What Medicaid Means to Wisconsin's 7th Congressional District



www.survivalcoalitionwi.org survivalcoalitionwi@gmail.com

# Medicaid Provides Funding for More than 20 Wisconsin Programs

#### **Medicaid Enrollment in CD 7 includes:**

940 children with significant disabilities in the Children's Long-Term Supports waiver program
5,487 people with disabilities who are working in the Medicaid Purchase Plan (MAPP)

9,402

7,366 people with disabilities and older adults in Family Care and IRIS

#### Total: 15,829

Medicaid Enrollment in Wisconsin's 7th Congressional District Counties:

Ashland	618
Barron	9,503
Bayfield	379
Burnett	3,499
Chippewa	9,631
Clark	690
Douglas	9,720
Florence	108
Forest	330
Iron	198
Jackson	654
Juneau	4,621
Langlade	4,279
Lincoln	741
Lincoln Marathon	
	23,548
Marathon	23,548 1,211
Marathon Monroe	23,548 1,211 6,777
Marathon Monroe Oneida	23,548 1,211 6,777 8,545
Marathon Monroe Oneida Polk	23,548 1,211 6,777 8,545 420
Marathon Monroe Oneida Polk Price	23,548 1,211 6,777 8,545 420 449
Marathon Monroe Oneida Polk Price Rusk	23,548 1,211 6,777 8,545 420 449 469
Marathon Monroe Oneida Polk Price Rusk Sawyer	23,548 1,211 6,777 8,545 420 449 469 9,178
Marathon Monroe Oneida Polk Price Rusk Sawyer St. Croix	23,548 1,211 6,777 8,545 420 449 469 9,178 435
Marathon Monroe Oneida Polk Price Rusk Sawyer St. Croix Taylor	23,548 1,211 6,777 8,545 420 449 469 9,178 435 530

Total Medicaid Enrollment in CD 7 Counties: 144,350

## **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.







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.

**80%** said without

Medicaid they

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



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

## Stories from People Living in Wisconsin's 7th Congressional District

Survival Coalition received the following personal stories from people who use Medicaid and live in Wisconsin's 7th 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.

#### **ABBOTSFORD**

I have someone to watch my daughter when I am at work.-Julie

#### **ALMENA**

With help I can function like normal people. I need constant assistance as I am not aware of my surroundings and I am non verbal.I am able to live with my parents in safe inviroment.—Julie

#### AMERY

Gives me a break. Being a special needs parent is demanding and overwhelming. Having a break is beneficial to the whole family.—Kerrie



#### **ARBOR VITAE**

Health care coverage provides for the many doctors and medical services my daughter needs. Without this, she would be unable to receive the comprehensive care she needs. Services provide support to train for, obtain and REtain employment. Without this service, she would not be able to be gainfully employed. Assistance for transportation to and from work and for medical appointments helps make sure she can get to work and receive the medical care she needs. Social integration and community services provide the interaction she needs to be as functional as she can be. It is not only the physical needs being met by the services she receives, but also her mental, emotional, developmental, and social needs.—Meg

#### **ARPIN**

My brother's group home and Threshold Adult Day Services give him a safe place to live and work. -Kim

#### ASHLAND

My family member is in a safe environment and receiving the care that we would not be able to provide otherwise. They are a person with significant mental illness and other disabilities.—Stewart

We live in the country and I would not be able to get to my job or appointments if I didn't have someone to take me. If the services were cut My job would end too. Where I work it is funded by these programs. It is a sheltered workshop. I would not get respite so my parents could have a break. I also get services for one day a week and I get to go to the Nursing Home and volunteer there.—John

Maintain good health and get regular prescriptions covered.-Name not provided

#### BAYFIELD

elps my husband to stay at home with help and live as an independent life he can at this time. He gets quality care from our clinic and many preventative treatments to help with his ailments. --Johanna

#### **BLOOMER**

These services allow my elderly father to live with dignity.-Jean

#### BOYD

For foster children in my home it allows them to be able to go to the doctor and get the counseling that they to help them with the trauma they have lived through. I also care for my mom and even though at this point she is not receiving these supports knowing that when memory loss gets worse there is help allows us to keep going. –Kathy

#### CAMERON

Need these services in order to complete daily tasks and be a part of my community.-Cindy

Disabled grandparent raising a special needs child. Need to have medical assistance.-Jill

