

# What Medicaid Means to Wisconsin's 8th Congressional District



**Survival  
Coalition**

of Wisconsin Disability Organizations



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# 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 8th Congressional District Counties:

**Brown:**  
45,233

**Calumet:**  
4,837

**Door:**  
4,249

**Kewaunee:**  
2,880

**Marinette:**  
8,695

**Menominee:**  
2,393

**Oconto:**  
6,123

**Outagamie:**  
24,391

**Shawano:**  
7,474

**Waupaca:**  
8,944

**Winnebago:**  
26,156

## Medicaid Enrollment in CD 8 includes:

**1,118**

893 children with significant disabilities in the Children's Long-Term Supports waiver program

**3,476**

3,476 people with disabilities who are working in the Medicaid Purchase Plan (MAPP)

**7,005**

7,005 people with disabilities and older adults in Family Care and IRIS

**Total: 11,599**

**Total Medicaid Enrollment in CD 8 Counties: 141,375**

# 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 8th Congressional District

Survival Coalition received the following personal stories from people who use Medicaid and live in Wisconsin's 8th 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.

## ABRAMS

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I can see the need for these services in the home and I am aware of the costs to provide these cares in a facility like independent living or nursing facility.-- Annette

## ALGOMA

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Honestly with out CCS I wouldn't be getting the help that I need with my son. The children waiver program has been a blessing to us. My son has many different things wrong. I wouldn't have been able to get him the autism services, transitioning skills, and such with out this program. We currently are on Badger Care Plus and in May we risk losing this program because of being over by \$200. I have been on both sides of badger care paying and not paying and I am grateful for the coverage. If we lose Badger Care I don't think I could afford health insurance for my family. We are currently paying in to Badger Care now. At least I know what coverage I get. -- Stacie



**M**y son would still not be able to talk if he went without autism therapy. Our gates and fence have helped him to live a more normal life without safety concerns. His needs were once so dire, I wasn't sure if I'd be able to keep him alive. We were able to get my son an iPad to help with speech and communication. Although he struggles with expressive language, he scored in the normal range on a vocabulary test, and will likely be able to attend school with typical peers.—Katie



My son is 15 and has severe cerebral palsy so he requires total care. I have been a stay at home parent since he was born due to his needs. I am currently in college attempting to get a degree that would allow me to work outside the home. Caregivers that are paid through the Children's long term care waiver allow me to have someone home to meet his bus after school on days that I cannot, and allow me to get the extra help I need to go to school and stay sane. Once I complete my degree, I will need caregivers and/or an adult day program for my son in order for me to be able to work. My son will also need an adult day program because he will be extremely bored if he has to stay home all day once he's done with school. —Meghan

Without Medicaid my son's would not have access to the mental health professionals as our private insurance excludes any and all developmental delays and behavioral counseling for anything. The Autism therapy I'd also critical to their future success.—Heather

My child is 10 and while learning to do so, CANNOT bathe, dress or feed himself. The daily living skills that are reinforced through autism therapy are essential. He cannot mimic, imitate, follow directions or problem solve like a non disabled child can. We also receive respite services. The needs of our child are similar to that of a toddler except it's not for just a year or two (he's 10). We cannot just hire a neighbor girl down the street to babysit so we can get a break. Also-the costs of co pays, deductibles, etc that are not covered by private insurance would be financially catastrophic for our family.—Jennifer

I'm a proud community member of Augmentative Alternative Communication , Kiwanis Community , disability community , education community , and my local community. I couldn't live without the community aides they drive my van to the place that I need to go to. Please remember this when you are in Washington, D. C. or Madison, Wisconsin.— Mike

Supports for my son during day allows him to live a Real life and allows me and my husband to work.—Sue

My son is currently receiving Autism Treatment Services. We would not be able to afford treatment without Medicaid. He also has a few expensive (over \$100 a month) prescriptions and with our primary insurance we would have to meet the deductible before insurance pays a portion.—Rebecca

The services allow my son to live in a place he feels safe and access the community as he is able.—Name not provided



They Have helped get a grasp on the situation and provided us with relief and resources when we had no where to turn and we're desperate.-- Cassandra

