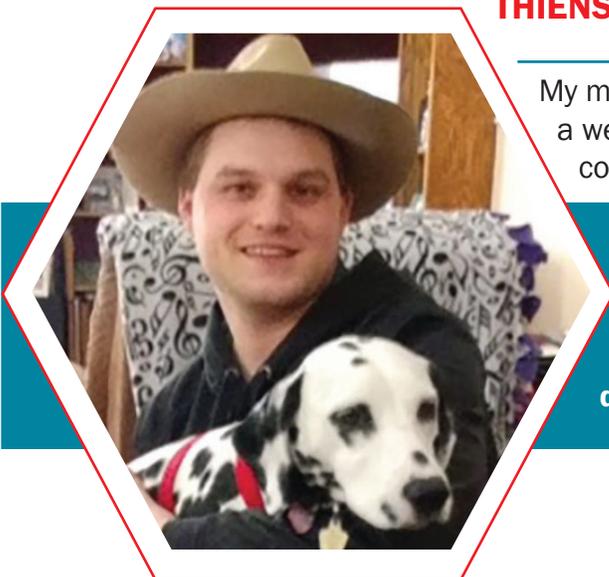
THERESA

Allows me to get the Medical help that my children need.— Jessica

THIENSVILLE

My mother who is 86 does most of my care. The daily use of ADS is a welcome help. I have lived at home all my life and would like to continue that.— Mary Elizabeth

The supports enable my adult daughter to live a more independent life. She is able to spend time in the community and feel more like a typical young adult. Without supports she would be very isolated and much more dependent.— Michele



My daughter needs all personal care: dressing, feeding, toileting, bathing. She must be fed 4 times and uses the toilet about 10 times per day. This is an exhausting and demanding schedule for me and her mother. I am grateful that I don't work outside the home, but I do have other responsibilities for my family members, including aging parents. It is critical that I have respite in order to take care of my other responsibilities, as well as to keep myself healthy to continue caring for my daughter as long as possible. Also, specialized formula and feeding equipment, and durable medical equipment such as a wheelchair, as well as doctor appointments really add up. The financial assistance through Medicaid is critical to cover these costs.—Ann

VALDERS

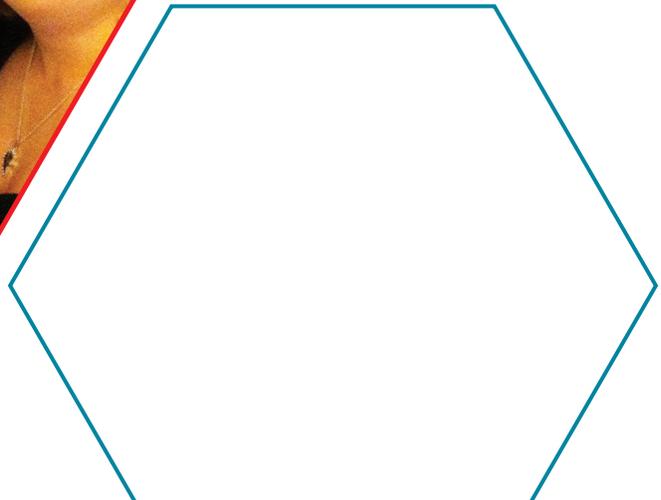
My daughter was diagnosed with Spastic Quadripaligic Cerebral Palsy & has a seizure disorder. Without IRIS, she can live in our home instead of a long term care facility. She is completely dependent on us for ADL, communication, transportation, medication, etc. Without IRIS, she would not be able to live in Victoria

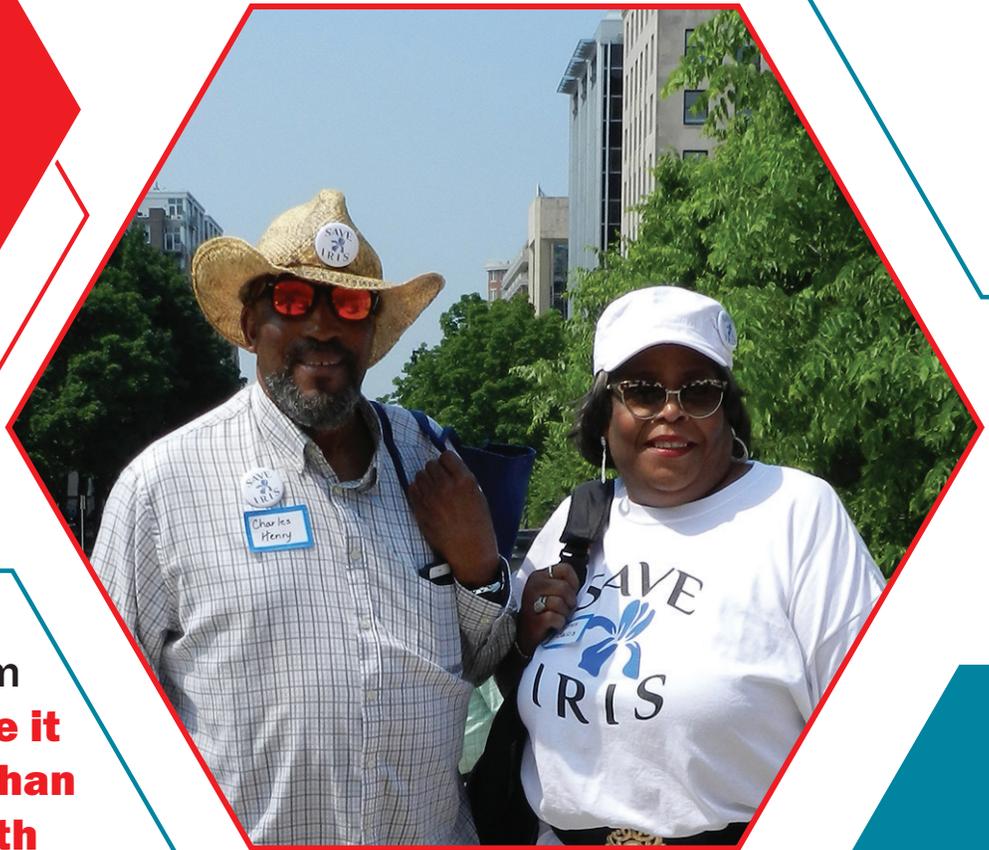
WESTFIELD

To improve health and medical conditions, so my nephew can live as typical a life as possible.—S

WHITELAW

Day services allow my daughter to get out of the house and into the community to socialize with peers and participate in activities that typically developed young adults are able to do on their own.—Nancy





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 long-term care waiting lists** for both kids and adults with disabilities.





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**

