

# What Medicaid Means to Wisconsin's 3rd Congressional District



**Survival  
Coalition**

of Wisconsin Disability Organizations



[www.survivalcoalitionwi.org](http://www.survivalcoalitionwi.org)  
[survivalcoalitionwi@gmail.com](mailto:survivalcoalitionwi@gmail.com)

# 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 3rd Congressional District Counties:

Adams: 5,333

Buffalo: 214

Chippewa: 9,631

Crawford: 3,290

Dunn: 7,117

Eau Claire: 25,054

Grant: 7,957

Jackson: 654

Juneau: 4,621

La Crosse: 48,035

Monroe: 1,211

Pepin: 195

Pierce: 2,356

Portage : 10,768

Richland 8,438

Trempealeau: 589

Vernon: 714

Wood 45,085

## Medicaid Enrollment in CD 3 includes:

**893**

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

**6,628**

6,628 people with disabilities who are working in the Medicaid Purchase Plan (MAPP)

**10,541**

10,541 people with disabilities and older adults in Family Care and IRIS

**Total: 18,062**

**Total Medicaid Enrollment in CD 3 Counties: 181,262**

# Executive Summary

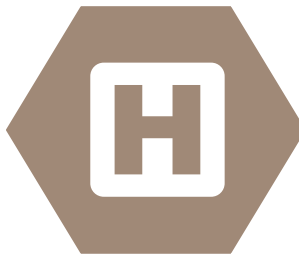
Wisconsin's Medicaid program provides critical health and long-term care services to more than 1 million Wisconsinites. Nearly two-thirds of Wisconsin Medicaid participants are older adults, people with disabilities or children, many of whom have disabilities.

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 3rd Congressional District

Survival Coalition received the following personal stories from people who use Medicaid and live in Wisconsin's 3rd 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.

## ALMOND

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I need to work and my son needs care well I am at work. Without it would cause a financial hardship during the summer months and breaks from school. Also we use Katie Beckett on a regular basis for all of my son's appointments.— Michele

## ALTOONA

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These every day supports are essential to participate in everyday life activities and personal care.—Name not provided

## AMHERST

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My son has autism and without the funding for his therapy I would not be able to afford for him to have this greatly needed service.—Barb



## BLACK RIVER FALLS

**M**y children both are disabled. They regularly see a therapist and a psychologist. My son also sees a psychiatrist. My daughter receives services through DVR and the Promise grant. Without these services she would not have been able to get one on one training for Drivers Education or her job shadowing. Both of my children also receive mentoring services as well. I am trying to help them be as independent as possible by the time they are adults. Without the services offered through the county and state to support them, this would not be possible. My daughter for sure needs a job coach and my son may need one as well when the time comes. I feel that without services like these with their ongoing therapies, I could never prepare them enough to be self-sufficient to the best of their abilities. I also feel that one or both will need ongoing services even after they legally become an adult and would not otherwise have access to these things without the supports and services offered through Medicaid. I am thankful they have some of the services they need and hope they continue to have the supports needed for them to reach their full potential.

– Mem-Gween



along  
alone

They allow those I care for to remain as independent as possible.— Sarah

## CASSVILL

Allow many of the individuals that we serve to remain in there own homes.—Mike

Our daughter requires 24/7 observation.—Name not provided

## CHIPPEWA FALLS

My son can get to his jobs that he has in the community. His seizures are now controlled because of the medicine that he takes everyday. Tests levels would not be done to know if he was going to have a seizure. He is not covered under our health insurance.—Name not provided

I need help with most things. So I can stay where I want to be, in my home with mom and dad. I have lots of health problems, and need lots of things, wheelchair, oxygen, and care. I can go to CRI to do some work. But, I need help with ADL's . I go to the doctor, my mom takes me. There is no bus to some of my doctors, many cabs don't have wheelchair ramps. I get some respite, so my parent's get some time off. It's important that I be a part of my community. There are lot of things that make life hard sometimes. I have to use part of my budget for oxygen services now, medical stuff keeps changing, good thing my parent's can help me.—Tammy

**M**y brother is intellectually disabled. He has issues with short-term memory, and personal care. Without the extra assistance our family receives through programs such as these he wouldn't be able to live a more independent and functional life. In a family as big as ours it means the world to us that our brother is able to live an equally enjoyable and productive life. –Name not provided