#### **CLEAR LAKE**

It is how we survive , To care for someone who requires 24/7 supervision can be the best and worst job you will ever have . When caregivers cost more then you can make working outside the home the stress seems overwhelming . –Karen

#### COLBY

I am able to work and care for my other children, knowing that Eli is also cared for. In addition, we are able to take our other children on an occasional "normal" outing.—Samantha

#### CORNELL

y sister has congestive heart failure and is unable to work. She worked part time once she was diagnosed until she could no longer manage that. She is on a BiPap machine, has an oxygen concentrator and multiple medications. She cannot survive without her Medicaid.—Nancy

#### **CUSHING**

If the services I currently provide for work are changed, I may have to change jobs.-- Krystal

#### **EAGLE RIVER**

My son has a moderate cognitive disability, he is complete care and needs supervision and support at home and in the community. He is 27 years old and so will always need long term support. He cannot work in a normal job setting so is currently going to a sheltered workshop for day services. He also has significant medical issues, daily medications. –Tammy

Need my prescriptions to continue to live a normal life.-Eugene

#### **EXELAND**

The services I receive allow me to not only exist but also provide me with the opportunity to give to my society thru my participation, volunteerism and paying for assistance helps to further encourage a support services community by their experienceknowledge base.-- Margaret

#### **FLORENCE**

My sister has mental health issues and are on very expensive psych meds that keep her from not killing herself. --Colleen

Help people remain in there homes with the services that they need.—Janet

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

#### GRANTSBURG

They allow me to be as independent as possible. They also allow me to be an active member of my community.—Tracy

Being able to have someone come in and help with family members is essential to them being able to live and thrive. Family is a great support system but often family member have their own kids, jobs, and life to live. They cannot be expected to stop their lives to help a family member. Knowing that care is being provided by a caregiver is the biggest relief so someone can be there to help and report to family changes. –Sarah



My mother in law could not have stayed home independently without help. It was unsafe for her to stay home by herself due to dementia. She would not cook or clean for herself. She may wander outside and not come back in. Without the help of home care she would have gone into a nursing home much sooner. She is now in a nursing home for her own safety. She is not happy about it. She had just declined to a point where she could no longer afford to stay home. She has a big family but all family members have full time jobs. It is a very big job. It is very stressful for all family members involved. –Beth

#### HAZELHURST

They keep my relative living in her home rather than in an expensive nursing home. -Janell

#### HOLCOMBE

My mother-in-law could not be living at home without daily in home care. She would also not be able to afford medical care for her diabetes without Medicaid. I so have a grandson who had a brain tumor and was left with cognitive delays who will rely on Medicaid for the rest of his life.-- Rose Ann

#### HUDSON

These services allow many people of all abilities to live in their own communities, rather than costly nursing homes. Without my personal care and supportive home care I would not be able to get up in the morning, others would not be able to go to work and pursue the American dream. I find it frustrating that anyone would want to do away with these programs, but yet we want people to get jobs and pursue the American dream. How am I suppose to get a job if these programs are cut and I can not not access care? These services are essential and must remain in place for all Americans. Hopefully people that are in need will still be able to access quality services to participate in all aspects of community life. –Name not provided.

The services allow our clients to lead the most independent, healthy and safe lives that they can.-Peg

The services we receive help us to parent our child and meet his needs, including mental health needs and behaviors - allowing us to be a family.—Name not provided.

amily member could not reside at home without the assistance of outside help. Speech and OT and exercise in home are vital to participate community activities, shopping, communication.—Jean

#### **IRMA**

Enhances the quality of life, supports involvement in activities and community, provides access to providers/medication/equipment, and sustains living in a residential home versus nursing home.--Kris

#### **IRON RIVER**

Without these supports, many individuals would be institutionalized. Institutional living is NOT typically a cost-effective program for life, NOR is it a proactive or positive support choice for anyone!—Martha

#### LADYSMITH

I am totally blind due to a lower back fusion. IRIS program enables me to stay in my own home and work in my non-profit Shedding Hope. I am very blessed to be able to do this and the cost is much less than a nursing home and the activities I am able to partipate in would not be offered in that setting either. –Ralph

#### LOYAL

Transportation to and from work .-- Aaron

#### LUCK

Just to be able to live a normal life.-Linda

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

#### **MARATHON**

Help me as guardian provide for 24-hour attention required for person with progressive neurological deterioration.—Nancy

#### MARSHFIELD

am the caregiver of my adult cognitively disabled daughter. She is unable to stay alone for any length of time. She also has many mental health issues stemming from her disability. She is on the IRIS program that allows for to live at home in an environment that she feels safe in. IRIS also allows her to have respite care which is much needed.— Name not provided.

