

# What Medicaid Means to Wisconsin's 1st Congressional District



**Survival  
Coalition**

of Wisconsin Disability Organizations

# Medicaid Provides Funding for More than 20 Wisconsin Programs

**IRIS**

**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 Program

**Birth-to-3** Family Care

Children's Long Term Support Program

Comprehensive Community Services

Community Recovery Services

**Forward Health Card**

Legacy Waivers (COP/CIP)

MAPP

## Medicaid Enrollment in Wisconsin's 1st Congressional District Counties:

Milwaukee:  
**310,776**

Racine:  
**42,486**

Kenosha:  
**35,050**

Walworth:  
**16,661**

Rock:  
**35,701**

Waukesha:  
**30,370**

**Total Medicaid Enrollment in CD 1 Counties: 472,044**

## Medicaid Enrollment in CD 1 includes:

**1,900**

**1,900 children** with significant disabilities in the Children's Long-Term Supports waiver program

**25,000**

**25,000 people** with disabilities and older adults in Family Care and IRIS

**9,000**

**9,000 people** with disabilities who are working in the **Medicaid Purchase Plan (MAPP)**

**Total Enrollment: 35,900**

# 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 1st Congressional District

Survival Coalition received the following personal stories from people who use Medicaid and live in Wisconsin's 1st 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.

## BURLINGTON

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*"I can't afford health care insurance. I've paid income taxes and SS my entire life but now that my income is drastically reduced as I have aged the Badger Care I receive allows me to stay healthy."*

—Michael

*"I could not work outside of the home without help for my child with a disability."*—Sonja

## MOUNT PLEASANT

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*"The mental health counseling that I receive in Racine is very, very good. My counselor and my Psychologist are professional and caring. They have helped me set attainable goals so I can move forward with my life after a very difficult time in 2014-15. I have floating anxiety and need to continue to see both doctor's on a regular basis to keep my life in order."*—John

*"Transporting to school and PT/OT services at school and other facility for private therapy."*—Ben

## KENOSHA

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*"These services allow us to focus on our time with our children by not working excessive hours to cover medical costs."*—Kenosha



**“E**very week my brother is given the taste of independence via aid from respite workers through IRIS. These workers include my mother and I, among others. My brother is a 20-year-old nonverbal man with autism who spells and is currently learning to type. The services provided to him range from toilet and hygiene care to our weekly exercise day (Saturday’s). Burnout is easy to get when supporting someone who needs help every day, but the other respite workers (more like family after all these years) ease the burdens he cannot help; IRIS offers relief a few times a week. This relief is not only for my family, but for Carlos, my brother, as well. Going to work with support from his aid, Heather, or walking around downtown to get an iced tea is a simple activity that holds in its hands the power of autonomy through action. This autonomy is a right, but is often treated like a luxury today. Taking care of those who need help should not be something we are debating about. Extending a hand to those who are differently-abled is something that should be woven into the fabric of America by now. Do not take this away.”—John

“He takes medication for mental health diagnoses, ADHD, behaviors related to autism spectrum disorder, as well as psychiatric care. He receives in home care for suicidal ideations, behavior treatment, support for ADL’s and iADL’s, daily living skills training, social communication support and safety in the community, and support for him to attend college and to live on campus for safety, socialization, and communication.  
”—Mary

“We could not afford her healthcare at all on our current health plan.”—Misty

“Peace of mind knowing my son has that additional coverage.”—Kristie

**“O**ur son had difficulties with nutrition early on in life. Early intervention program has helped provide a speech therapist as well as a physical therapist to help get him on track. He has made huge progress in the last few months both nutritionally and developmentally. Without these programs in place we would surely be frequenting the physician’s office as well as hospitals on a regular basis.”  
—Stefanie

“My 24 year old daughter is living independently with modest supports. She recently started working. Transportation remains a problem.”—Mary



**“T**he medications and therapies help my sons to be able to function in their daily life. Without them they would probably be in an institution.”  
—Gail