My father is able to go to his medical appointments and get his meds with these programs without me having to use my limited vacation time to take him to these appointments.—Kari  
They help promote the most independent life possible and the ability to thrive with assistance while still gaining independence. — Angela

Without help from others I would be living in a group home or nursing home. I couldn't live at my home without Iris.— Dave

My 19 year old developmentally disabled daughter will need more supports as she moves from high school into the community. I will not be able to be there every second to assist her as I have a full time job. She will need access to resources that can help her to be more independent.—Tammy

## COLFAX

My loved ones would be greatly affected if their funding was cut. They rely upon the services provided by Medicare/ Medicaid in order to live as independent and productive life as possible. — Dina

## EAU CLAIRE

**T**hese supports make it possible for my son to see the doctors and therapists that he needs, and continue to live in our home. Without these supports a long-term in patient hospital stay or out of home placement would likely be imminent.—Stephanie



My son has 24/7 cares in his own apartment . He will never be able to live on his own and the cares he receives allows him to live as independent a life as he can. He is severely mentally delayed and non verbal, has seizures -along with many medications. He is a happy, sweet young man in his own apartment with mom and dad as close as possible and helping all the time. – Christine  
Short answer-He would have to live in a nursing home rather than a group home. A nursing home costs taxpayers more and reduces the quality of his life.— Laurel

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

Our daughter, who is now 18, requires 24/7 care. She is unable to do any daily living tasks herself and requires someone to help her engage in the community. We have found, trained, and supervised caregivers for 10+ years (having an agency hire these gals and pay them as they couldn't find workers for us). Over the years, the pool of applicants after placing an ad has dwindled. I had to take early retirement in order to be home to get her off the bus and care for her at home. Though we love her very much, the constant care has worn us down: physically, emotionally, spiritually. The care is not only her 1:1 cares, but all the coordination, scheduling, ordering supplies, planning "on behalf" of her, which is quite a lot. We used to have a person who provided a weekend a month out-of-home respite, but no longer does and we cannot find a replacement. That respite out of home was necessary to "refuel" ourselves. – Deb



The stress associated with having a disabled adult child is a major concern that is frequently not thought of as often as other concerns. Having support greatly reduces that stress.—Myron

Allows me to continue to live in my home not in a nursing home.— Diane

Helps me get a shower, get dress makes meals for the week. Shoveling of snow in the winter. Seeing different doctors for my disability.—Jason

These Services are vital in helping me to live an independent life and continue to be a contributing member of society.— Sonia

## ELK MOUND

I am able to pick my providers that work best for me and care about my needs and wants. I am able to live at home and have a "normal" life, able to participate in my community and with family and friends. —Patricia

We adopted our daughter who has significant developmental delays and autism. We able to receive health care for her.—Anne

## FALL CREEK

My son needs 24Hr. Supervision. He has behavior issues and needs help performing day to day tasks . He can not understand the concept of money, or understand why things are dangerous.Without the services we provide, my son would probably end up in an institution. I retired from work 18 years ago to become my sons full time care giver. –Adam

## GALESVILLE

I could not survive without them. I am totally dependent on the services they provide.— Patrick



## HAZEL GREEN

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They help to keep me in my home which is where I want to remain and I get to make my own choices.  
—Heidi

## HILLSBORO

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I'm able to live at home with my husband instead of a nursing home.— Nancy

**T**he iris program allows my wife to remain in our home. She needs 39 hours per week for personal care and 40 hours per week for support care. If it were not for this program, my wife would be in a nursing home.— Joseph

## HIXTON

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Without health care, my son will die. This is not an exaggeration. He is a senior in high school, he also has Asperger's Syndrome, Epilepsy, and survived a partial arm amputation and reattachment 15 months ago. He also sees a therapist due to the trauma of his accident. I am a single mother of three children. I will lose my job if he loses transportation, there is no one else to bring him. If work supports go away he will not work, with supports he isn't considered disabled. Without a job, he has no chance for insurance on his own. Without insurance (which isn't an offered benefit for my dependents) he will become either severely brain damaged or die due to seizures. This is life or death for my family.—Rebecca

## HOLMEN

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My daughter lives in a group home for mentally challenged adults. She requires transportation and help with her job.— David

