

What Medicaid Means to Wisconsin's 5th Congressional District



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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 5th Congressional District Counties:

Dodge:
10,844

Jefferson:
12,457

Washington:
12,748

Waukesha:
31,519

Milwaukee:
311,549

Medicaid Enrollment in CD 5 includes:

1,537

1,537 children with significant disabilities in the Children's Long-Term Supports waiver program

7,179

7,179 people with disabilities who are working in the Medicaid Purchase Plan (MAPP)

22,667

22,667 people with disabilities and older adults in Family Care and IRIS

Total: 31,383

Total Medicaid Enrollment in CD 5 Counties: 379,211

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 5th Congressional District

Survival Coalition received the following personal stories from people who use Medicaid and live in Wisconsin's 5th Congressional District. They illustrate the different types of critical supports provided by Medicaid and the impact these services have on people's ability to lead independent and healthy lives in the community.

BEAVER DAM

My son receives physical therapy 2-3 a month, which is much needed for his disability. He is on multiple medications that are also needed. He has many checkups that are needed for his well-being to monitor his development and keep an eye on any possible health issues requiring surgery.—Taylor

BROOKFIELD

Helps Kimberly to have an enjoyable life with support!!— LaMar

Financially we would not be able to afford the care from the doctors that our son sees. Our son has five specialists that he sees. He has Down Syndrome, and also has several auto immune disorders, including Type One Diabetes. We would not be able to afford his insulin without his Medicaid. Respite care and camp provides us with some sense of normalcy with our other children.—Kimberly

Our private health insurance does not cover ABA therapy for our 4 year old son with autism. We are currently under the Katie Beckett Program as a secondary insurance. –Debra

Help us with my daughter's recuperation from leukemia and a bone marrow transplant. Home care supplies for her pick line, many prescriptions and medical bills.
— Petrina



I want to be independent and live on my own. NOT with my parents. Just like my brother. I get help now to help me get ready to live on my own. Plus I have helpers who I know who take me to the Y and out into the community to do the things I need to do (not my parents!) wish how I want to live. I also have a job in the community that I love and I hope to go to Project Search so that I can get a full time job just like the rest of my family.- Kathryn

This gives her the maximum amount of independence. Builds her up as a part of community that is valued.—Kendall

CAMBRIDGE

My daughter was failure to thrive as an infant. She would take very little by mouth. She received her gtube at 9 months. She still takes very little by mouth..she relies on her gtube and special formula EleCare Jr for 95% of nutrition. We work with different therapists to hopefully train her to eat by mouth. She has Neurofibromatosis 1. Where tumors can grow anywhere there are nerves. She also has a VSD. We see different specialts throughout the year for checkups. Neurologist, Cardiologist, GI doctor, eye doctor, NF Clinic, etc. in hopes that if a problem does occur we can catch it early.—Teresa

COLGATE

Jake needs 24/7 care for his severe Epilepsy and Autism. He would lose out on ABA therapy in the home. We would be unable to find anyone to care for him if we cannot pay them. There would have to be an institution for him to live with nursing and 24/7 care. Would be extremely more expensive then keeping him at home.— Sherri

We couldn't afford the doctors, prescriptions or respite care needed.—Pamela

DELAFIELD

My 21 year old daughter, who has seizures and is on the autism spectrum, was recently diagnosed with mood disorder. With the help of IRIS funding, a work program and wonderful doctors and behavioral therapist, I have been able to take care of my daughter - I'm a single mom - by myself. -- Jolene

ELM GROVE

The service we receive allow us to have respite and allow my daughter to have her own life and not be completely dependent on us.—Julia

FORT ATKINSON

Promotes independence, decreases falls and injuries, reduces nursing home stays.—Michelle

My 9-year old son Joshua is on autism spectrum and receives in-home services to help support him in community and school environment as part of Children's Long Term Support Waiver.—Matthew