“They help my autistic sons be more functional and independent.”—Peggy

“My son gets to be home and be loved and taken care of the right way. It is 24/7 care as a parent I don’t have to worry I know he is happy and could not be taken care of any better.”—Linda

## RACINE

“If it wasn’t for Iris my daughter probably wouldn’t still be able to live at home or go to her volunteer job with a job coach or receive medical care she would not be able to handle the change or environment of a group home her life would fall apart”—Paula

“I have cerebral palsy by birth. With services/health, I’m living independently in an apt. without medicare/medicaid, I’d be in a nursing home...”—Anita

“Helps me maintain my mental health so I can be a help and not a hindrance to my family and friends.”  
—Pete

**“K**evin is able to live an independent life, explore and enjoy his community, and travel safely with support from caregiver team. This allows family to work and live a life separate but connected to Kevin’s.”—Mike

“To live as independently as possible while needing constant supervision because of autistic savant behavioral issues.”—Linda

## FRANKLIN

**“I**’m a ventilator dependent quadriplegic and my nursing care is provided by Medicaid. Without it, I’d have to leave my home and go into a nursing home. A nursing home would be a literal death sentence for someone on a ventilator. Pneumonia, pressure sores, and neglect are the norm.”  
—Eric

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

*"Without services for a family member he would not be with us. He has severe mental health and addiction issues the Badger Care program has allowed him to get the medical and psychological attention he needs as he is unable to work due to his medical issues. I work with children ages 3-21 whose parents rely on the medical supports they need to keep their children alive. I have several children within my oversight that have daily medical needs, will need the long term support, they currently are receiving medical and psychological support along with strategies to support their child with needs such as Autism, behavioral and learning needs. People who are making these decisions need to attend a school early childhood program or a program with students who have Intellectual Disabilities for even an hour to see the huge amount of care and services that children need not just at school, but in and around the community. Even middle class and above income families need supports for their children with multiple needs."*—Karla



*"For my ward, they have kept her alive. She was very ill and ended up in hospice. With assistance and supervision of her case manager and myself, she was nursed back to health and was just taken off hospice services. She is a survivor."*—Christina

## GREENDALE

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*"My son has many medical issues and the Katie Beckett program assists us in paying for these medical costs. I don't know how we could afford his care without."*—Laurie

*"I am able to stay healthy, stay safe, live in my home, keep me active, and spend time with family, friends, and people I know in the community."*—Ben

## WATERFORD

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*"The current supports through IRIS allow my son to live at home with his family. Without this support he will be forced into institutionalized care."*—Julie

## MUSKEGO

***"We would be impoverished or my son would be in a facility instead of being happy and healthy at home. Our insurance does not cover his diapers or gtube feedings which is over \$1200 per month without including his daily meds which would be out of pocket over \$800 after our insurance. We are so thankful for Medicaid."*** —Tracey

## NEW BERLIN

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*"These services allow my daughter to be cared for in her own home in familiar surroundings and with people familiar to her who are well trained and long term employees, including me."*—Sharon

## WAUKESHA

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*"We wouldn't survive without them. My child needs 24/7 care."*—Nancy

## DOUSMAN

*"It puts us at ease knowing that max will be cared for no matter what."*—Kristen

## NORTH PRAIRIE

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*"Our family paid more than \$300/month our daughters prescriptions (with insurance) without Medicaid. My daughter is planning on living independently in 3 years. This would not be possible without Medicaid. Also, we are using her IRIS funding to prepare her and sustain her with independent living. We absorbed all of this financially prior to receiving support from the state. We have two other daughters who need care, funding for college, etc. Medicaid and IRIS are helping our family financially and enabling us to invest time and resources into all of our children."*—Name not provided

## DECORAH

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*"My daughter is able to live independently with help because of her cerebral palsy she could not otherwise."*—Jacqueline