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





My ward is a woman in her 50's who has been part of the long-term care system for much of her life. She was removed from an abusive family at the age of 6, and has lived in alternate care for the remainder of her life. She is a Fond du Lac County resident who is currently being served by the Department of Community Programs due to a mental health related hospitalization. Her Family Care case manager has found her a new living situation in Dodgeville, WI and will be moving there soon. This woman is cognitively disabled, and has significant mental health issues. She will never be able to live on her own, and she needs long-term supports to keep her safe and as independent as possible for the rest of her life. I am a volunteer guardian who has been a social worker/case manager for many years. Since the state does not have the funding necessary to pay for the number of guardians it needs for people without family, the counties have to rely on volunteers to pick up the slack. – Dawn

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

## KENDALL

**If we didn't have BadgerCare we wouldn't have found out about my husband's lung cancer. May 28, 2017 will mark one year from last chemo treatment. He is doing well with a good scan a week ago today. I'm able to go to Dr and dentist regularly.—Name not provided**

## KNAPP

My two granddaughters are covered by Badger Care.—Pamela

## LA CROSSE

He would have no health care at all.— Anna Mae

They are invaluable. Myself or another family member would not be able to be employed full time because we would have to dedicate a lot of time to caring for my disabled mother. If my mother was not able to receive the same level of health care coverage there is no way she could afford to pay for it on her own. – Toni



I have rheumatoid arthritis, a heart block, and major neuropathy. My wife has had a heart attack - requiring her to have an artificial heart valve installed, a stroke, and surgery on both eyes. Neither of us is able to work. We are living on my Social Security; our budget cannot be stretched to include our medical expenses.— Patrick

I am paralyzed from the chest down. I need services to get through most aspects of my daily life.—Sandy

Assist with medical bills and necessary treatments.— Pam

These services helped my sister, who died 2 yrs ago this June. The services help 3 grandchildren in another county and their mother.— Josephine

It makes it possible to continue to allow my son to live in our home and not at a residential treatment facility or become incarcerated. It allows him to continue to work toward some level of independence and look forward to contributing to the workforce, perhaps, in the future. It keeps him away from poor influences and off the streets and helps him continually refocus on goals and what he needs to do those goals and it helps keep the rest of our family, mostly, safe from his outbursts.—Name not provided



## LANCASTER

For our adult daughters to remain healthy, stable and supported in the community per their wishes. For our adopted little guy Medicaid is already failing him to help him access needed equipment etc. and I am worried about the future when he is already struggling.—Ann

They allow me to work.—Katy

## MENOMONIE

Gives me a break to recharge. Helps teach skills by giving more interactions w people who understand and can help teach appropriate behavior. —Shayna

Support my life and daily activities.—Tim

These services allow my family members to remain healthy and be able to work.—Tricia

Residents would not be able to sustain life without our services.—Sandy

Critical care for my mother.—Audun

My daughter is 7 and has autism, adhd, anxiety, sensory processing issues, as well as other medical illnesses. She requires daily PCAs to come to our home to assist her with daily living and safety. She also requires behavior therapy 5 days per week which is not covered by my regular health insurance, nor is her occupational and physical therapy that she receives 1-2 times per week. Her MA coverage allows us to give her the proper care she needs to function daily and to give her a better chance at functioning in the future mainstream. We also have received therapy equipment provided by the waiver program to enhance her therapies she does outside the home so we have been able to reduce the number of appointments she has outside the home. MA also helps alleviate the cost of her medications as she has daily meds she takes that can be expensive. By having a PCA in our home, it allows us to help her and function more as a family unit instead of supporting just her.-- Lexi

## NEKOOSA

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My mom is bed bound and needs a hoyer to transfer. She can not do anything for herself other than feed herself. Without us being able to be paid to care for her we would have to get jobs outside the house and she would have no one to care for her. She was in a nursing home before she moved in with us and she would be dead right now if she was still in one. I will never send her back to a nursing home.-- Tracy

I require round the clock care and supervision - unable to be left alone or provide any of my cares. - Kay

Without direct support for daily living and community activities, the person that lives in my home would be at risk of being placed in a group home. This living arrangement allows him to live as independently as he can be and enjoy being a part of the local community. He volunteers his assistance to elderly neighbors to do yard work and snow removal. He enjoys having his own space in my home while having oversight and care. He is not currently in a LTC program but has Medicaid paid health benefits. He has received job coaching and transportation supports in the past in LTC. He is an awesome person.-- Catherine