#### MELLEN

Budgets, scheduling, moving forward, not just receiving SSI but contributing to society too. —Mary Jo

#### MERRILL

It helps keep him in his home, in the community, and living a normal daily life to the best of his ability.-- Tricia I would not be able to leave in my group home without these services.--Stephen

Mother (speaking as he can't) and sister are paid to do my personal cares and anything else I need to be home and in my community as I can't do anything Medicaid brings about \$5 billion to Wisconsin which supports hospitals, providers, and jobs through 20 Medicaid-funded programs as well as program participants.

else, in a wheelchair and have brain damage. My mother uses her money to make sure I have a fulfilled life to the best that can be done. I wouldn't have any life with that.—Marcia

#### **MILLTOWN**

My daughter is disabled, adult! She has IRIS!! She also attends a day service program!! She receives ALL her CARES, personal, and supported, through the IRIS PROGRAM! I'm one of her caregivers, her father is the other. she lives with us in OUR HOME. This would affect everyone's life!!!—Ann

#### **MINOCQUA**

Helps me be more independent.-Lisa

#### MOSINEE

Receiving services allow my sister to continue to live independently in her own home. If she was not able to receive these services she would have to move either home with her aging mother or she would have to move to an adult family home as she is not able due to physical disability to complete all activities of daily living. –Name not provided

#### **NECEDAH**

These infusions help me immensely. Takes the joint pain away .-- Myrna

#### **NEW RICHMOND**

Help me to live independently in my own home, and to be an active participant in the community in which I live.—Wanda



#### NEILLSVILLE

The services help my family as I have both a disabled spouse as well as 2 children that are autistic that get therapy 5 days a week that helps them more and more. If this is taken away I would have to get another job plus try and fridge out how I can help my family not fall completely apart and get whatever services that helps them advance in there every day life.—Lori

#### NIAGARA

Without these my Mother would not be able to survive.-Connie

I need my water pill to keep my blood pressure in check. I need 2 amoxicillin before I see the dentist and 2 after and if I get punctured as I have a replacement knee. I also see the doctor annually to monitor my blood pressure and have lab tests as I have 3 kidneys and stones in a ureter. I must test to see there's no infection. –Helen

#### **ODANAH**

It helps with my family member being able to get out of the house and get active in the community and be involved for social activities. Also helps with the stress, dealing with special needs. --Marilynn

#### OGEMA

These supports allow my son to live, work and participate in our community instead of an institution. It helps him stay connected to the people that he knows and that know him. This makes all the difference in his quality of life and his ability to continue to grow and develop his potential. Supports also allow me as his care provider to work part time due to respite services. This helps me maintain a healthy mental balance which helps prevent caregiver burnout. –Krista

#### **OSCEOLA**

RIS helps keep my son in our home and living as independently as possible. Medicaid helps pay for his medical expenses which we would not be able to handle at this time on our own. IRIS also helps my husband and I as we are taking care of his needs. The family needs an income because every hour spent tending our sons needs is an hour we are not out earning income to support the rest of the family. While it does not pay a lot, it does help with the gap of hours we need income for but are unable to work elsewhere as we need to meet his needs.— RaNaye

I am able to affordably keep my son's prescription's filled.-Whitney

They allow them to stay in a safe environment.-- Gale



#### **PARK FALLS**

I am able to go to the doctors without worrying about how I am going to pay for doctor visits.—Name not provided

#### RHINELANDER

Help keep my children alive and be able to function. Help with life saving meds and doctor's visits and medical equipment needed. –Elizabeth

Allows for my daughter to live in an apartment, independent of her parents like any other adult. Allows her to be as independent as possible. Many tasks she can do partially for herself but needs help with the other part. Can grocery shop but can't reach the shelves or carry the bags if they are too heavy for her. She is in a wheelchair due to paraplegia and has restrictive lung disease as one example.—Melanie