My mother is 89. She just got approved for long-term care in her home. She's a retired Catholic school teacher with no retirement funds except Social Security. So, she gets about \$1000/mo. She has dementia and hyper tension. Medicaid provides one meal per day, visiting nurse, medication assistance, a pill dispenser, house cleaning, Lifeline, incontinence products, grocery service and eventually assisted living for her. My brother, who has multiple disabilities, is 47 and has lived in an adult group home for over 25 years. Most of his daycare is supported by Medicaid--food and food prep, personal care supervision, transportation, safety and supervision, . He is able to have his own life and friends. His healthcare is covered by Medicaid. I am able to work full time because Medicaid exists to help with my family members. I have great anxiety about it being ended. I do not have the finances or Skills to care for them myself. I am single and a teacher in a small private school. I make 20k less than my public school colleagues.-- Maureen

We are able to be family rather than managers and caretakers and he gets the cares he needs to live as independently as possible. -- Sarah

The services clients I serve helps them immensely. The services they receive all contribute to their ability and opportunity to work in the community which in turn helps them live purposeful lives. -- Melissa

Cliff is in a wheelchair with a vent, he wears the vent 20 hrs a day. Medicaid pays for his vent and equipment, prescriptions, Community care takes care of costs that Medicare, Medicaid and Network do not cover. My husband can only slide to toilet, shower chair and bed. Community care provides what ever transfer equipment needed. They are here once a month to asses our situation for safety. Financially and physically this makes it feasible for us to stay in our home. If I can not care for him, he would be in a nursing home. Me in a small subsidized apartment. We would be separated.-- Debbie and Cliff



I need services the minute I wake up everyday in order to get to the bathroom, take a bath, shave, prepare breakfast, eat it, get my clothes on, my shoes, check my health, make sure I don't fall down, get to work, do my work, etc., etc., etc.-- Phillip

No insurance without it. No insurance for adopted children without it.-- Denise

Many of these individuals, especially the disabled folks and frail elders depend on these programs for their very existence and also for their dignity and quality of life.--Gale

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

My ten year old son receives in-home autism therapy that is allowing him to grow to have the best life skills that he is able to have. We have Medicaid as a secondary insurance which helps to pay our deductible from my husband's employer based insurance. The strides that he has made in the past two years of receiving therapy have been incredible and the idea of losing or having time limited is very upsetting. Not having Medicaid as a backup would be an incredible hardship for our family.

–Elizabeth

We have a caregiver who comes in and gives me respite from constant 24/7 care for my daughter. I have a husband who receives counseling for depression from prior cancer treatment

that Medicaid was a huge help with paying of medical costs at that time. I've been on Medicaid because of income and will be taken off soon because our income will have risen. I didn't need to worry about paying high bills for doctor visits and prescription costs.—Lisa



## BLACK CREEK

**I am a parent of two children with special needs that we adopted from Wisconsin Foster Care. Both of my children are wheelchair bound. They need help with all personal cares. We need lifts to manage their care and personnel to assist us. They have multiple medical needs - the oldest has cerebral palsy, Asperger's, anxiety, and limited use of limbs. He needs to be taken swimming for exercise and special care for his back due to spinal fusion. Our daughter is even more complex with cerebral palsy, seizure disorder, non-verbal, g-tube fed, eye gaze communication and severe tone issues. She is needing surgery again to relieve pain and give her the ability to stand in a stander. She suffers from digestive problems and sees several specialists in Madison to keep her healthy. We have had to modify our home to accommodate their needs - ceiling and stair lifts, vinyl flooring, ramp, door widening, bathroom remodel, etc. Taking care of our children is expensive and exhausting and taking a toll on my husband and I. We need all the help we can get to keep up.—Name not provided**

## BRILLION

Allow me to see Doctors and Specialist to treat and manage my epilepsy and heart condition.—Davide

## CLINTONVILLE

I would not be able to work without the help. My daughter is 24/7 cares. She can not be left alone at all. My daughter is 20 years old but has a mind of a 5 year old. She does not realize safety issue. She will walk out in front of a car go with people she doesn't know that is some of her issue.to many to mention on here. she needs the extra help she gets from Medicare other wise we would be homeless because of me not being able to work without the help.— Penny