## ONALASKA

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For me, this is not applicable. However, I meet many families who utilize and depend on the supports and services that are provided through Medicaid funded programs. Their lives will change drastically, from being able to live a daily life with outcomes which benefit their situation, to being challenged, and their well being ultimately being effected. -- Vicky

## PLOVER

**Every day caregivers spend 6 to 10 hours in my house providing my personal cares, such as bathing, dressing, assistance with eating, housekeeping and transportation. By this care, I am able to live on my own and not required 24-hour a day nursing home care. The daily work of these caregivers allows me to be an active member of my community. I can attend appointments, meetings, visit members of my family and get prepared for and go to work. I work by being a member of the Board of Directors of my local Family Care Organization. My doctors are paid by Medical Assistance, and these medical professionals oversee my physical health care by providing medical information, tests and the required signatures for all my medical supplies and services. The staff of my local Family Care organization, Wisconsin's long-term care service provider, coordinates my long-term care services to best serve my individual needs, allowing me to stay living in my community, in my own home, while saving taxpayer dollars compared with the alternative of me requiring 24-hour a day care in an institution.-- Janis**

If I did not have any services, I would not be able to live independently or live a normal life. Since it is so hard to find good quality people to work for me, I have to rely on my family more but they are getting older so it's getting harder for them to help me.— Jeff

My daughter was born with Down's syndrome and has greatly benefited from the different Services provided for her. She needs assistance with daily activities such as daily routine brushing her teeth, bathing, wearing appropriate clothes for the weather, etc. It is through the services she has been provided that I have learned that I don't have to do this alone and there are people out there that will give me the right directions on where to go to get the best help for her can.— Angela

## PLUM CITY

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These services allow me to care for my children and help them be as independent as possible. — Mary

## PRAIRIE DU CHIEN

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My husband also is receiving medical help thru Medicaid. I unfortunately, use Medicaid services, much more often than he does... without that help, I would not be here today.( Medicaid has saved my life)... I would not have been able to afford medical help without it!— MaryAnne

## RIVER FALLS

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Supports enable our son to stay in the home rather than in a care facility.—Tracey

Enable my son to be cared for in his home instead of a more costly group home placement.—Nora

Without assistance I would not be able to function.—Amy

## SPARTA

**M**y mother, from age 86- 93 was a caregiver to my dad at the beginning of his illness and for 5 years until he was admitted into a memory unit where he lived for 2 years until he died this past September at the age of 89. The personal care and home-making services they were provided through Family Care program (Medicaid) helped them stay in their own home together and, I believe, helped my Dad stay connected to life and living. I provided additional hours of caregiving and took over when my mom was ill and couldn't continue. Housekeeping, shopping, respite care, and some supplies were all part of the services provided to us. Although the turn-over of caregivers, differing quality of care, and difficulty in getting enough hours were problematic at times, we were so grateful for the assistance and couldn't have done it for as long as we did without the programs my Dad and Mom were on. Support for the family caregiver was critical. My mom now lives in assisted living through the Medicaid program and Western WI Cares. She pays a co-pay and the program does the rest that enables her to have the comfort and support she needs to live, and to live well. My role as a caregiver for my mom is manageable and limited to transportation to appointments and money management. Our relationship feels more balanced as I am no longer consumed with the cares and the tasks and the worries. We can simply enjoy being together. Without the Medicaid program for my mom, she wouldn't be able to have this type of old age and this much health.— Andrea



## STANLEY

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Relieves stress.—Terri

## STEVENS POINT

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My brother, Will lives across the street from me, my husband, and our children. He is lucky to be able to continue to live in my parents home and be able to be a part of the family on a daily basis. In order for this to be possible he requires services throughout each weekday to allow my parents, my husband, and I to continue our livelihood at work (we all work full time). My brother also works and is quite proud of his 15 year tenure at Goodwill. He is always excited to pull out his employee card and/or show you the latest bonus or newsletter from his employer. In order to do this he requires side by side support to ensure his quality of work and reduce his distractions. When he is not working, it is important for Will to spend time with his peers, participate in Special Olympics, and have a live outside of the home. This would not be possible if we had to pay for all of the support he requires to do these things. We would either have to have one of us quit our jobs and supply these supports ourselves. Since this is not financially a possibility, he would not receive these services. Will enjoys the independence of living his own life each day, separate from the rest of us for a period of time each day. This is important to all of us. – Amy