Can remain in own home with these programs.--Dawn

#### **RICE LAKE**

Home Sweet Home served an elderly man who before our services, in one years time had 13 ER visits, 2 hospital stays and a nursing home stay. 16 medications. The following year after Home Sweet Home started providing in home support. He had 0 hospital stays, 1 ER visit and 0 nursing home stays and was down to 4 medications. Happier, well cared for in his own home with his little dog, watching birds, going to baseball games and school picnics too spend time with his grandchildren. Smiling from ear to ear!—Carla

I can live in my own place and be more independently.-Lindsey



Matt has full 24/7 support from skilled direct support professionals, each of whom were hired to provide specific qualities that Matt needed to lead a very active and fulfilling life. Matt lives independently in a low income apartment with direct support professionals coming in to help him. Three years ago, Matt's numbers for blood sugar were really bad and he started seeing a Weight management doctor through Marsh field Clinic. He lived at home up until age 20 and then he wanted to move out and learn how to live on his own. At this time his diabetic numbers were borderline diabetes. He wanted a team of direct support professionals with certain qualities to help him with the parts of his life he could not manage by himself. So he hired someone that was well versed in Gluten Free, Casen free and low carb cooking; a exercise trainer to help him with his exercising routine and direct support professionals who would take and support him to volunteer and work during the week out in the community. Matt is capable with the help from his direct support providers that are paid through his long term option, IRIS. With out IRIS, Matt could not be as active, healthy and happy as he. Since Matt moved out into his own apartment, he has gained self-confidence, learning how to advocate for himself, and is really learning how to manage his health. Obesity is high with teens and young adults today, Matt, still is in the obese category for his height of 5'7.5" but he is on his way to understanding what he needs to do to continue to lose weight and get healthy. Matt is no longer as risk of becoming diabetic and all his health numbers are great! Matt became disabled at the age of 5 days old when he acquired a virus on his brain along with a 105 degree temperature that took over 6 weeks to stabilize. Matt was in the hospital for another 6-8 weeks after that. Matt is now 25 but mentally and emotionally about age 10-12 years of age, has a short term memory, can't read or write and has some mental and behavioral health issues that accompany him in his life. Matt would not be able to be so self directed without IRIS. Our family provides as much natural support to him as we can since both Matt's Dad and I work. We pay for him to have his health club member ship for both his staff and him; we provide additional funds for his groceries for when his Foodshare or his SSI can't cover since he is on a very strict meal plan; we pay for a support broker to help us part time and for her to provide instruction and education to Matt so he can learn how to manage his team and learn to advocate for himself. These are just some small expenses we can cover to help our son. However, if we had to provide for all of his care, we could not be able to afford it. We also could not provide the care to Matt physically either as both Matt's Dad and I have our own health issues. Our Matt that was not supposed to live past the age of 5 or thrive now is 25 and a contributing citizen to our town of Rice Lake. He has worked at Arby's for the last 6 years, volunteered at the public library for the last 5 years, volunteers at his local church and just recently signed up to volunteer to work at the local Restore. Since coming on to IRIS, the goal has always been to help Matt reach a level independence and self-direction where he could feel good about himself and his future. Matt needs IRIS as it is right now, any cuts to it will result in a huge absence of the progress Matt will be able to make in the future. -Jane

Job coaching and transportation are essential in my adult son's day to day life. Since he has impaired communication, he can't work without these supports.—Name not provided

#### **RIVER FALLS**

I would be lost without the IRIS program. I would not be able to live independently without it!-Julie

#### **SCHOFIELD**

Be able to stay healthy to work, eat and not be homeless.-Darla

They help me to live independently and participate in my community. Right now I am disabled due to a brain tumor and the side effects from that. With appropriate aids and supports my goal is to return to working again. If I lose the supports my hopes of returning to work will be over because my worker practices my therapies with me because I only get so many sessions per year with a professional. My worker accompanies me to the gym to build strength and I show improvements steadily. My worker helps me get to other natural therapies too which keep me off expensive medicines. The health efforts my worker helps me with keeps me off medications which would cost \$2600 a month the cost of her and the other choices is less than that and won't cause other effects down the line. I react badly to medications if I have to resort to those I will have to go to a nursing facility which would cost thousands a month versus my current budget of \$1300 a month which also keeps someone employed too. –Christine

All aspects quality of life, transportation social interactions prescriptions, for my health workers to help me be clean and taken care of feeling of being safe from people who would take advantage of me or hurt me. some one there when I need them.—Amanda