## DE PERE

It would be impossible for my husband and I to both be employed if Our son didn't receive any assistance, and I am also a sister to an adult with disabilities and my mother is aging with medical issues so she would be unable to get out of these services were not available. –Amy



## FORESTVILLE

Living with a developmental disability has been challenging. I rely on the help of my family for nearly every aspect of my life. –Emily

## FREEDOM

If I didn't receive this help, I would lose everything..my freedom, my home, my health..everything...– Tracie

## GREEN BAY

**T**he supports allow my son to be able to receive autism therapy. This therapy helps him learn more, and grow more like other children his age. He has made so many gains from this therapy, that if it wasn't for the therapists, he wouldn't be as far along in his learning as he is today. With the clts, we are also able to receive such things as fidget toys and a weighted blanket, which would otherwise be too expensive for our family to afford.– Eileen

My daughter needs 24 hour supervisions. We help with her personal needs, give her medication, transportation, financial needs. She leads as independent live as possible, she lives at home and we adjust our work schedules so we can be with her. IRIS has helped with getting respite care, helped source programs for her and let us keep her in a safe loving environment.—Julie

Medications, and sometimes surgeries, to keep my disease under control so I can work. Regular check-up and basic health care also.—Name not provided

Make it possible to afford medical visits, medicine, and needed therapy.—Erin

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





Allows son to live in his community.— Cheri

They help me lead a quality life as independent as possible.—Jessica

Mother in Law is 96 yrs of age. Lived in her own home until 3 yrs ago when she had a stroke and needed care in an Assisted Living. She privately paid for 3 yrs and recently went on to Family Care.  
— Mary

They help me with cleaning and cooking and shopping.—Karrie

ABA therapy, medications, medical coverage, community programs.— Miriah

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

## GREENVILLE

**M**y disabled and medically complex son is completely dependent on a caregiver for his daily needs. Our home health nurses are our only option for a secondary caregiver as none of our friends and family are willing to learn his cares. It is necessary for two trained caregivers to travel with him to doctor appointments out of town. Also, my son's medical and therapy needs requires prescriptions, appointments, & equipment. While Medicaid is not my son's primary insurance it has been vital to helping my son to be his healthiest, to avoid the expensive hospital stays, and to help him work towards being an active, contributing member of society.—Katie

My severely autistic, non-verbal 10 year old daughter would not be able to function day to day without significant support and therapies. Without them, her quality of life (as well as that of her caregivers) would be severely compromised. She would not be able to communicate or take care of basic needs. She still relies on diapers and drinks from a bottle. It takes 2 people to brush her teeth or bathe her. We have to put her under anesthesia for basic dental check ups. The average person simply has no idea.—Catherine

I run an Owner Occupied Adult Family Home for clients who are Developmentally Disabled, Frail Elderly or who have some other disability that prevents them from living independently. While I provide a safe, loving home and a family environment, access to opportunities in the community, skills training to reach their highest level of independence, I am not able to provide some of the therapies, personal cares or treatments that Medicaid has been able to make available. Co-pays and other expenses are often cost prohibitive to the people I serve.



## HORTONVILLE

Medicaid pays for incontinence supplies for my son as they are not paid by health care or medicare. He is enrolled in IRIS and receives services through that program that are not covered under other programs. Without medicaid assistance he would not be able to afford the medications he needs. He also would not be able to be out in the community or at programs like Adult Day Care and Lakeside Packaging Plus.— Mary Ann

It is amazing and honestly we could not do it all without help.—Katie

These programs are crucial for helping towards to cost of autism therapy, medical appointment and prescription drugs that have become a part of our (my son's) daily life. Without these services as a single mother I could not afford the therapies/medicine that he needs to function on a daily basis.— Audra



## KAUKAUNA

The Katie Beckett program prevents us from going under financially due to the extremely high costs associated with my daughters seizure medicine. We have a high deductible health plan and her medication costs \$3600 per month. This would be a devastating expense for us.—Sherri