Without these services my child would not get any care she needs. Because of the daily medications and life support needed we would be living well below the poverty level if we had to pay out of pocket for all of her expenses.—Natasha

My sisters and I are able to work and raise our families and have a great relationship with our mother. Without the 24/7 assistance of caregivers we were having to take time off from work, miss time with our families, and it was becoming a “job”.— Evelyn

Family member has professionals who come into the home administer her medications to her daily.— Paul

I am a diabetic I work full time. I have depression.— Cheryl

Our son has extremely fragile health. We have to be proactive in our efforts to not get ill, so we don't pass viruses to him. Respite allows us the chance to go places and do outside activities while knowing Brandon is cared for. It also allows me to work outside the home. – Cathleen

**W**ithout the supports offered through Family Care, my cousin would not have the ability to work in her community, get quality medical care (including someone attending appts with her to help her with follow through), and would not have transportation to go where she wants and needs to go. Long term care supports have helped her grow in her independence to where she needs much less daily assistance than she used to. She used to need 1:1 support in a job but now can work fairly independently with weekly check-ins and occasional increased supports when there are changes in her job. Transportation has allowed her to navigate her community independently, not having to rely on others when she needs groceries or has a routine medical appt. Having a Family Care RN attend doctor appts has helped her when she has a new medication that she needs more info on, or when she injured her ankle this year and needed the RN to advocate for her to get a second opinion to get adequate care. Family Care staff have helped my cousin find her voice, by providing her with the supports that she needs to LIVE. – Mykeerah

## TOMAH

My MIL needs many daily services to live. She is 95 and has Alzheimer's. Her money from farming is gone, used up, and she needs these services.-- Rita

## VIOLA

Keeping Healthy, having the health to be able to continue to work. Health equals quality of life.-- Patricia

## VIROQUA

I could not afford to pay my mother's nursing home costs and she needs to be in a nursing home.-- Cyndy

When I had knee replacement surgery and had problems, I was able to have home health care services, which helped out a lot.-- Charlynn

## WESTBY

Allows them maximum independence vocationally and living at home.-- Anthony

CSP helps my family member function in the community instead of being institutionalized/hospitalized frequently. -- Kathy

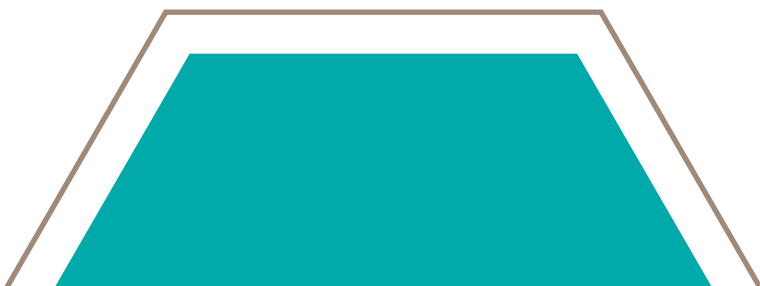
## WILTON

Without my doctor, my medications and my IRIS worker's help my life would not be worth living. I would be living in pain, unable to prepare food, my home would be filthy. I'd be unable to get to the stores or the doctor. I'd be isolated in my apartment with no human contact. Medicaid is literally my lifeline!-- Joan

## WISCONSIN RAPIDS

My mom suffers from depression, has fibromyalgia, & has had multiple strokes. Her vision is getting really bad, & her mobility is decreasing rapidly. My mom has a PCW come in her home to give her showers 3x per week. They also do a little housekeeping type stuff (dishes, laundry, mopping). They also do some meal prep for her since her hands are shaky & she can't cut stuff up any more. -- Melissa

Seniorcare allows my grandma to be able to get the medical health insurance assistance to get her prescriptions and stay healthy so that she can maintain living independently in her own home.-- Jill



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](http://www.survivalcoalitionwi.org)  
[survivalcoalitionwi@gmail.com](mailto:survivalcoalitionwi@gmail.com)**