## GLOUCESTER

*"My daughter would not be able to survive without the supports she receives daily. She is very vulnerable emotionally and without the guidance and supports she receives she could not lead a fulfilling life."*—Christina

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

## BRISTOL

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*"These services allow my adult son to live in an adult family group home with support for his living skills, care and access to a supported work environment."*—Jennifer

## DEHAVAN

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*"They allow her to attend VIP Services, which provides her with a social network of friends who are also disabled. Without them she would be at home most of her days. Family Care also helps with in-home support she receives for a short time daily and with equipment (wheelchair) and medications she needs on a daily basis."*—JoAnne



## EAGLE

*“The young man I help is epileptic, autistic, bipolar, and non-verbal. I assist him both at home and in the community. He has some very extreme behavioral issues, but his mother is trying to keep him living at home and involved in the community. Without extra services, I don’t know how she would manage. She cannot take care of him alone and support them both. He has made great progress in his 22 years of life, and he has the potential to do so much more, but he needs more time and lots of patient help.”—Laura*

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

## EAST TROY

*“My daughter has cyclic vomiting syndrome, eds, along with several other disorders and we are a single family household. I rely on mileage reimbursement to help pay for the cost of trips back and forth to physical therapy and hospital/clinic appointments. My daughter needs access to physical therapy 2x weekly and insurance has helped greatly. She’s on several medications we need covered to keep her well and out of the hospital and we need BadgerCare to continue to cover it.”—Sara*

*“Because she has service in the home I am able to work. She is also a hoyer lift and needs assistance due to being in a wheel chair. Her evening workers are from the local high school. This has helped them earn money through Consumer Direct as an employee. So far 2 of the workers are going on to be nurses. Amanda is able to teach them proper techniques in caring for someone with medical challenges. I believe the high schoolers benefit in having a flexible evening shift. They can still attend after school functions for athletic events. The young adults are also learning job skills for the medical profession, how to care for and understand someone that has a disability. Not to mention their pay helps them save for college. When we say there are cost involved in keeping disabled people in the home/ community independently the benefits this brings others is often overlooked.”—Sonja*

*“Helps teach our daughter to daily activities, and teach her to be more independent.”—anonymous*

## ELKHORN

*“The services/health care do not help me personally but help countless people I know through guardianship services and through my employment. One example: One of my wards is a 53-year-old female with symptoms of Schizoaffective disorder so severe, she requires occasional hospitalization. Plagued with delusions regarding the AF that had successfully met her needs for about 20 year, she had to be transferred to another placement. Her hygiene is so poor, she was hospitalized 2 or 3 times in 2016 with skin-related infections. And this was with excellent caregivers. Without her currently funded services, my ward would be floundering on the streets.”—Carolyn*

*"I would not be able to hold a job and provide a home for my son without in home care."*—Jill

## FRANKSVILLE

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*"The iris program has allowed my daughter to live at home in a safe and stable environment, it has also helped her cope with many physical issues and given her the opportunity to function in today's society."*

—Thomas

***"M**y family member would not be able to stay at home without the services. She is medically fragile and ventilator dependent, with a cognitive disorder. Placement for her would cost the state much more than staying with us in community if they had to try to find placement. She would end up in a ICU hospital setting."*—Brenda

## GENOA CITY

***"I**mmensurably. With the IRIS program, we have been able to seek out & utilize the supports needed in order to lead a productive, meaningful life."*—Cynthia

## LAKE GENEVA

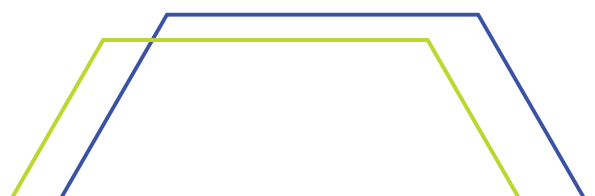
***O**ur son's needs are great and the resources we receive through the IRIS program allow us the ability to meet his needs. He meets the criteria for institutional care but our IRIS resources allow us to keep him in our home with our staff of trusted caregivers helping us care for him. We are older parents and I don't believe we'd be able to keep him in our home without our helpers that are paid by IRIS. "*—Kathy