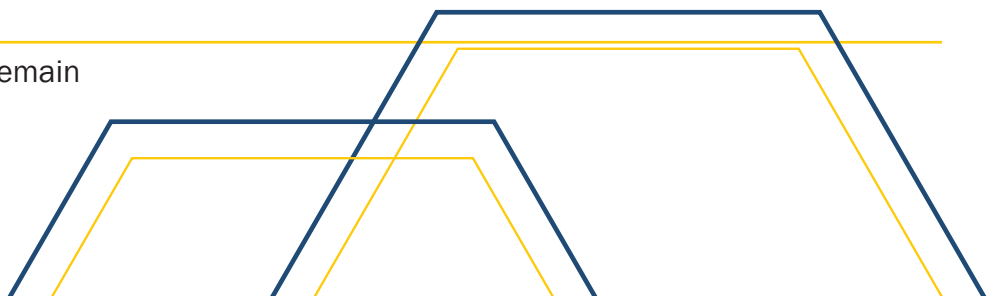
We carry a primary insurance and Medicaid as secondary. With us having 2 children with disabilities we often run across items that may not be covered by our primary insurance and often then the Medicaid will cover. This helps assure that both my children get the support they need. I have one child with more of a cognitive disability (Autism and seizures) and the other one with a physical disability so we basically cover the spectrum of needs. We also have 2 other children, so being a family of 6 the financial help is a plus. When I specifically look at my son with the physical disability these programs have helped us give him independence (ramp for his wheelchair, hard surface flooring, roll in shower) and the medical supplies to keep him safe (thickener for liquids, Pedisure for calories). I think the one message I would like to convey is with all of the help we get through these programs, there are also 'extra' needs not covered by the programs. So without these programs I don't think we could survive - they help create balance.—Kim

## KESHENA

It helps with getting needed services for chronic health illness and long term care with in their home and not having to be cared for in a nursing home.— Melanie

## KIEL

The IRIS program helps my client to remain independent and out of a nursing home. – Daphne



## KIMBERLY

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My sister needs 24/7 care and received wonderful care at her assisted living home. She pays her room and board costs and Family Care takes care of everything else.—Barbara

The services allow myself and my adult son to remain in our own home. They also keep us as independent and as healthy as possible as possible. —Lori

## LITTLE CHUTE

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My daughter will be 15 years old soon. She has a rare chromosome disorder and Autism. She requires help with everything, she is non-verbal, and not potty trained. I am able to have a care provider come M-F for an hour to give her a bath, get her dressed, feed her breakfast, etc. Since this has started I am able to lead a healthier lifestyle myself as I have time to workout in the morning and get myself ready for work. She has one on one care throughout the day at school and one on one care after school so that myself and her father are able to work. She can be difficult to manage and often requires two care providers. We also receive hours of respite for the year which allow us to live more like a normal family and be there for our other children. My daughter is not able to handle going to her brothers sporting events, so we are able to use the respite hours to have her take care of while we spend time with our other children. I also use hours of care providers so that I am able to attend church on Sundays. The waiver has also provided me with sensory items to help calm my daughter in her sensory room when she is having a meltdown. These services are very important to our lives.—Sara

## NEENAH

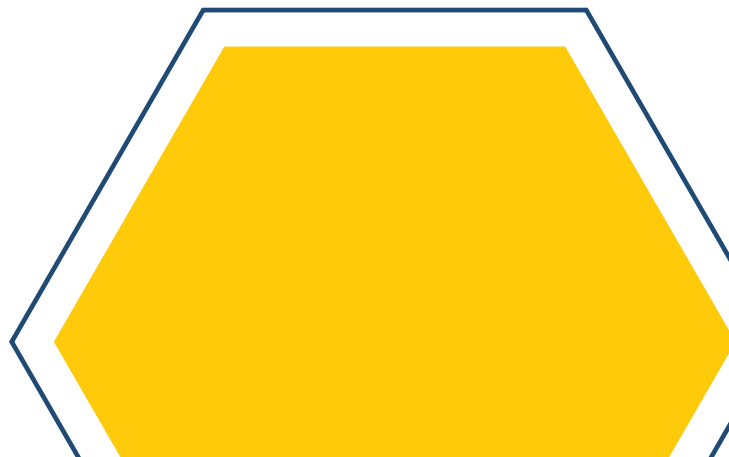
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Helps Jim be fed properly, groomed and get out and about for appointments, work jobs, volunteering and community outings. —Katie