These services help us so that my husband and I can continue to work to pay bills. It also helps my daughter to live the most normal life she can have at this point. born with a brain tumor she has had many struggles all of her life. This help has helped my husband and I be able to transition our daughter to an adult family home which has helped her become stronger and show some independence as she does. we would not be able to pay for her medical needs with out this help. –Gail

GREENFIELD

It is my only means of survival as I am totally dependent on others.– Cindi

My daughter is 19 and is severely disabled, both cognitively and physically. She requires 24/7 supervision, and help with EVERY ASPECT of her life.–Tamara

HARTFORD

Staying safe, learning and helping him with communicate skills, helping build up physical strength.–Jean

Our daughter has many health issues and is developmentally disabled. IRIS allows her to continue to live at home receive her personal and supportive cares in a safe loving and happy environment, her home. And live her life as happy as she can. –Gala

Without these supports I would be a prisoner in my own home, no transportation and no where to go all day.—Danielle

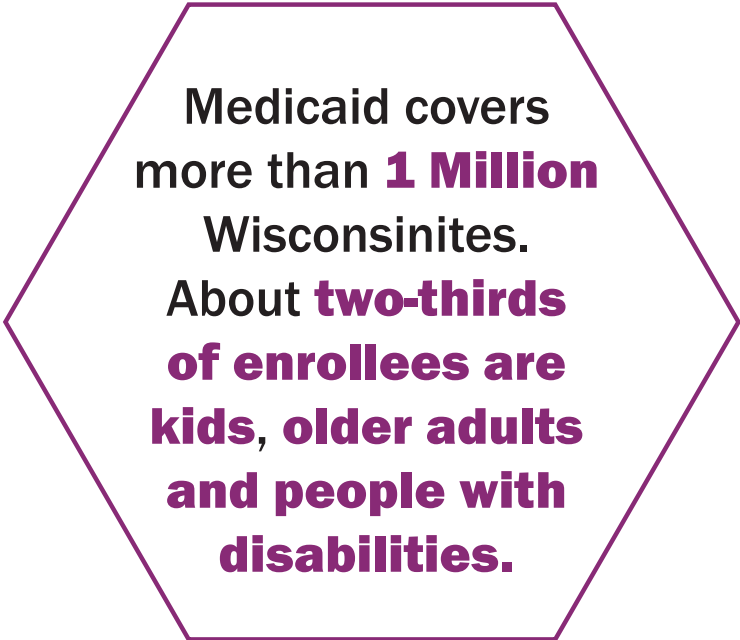
Yes they help my son achieve milestones with the therapy he receives he has cerebral palsy and optic nerve hypoplasia and I am bipolar on methadone maintenance.– Cheri

Our son is cognitively disabled, has severe vision problems, diabetes, asthma, foot anomalies, and a thinking disorder in the Autism Spectrum. He cannot drive, so he needs transportation help. His day services provide him with opportunity for meaningful work and intensive social skill training. We are dependent on his doctor and the health care he provides to optimize our son's on going health situation.– Michael & Roberta

Let's my daughter live in our house. With out iris and they help I get to pay for care workers she has a great life in her OWN home:–Jackie

I WOULD NOT BE ABLE TO TAKE CARE OF MYSELF OR ENGAGE IN RESIDENTIAL ACTIVITIES. I WOULD REMAIN IN BED ALL THE TIME AND LIKELY DIE.— Nancy

Right now the mental health piece and work support is helping her get thru her senior year of school with making good choices. She has school to work support services, transportation to get there, support to understand social interactions about her. If she lived elsewhere she would need transportation, medication assistance and monitoring, help purchasing and preparing food, minimal personal care, more so help with



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About **two-thirds**
of enrollees are
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disabilities.**

social understanding and monitoring. Had brain injury at 9 weeks old from shaken baby and skull fracture. 9 broken ribs at different healing stages were found, 3 long bone leg fractures, tip of shoulder broken off. She is missing part of right side of brain which symptoms mimic nonverbal learning disorder/autism spectrum. She has other brain damage including cortical vision loss, left side weakness, inability to lose left hand or wrist. Interpreting social interactions can be frustrating and she needs daily help interpreting and processing feelings. She has PTSD from abuse and anxiety and depression. We adopted her from foster care with T19. This summer she graduates high school. Her adoptive dad was killed last spring when she was a minor so she has his SS. I am her legal guardian. She will always need monitoring and assistance in life.—Christine