#### **STONE LAKE**

Due to mental health problems, I have had great difficulty finding & keeping employment. I rely on Medicaid for access to medical care & prescriptions without which I would be a danger to myself & others. Also, I have relied on SSI for all my other needs most of my adult life as I struggle to become self supporting through employment. Even with the support of SSI & Medicaid, I have needed extra support from my mother to be able to get to a job when I have able to find work.—Curtis

#### **SUPERIOR**

be

My son is a person born with Down Syndrome. If the MA prescription authorization was altered my son would be at a health risk of receiving his insulin for his insulin pump and the many diabetic supplies that the Ling Term Care covers. My son also has been fortunate to recive DVR services, job coach services and attain a community job. He is proud to work, healthy with medications. If he is unable to afford life saving medications or supplies or his synthroud, his quarterly diabetic appointments for complex changes, it would compromise his health and wellness short term. Long term result would

compromise his health and wellness short term. Long term result w harmful to his life.—Michelle

My daughter is 100% care since she has no functional use of her hands. She cannot complete any activities of daily living (ADL's) independently. All ADL's are completed by staff and parents. – Dina I need total help with everything including help driving my chair. I like to volunteer in the community with my church and need a handicap vehicle which my family have to have in order for me to do what i love. They also keep me active in my yearly physical hoals , with gait walker walks, swimming at family cabin, and i feel safe with the ones i love that have taken care of me and know me best. I dont speak and could be in dsnger in an institution. I am a real person who should have choices like everyone else , along with quality Drs of my choice, and great medical care. Thank you. Please help us keep what we need to be healthy and happy..in place—Leah.

Some take medications for Depression and could not function without them. One has ADD disability and needs regular care visits. Another is a young disabled girl that will need assistance her whole life and currently has work assistance and home health care. My parents are both disabled and receive state assistance and me and my family have conditions like asthma and eczema and could not afford the medications without the state assistance we currently receive.-- Antonett

#### TREGO

Makes my adult child be independent n live life as an normal adult that walks with crutches n has only 4th grade comprehension.-- Christine

#### **WASHBURN**

It keeps him out of the institutional placement.-David

The work I do taking care of my disabled young adult son are hours I can't spending working a job or building my business. IRIS pays for those hours, allowing me to provide my son with the best care without sacrificing financial stability. Both my children have disabilities. Medicaid's health insurance has allowed them to receive the medications, surgeries and devices they need to live a healthy and productive life. My daughter has been wearing hearing aids since she was 6 months old. Without Medicaid to cover those hearing aids, her world would be reduced to a chaotic world of whispered and half-heard sounds. –Michelle

#### WAUSAU

I became ill at 21 with MD and was almost placed in a nursing home because of a delay in getting disability, home care, and accessible living. I did not have family to rely on. However, just before that happened a community advocate got involved with the hospital and arranged all the survives I would need to live in the community. I am so thankful for that because I cannot imagine living in a nursing home at age 21. Prior to getting sick, I was attending an undergraduate program at UW-Madison. So after intensive rehabilitation and the support of numerous long-term programs, amazing in-home caregivers, doctors, DVR, etc. I was able to successfully return to UW-Madison and not only earn my BS but also earn my MS in rehabilitation psychology. While there are definite improvements that need to be made to these programs (problems largely resulting from massive budget cuts, not employing people with disabilities who actually understand what is needed to design and lead programs, lack of continuity of care between programs, the fact that people are largely looked at in terms of dollars and numbers instead of real, feeling people who are not stupid or helpless) there is absolutely no way that I would be living successfully and happily in the community but rather I really would be dead. Now the fact that I would be dead may not matter to the President or Senate, but it most definitely would matter to my 25 and 28 year old sisters and mom who would be responsible for burying me. And I'm sure it would matter to my friends, classmates, professors

co-workers, clients, and most importantly my service dog who loves me more than anything. You all must remember that we are real people with real families-maybe try to sit there and decide which of 1 in 5 of your family members you would like to bury or locked away in a nursing home before you begin to cut these programs.—Name not provided

Our daughter takes several medications for seizure control. The meds are very expensive. She works at low paying jobs because of her health. –Barbara

#### **WEBSTER**

I have several health issues that affect my daily life, from thyroid to back issues to major skin issues, and living in a fixed income. Without the needed medications, my daily life would suffer more than it already is. –Dawn

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.





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