*"Keeps me in my home where I feel safe. Group homes are scary and she meters mes they hurt you" My mom is the only person I really trust."*—E

## MUKWONAGO

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*"Keeping him healthy is essential to decrease progress of deterioration d/t having a genetic disorder. Regular MD visit & blood draws to monitor labs for health of vital organs and assessing medication dosages."*—Rebecca



*"Because our daughter is still in high school and lives at home, we do not have need for other supports at the moment. My husband and I are able to provide everything she needs right now. However, when she goes away to college and when she becomes employed, she will need MANY more of the listed services to support her in daily life."*—Lori

## **OAK CREEK**

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*"I don't currently receive services, but when my son was 3 years old till 6 years old we received the necessary supports for Autism."*—Amber

## **PLEASANT PRAIRIE**

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*"Mother unable to care for self, without these services would need to be in a nursing home."*—Anonymous

*"They allow my family to keep me at home."*—Anne

*"They allow us to work full time and allow Christine to remain home with us safely."*—Karen

## **SALEM**

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*"It allows the family member to live at home, instead of a nursing home."*—anonymous

*"I receive my Ms medications from the cancer center monthly with help from Medicaid."*—Dennis


*"It helps provide care for my daughter while I am at work, otherwise I would not be able to work. It also alleviates some of the work taking care of her."*—Dannette

## **SILVER LAKE**

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*"home & care provided"*—Juddie

*"I have degenerative disc disease, fibromyalgia, depression, high blood pressure, migraines, insomnia, severe low back pain, neuropathy, and obesity. I am in the IRIS program where I have help come in to clean my home and help me shower each day. Without this help I would be struggling to have a clean home that is safe to walk in. I would not be able to shower daily without help. The program helps pay for my medications and copays. Being on a fixed income it is very hard to have the money to cover medications and copays and my daily living expenses. I have had to rely on my family a lot before I was approved for the program to get to my appointments, clean my apartment, and help pay for my medications and copays at times. The IRIS program has helped relieve some of the stress I feel because of my low income. I had not thought I would be in this situation at my age. I am use to working. I have worked up until about 3 years and 4 months ago. I grew up on a farm and I learned that you sucked it up when you were in pain or sick because the animals came first. They had to be feed, watered, bedded, and the cows and goats milked. When I started to work off the farm this mindset came with me to each of my jobs. My last job at American Girl, I was with the company for 15 years. I believe I only missed about 10 days total being sick. Now I did miss work when I had a couple of surgeries however I made sure that I was able to be back to work within the shortest amount of time. When the problems with my back became to the point that my pain level was a 8-10 each day I took a short term leave. It took my doctor and psychologist 3 months to get me to understand that I would not be able to return to work. They worked together showing me the arthritis and damage in my lower back using x rays and MRIs. So I have had a very very hard time coming to terms with my limitations and the services that I am receiving are helping me face that I still need to make changes each day."*—Candy



## WALWORTH

*"I ABLE TO DO WHAT I WANT ANY . IAM MORE ABLE TOMAKE DIECSION TO GO OUT TO VISIT OTHER AND GET MY OWN GROCERY."*—Donna

## WHITEWATER

*"helps keep him at home and not in a group home and keeps him in public school keeps him out of jdc hope for the future."*—Linda

## WILLIAMS BAY

*"I have people who can care for my son so I can work."*—Becky

***"B**ecause of the rarity of my daughter's disease, she must see certain specialists, and take very expensive daily medications to keep her heart beating in a typical way. If those doctors or medications were no longer covered, we would not be able to guarantee her physical safety. The leading cause of death is sudden cardiac arrest and she has already surpassed published life expectancy by 6 mos."*—Courtney

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.