My adult son would have some quality of life. He's paralyzed with anxiety and depression and without medical attention he lives his life as a hermit.—Kim

HARTLAND

If these services were not available to my adult daughter, I would be unable to work outside the home, my daughter would not live as independently as possible.—Angie

Intensive behavioral therapy assists in developing independence in all facets of life skills. —Nancy

Allows independence for the individual with a disability and allows parent to work part-time away from the home.—Paula

Financially they are a huge help. Knowing we have these services gives a relief and lessens the impact of having a child with a disability.—Marybeth

IXONIA

Allows her to live with people she knows, interact with other disabled and younger and older people. Eat foods to improve her health. See healthcare providers chosen for their care of her. —Name not provided

JACKSON

They keep my disabled family member healthy, strong & happy, living their life to it's fullest at home in their own community.—Gerri

By living in a group home helps to support my sisters independence. With the assistance of the group home caregivers she is able get the help and support to maintain an independent lifestyle according to her needs. She is also able to work at the Threshold, which gives her a sense of participation in the community and belonging. Her family is also able to she is in a safe, healthy environment. —Sandy

The Katie Beckett program takes a financial load off me and my husband-we would not be able to pay for his therapies and doctor's visits without it.—Tammy

Maintain independence and dignity, provide access to necessary medical supports, support in living more independently than if in a nursing home, provide assistance with all personal cares and hygiene, involvement in the community.— Vicki

JUNEAU

I have a 7 year old grandson who had bilateral strokes in utero. He has many medical needs. He has cerebral palsy in all 4 quads. He is vision impaired and is nonverbal. He is severely epileptic. He is also tubed fed with a special formula to help with his seizures. Without the help from Medicaid this child would die.—Bonnie

Without these services, there would be no daily life at home. Someone has to be here to help with her daily life functions! Without these assistance, a lot of individuals with special needs would be in nursing home facilities. The cost of having an individual at home verses in a skilled nursing home facilities is a lot less!—Mary

LAKE MILLS

The supports that I receive help me live as normal life as I can possibly live. Without the supports, I would have to stay home and not be able to go to my job at Opportunities, Inc. in Fort Atkinson. I would lose my choice of where I want to work and live in the community. I would just stay home with nothing to do all day or else have to live in an institution.—Sharon

LOWELL

If we did not have this services, we would not be able to work, my son would not be able to go to school, my son would not be able to live in our home.—Amy

MENOMONEE FALLS

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

Liam has shown us that despite what developmental doctors said about him being at a 10 month developmental level, he understands what most other 9 year olds do. His therapies and personal care workers allow our family to have some respite from his total care needs.—Wendy

The IRIS program allows our son to stay in his home where he is comfortable. He receives care & services from those who know him best & care for him. It also allows us some time away while he is cared for by others who we trust.—Name not provided

MILWAUKEE

Adult Day Services, Senior Services, Physical Therapy, Speech Therapy—Julie

NEW BERLIN

My son receives care in his apartment so that he can live as independently as possible. His caregivers provide transportation, daily living assistance like cleaning, shopping, cooking, planning social activities so that he can be a part of the community and personal care for shaving. –Cyndi

My nephew is able to live at home because of Iris. He would need to be in a full time care facility if it wasn't for this program. He is able to spend time with his family and enjoy his life, living it to its fullest potential.—Julia

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

We rely heavily on the home physical and speech therapies because our daughter is very developmentally delayed and also has a weakened immune system. Without assistance, we would be bankrupt, as our daughter sees 14 specialties for ongoing care needs. –Ryan

We primarily use the Katie Beckett program. It is our secondary insurance, but since we have a high deductible policy through my husband's work it does help with many medical costs. Our special needs daughter has medical conditions that need to be monitored every year including congenital heart disease, thyroid issues, and hearing loss.— Sarah