## NEW LONDON

**O**ur son is transitioning from school to work. He will always need a caregiver to help him live independently, and be safe in his community. IRIS funds are critical to allowing our son to live independently in his community, to have paid employment, to be a taxpayer and a consumer. He is healthy and thriving thanks to his enrollment in IRIS.—Mary

i cannot support myself without Medicaid.— David





## SHAWANO

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Without the supports my son receives he would not be receiving his education as the school system in Shawano wants to just expel all special education students so they will not have money on providing essential services so the students can be successful and learn. The therapies my son received are vital, they are teaching him how to interact with others and manage his emotions so that he can be a functional productive adult. Without his medical assistance there would be no way I could pay for his hundreds of medical appointments a year not to mention the chronic changes of medications requiring med checks 4 to 5 trips to the pharmacy to get new meds new doses refills etc. I work full time and have a good career with wonderful insurance and I still would not be able to afford his care and treatment without MA. Before he was placed on a waiver program I had to file bankruptcy because of his medical bills and hospitalizations. Without these services he would have to be placed in an institution because one person on their own can not meet all his needs to live a safe and productive life, which is every American's inherent right.—Nicole

I am a parent of 2 adult children with physical and cognitive disabilities who require 24 hour a day supervision. One of them has significant behavior problems. Having someone who takes them out into the community is not only respite to me but makes their lives more enjoyable. –Name not provided

## SHERWOOD

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My daughter requires “total care”....as she grows to adulthood, I may become unable to lift her on my own (she currently weighs 71 lbs). At that point, she will need increased supports in order to stay at home. She also is on expensive epilepsy medication. Without the assistance from MA, we would not be able to afford her medication. It is over \$3000/month. It is worth it though since she tried 7 different medications to find one that gives her control while allows her to have a great quality of life. We also use the NEMT system for gas mileage reimbursement. She has many appointments and this helps cover the gas to get to her appointments, many of which are in Milwaukee at Children's which is 2 hours away.—Lisa

## STURGEON BAY

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She is unable to live independently and needs constant supervision to perform the simplest tasks of self cares etc. She is almost 26, needs training and retraining in Life Skills. She is in a temporary Adult Family Home right now. She works 8 hrs a week and has a job coach. She also takes classes at a center for people with disabilities. She will be starting Occupational therapy to work on Gross and Fine motor skills and ADLs to move her towards more independence. She cannot drive and needs to be transported to work, therapy, medical appointments, classes etc.—Nanette

**M**y daughter's therapy saved our family. Four years ago we had a very frustrated young lady who couldn't express herself or ask for many things she wanted. This led to violent meltdowns which resulted in many scratches and bruises on myself, my husband, and our younger son, but also a couple of broken windows, a door, a tv, and multiple holes in our walls. We were blessed because our daughter was able to gain her speech which has virtually eliminated the meltdowns and has made our home a safe place again. I credit this to the countless hours of speech, occupational, and ABA therapy she receives. —Chastity

## WAUPACA

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They help my adult children to stay living in the least restrictive environment.-- Karrie

## WINNECONNE

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Family support through our Autism services, and a necessary 'break' through Respite!-- Ashley

## WRIGHTSTOWN

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My 52-year-old sister has Down syndrome and mild Alzheimer's disease, as well as moderate to severe arthritis. She has regular medical and dental appointments and participates in community activities. The funding she gets that helps pay for her care in the Adult Family Home is critical in allowing her to stay in the community where she has lived her entire life. Her father is 96 and in an assisted living facility and no family members live closer than 60 miles. Because she is able to live in an AFH, she is able to be as independent as possible while still being safe and getting help with the things she can not do for herself.  
-- Kathi







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.**

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