OCONOMOWOC

Tony receives 24 hour care and supervision to prevent him from engaging in unsafe behaviors related to his disability. He works and attends a day program that allows him to be productive and engaging within the community in which he lives. Without the support he receives, Tony would not be able to be a productive, engaging member of his community. We, his parents, are getting older and would not be able to provide the care he needs.—Anthony

My Stacy looks forward everyday to going to work at Easter Seals with her friends and peers! She is provided needed transportation to and from work! She also is provided excellent health care! Please do not take away services from our mentally or physically challenged individuals. They deserve a descent quality of life just like everyone else!—Judith

I life skills trainer and helps me schedule things in my life.—Andrew

Provide support for day programming when he is healthy enough to go. Provide support for me as a single mother to care for my son who is completely dependent. Kevin is 24 years old and functions as a 2 yr old. He is non verbal, incontinent and has a seizure disorder. He has not consistently attended day programming in the last 2-3 months due to serious illness. I am unable to work outside the home.— Faith

PALMYRA

Support of my daughter allows us (her parents) to work.—Tamara

PEWAUKEE

Our son has Autism and struggles with many challenges, special diet, mentally/behaviorally behind his peers. Personal hygiene is done by adults and therapists. At times he still needs to be fed. He doesn't know how to control his emotions and needs help regulating, if not results in hitting, kicking, biting and melt downs. Outside play can be difficult as he is easily distracted by bird, chipmunks and other things causing him to chase them wherever they go. –Jennifer

Taught me how to cook some basic foods, helped teach me kitchen sanitation. Learned how to do laundry.—Travis

RICHFIELD

Without the care my sister receives, she would not survive. I do not have a home that can accommodate her needs and have 7 children of my own that I cannot care for her too. –Gloria

RUBICON

My sister has been mentally disabled since birth and needs help with most everything. With her living in a group home, this helps her have the feeling of independence and us a great support team.— Cindy

SLINGER

My son is in a group home and is cared for with equipment and transportation we could not have at home or afford.—Lynn

The group home is on top of taking care of my sister. They always keep me informed. They let me go to all doctors appointments.—Sandra


The clients I serve are both intellectually disabled and elderly. Some have dementia, some have other physical or mental health problems. Every service they receive is crucial and appreciated.—Mary

SUMMIT

Help my husband and I to be able to work outside the home.— Tammy

SUSSIX

Having an Adult with special needs that required 24 hour care makes it difficult to attend work without help from outside family to care for our child and maintain gainful employment. For her, she is able to maintain a least restrictive environment by being home with her siblings and family. Without her Seizure medications, GI supplies, wheelchair, and other adaptive equipment like communication devices, her life would be seriously restricted and life expectancy would be greatly reduced.—Patrick



WATERTOWN

I can't survive without it. Literally will have to go without meds, and oxygen and nebulizer.—Pamela

Services and health care allow my daughter to have a life to the best of her abilities!— Cheryle
I can stay in my home and be with my family. My daughter can get the help for her major health issues.—
Amanda

Could not live with my family without this support, would not be able to be involved in community, would not be able to care for myself.—Name not provided

WAUKESHA

Allows my son to function—James

The medical care is so I at least have some type of medical insurance so I'm not just paying out of my pocket. I need medication to help me function and therapy, as well.— Brennan Rose
Ongoing therapies will be the only way that my 10 year old could ever possibly become somewhat independence in a group home type setting, not getting these therapies would be life alternating.—
Shannon

I moved my daughter from a group home that was very restrictive and abusive to my daughter to her own apartment and her happiness and life has improved 200%. She is also learning to advocate for herself and directing her own life instead of others controlling her life. She's very proud of herself now.—Kim

My daughter is able to work, have a job coach, transportation to work, access the community both for leisure and also for volunteering. Without these supports she would have to be at home. –
Marion

To have a relatively normal life I need help with things like personal care, daily living skills, respite care, tutoring, getting places, because I do not drive and do not have the focus to drive, and just mentoring in general.— Cory

They provide positive interaction with the outside world, present the possibility of improving the chronic illness and lessen the strain on family.—Bonnie

The respite care we receive for our son is very valuable, and allows us to have a break once in a while. –
Judith

I need them to remain independent.—Chad

Having no family members in the state we really need what little hours we get per month for respite. Most of the time we can not get alone time which is hard on a marriage.—Jean

WAUWATOSA

Supports allow my daughter to have a job in the community. Allow my daughter to use her funds for other necessities besides RX.— Mary

Having Medicaid and the waiver services allow our young adult to be engaged in the life he is capable of having. He is in a setting that is safe and provides the intensive/personal caregiving he requires to be happy and healthy. These services allow us (his guardians) to work full time and provide a home for him to live in which meets his specific needs. These services allow us to take some time away from our daily caregiving (4:00 p.m. - 8:30 a.m. each day) to re-energize and take care of ourselves.—Name not provided

Allow us to work while our son is being cared for, allow us respite, pay for medical bills beyond our ability to pay.—George

Our son is very independent with ADLs. Needs help with independent living skills and job training.—Mary
We couldn't afford all the dr co-pays, g-tube supplies/formula and medications without Medicaid.—Wendi

My son suffers from chronic sinus infections and a variety of speech and language challenges. The chronic sinus infections result in fluid in his ears which leads to reduced hearing and impacts speech production . Katie Beckett helps cover the deductibles and copays that our primary insurance doesn't and enables my son to recuperate quickly, get back to school and therapy. Without this proactive care and financial support, our ability to respond this way would be greatly diminished and create a serious financial hardship. –Jennifer

Help me get dress wash and comb my hair. Preparing my meals and taking me to doctors app.— Afrishwn's

My mother had a stroke which affected her right side and her speech. She also has aphasia. Under Family Care she is able to live in an assisted-living community-based residential facility where there is someone available 24 hours. The caregivers help her with medications, dressing, eating, toileting, bathing. I do not know what might happen to my mother if Family Care is no longer an option. Her monthly income alone is not sufficient to cover the cost of her care. –Luann

WEST ALLIS

Without pcw my child would need to live in a home I would not be able work and support us. I would lose my home!—Tiffany

My Mom would not be able to function without the pain management. –Holly

Transportation and Job Coaching—Edward

WEST BEND

Ryan is non verbal, he does not have the ability to even scream. We are confident that he is in safe, non threatening living and working situations, and this gives us peace of mind. we are in our 70's and the cost of our medications requires that we both continue to work. If Ryan were to have to move back in with us, one of us would need to quit our job because he cannot be safely left home alone. He would miss his group home housemates, and friends at work and special Olympics. –Judith

My daughters' supports enable her to be safe, healthy and happy in an environment that she loves and chooses.—Debra

Many of our clients were institutionalized prior to receiving our supports. Others would be institutionalized if these services were not available. With proper support our clients live healthy, meaning full lives in their home communities. Many live much longer, than expected in consideration of their complex needs.—Kathy

It helped my family member remain living in her home and not force into living at a nursing home. – Thongnhi

Our daughter is able to participate in a variety of community activities, including volunteering with a special education class, working in a sheltered workshop, working in a community business, being in community theater and Special Olympics. She uses a shared ride taxi service, occasional respite care, used to have a YMCA membership to keep fit and uses supportive home care to keep her on a schedule, give her cues for independence, aids her time and money management, helps her access medical care and community services.—Joy

Our daughter's intellectual disability complicates receiving and treating her mental health issues. She needs regular visits to her psychiatrist to manage and tweak her medications and their side effects. She sees herself as an independent adult who can make choices that get her the life she wants to live. Without her IRIS budget at needed levels, she would be forced to relocate to a more expensive group home or home with her aging parents. Either of these would create total disruption to her routine and increase her mental health issues (per past major changes). Overall her medical costs would go up and her contentment and self-concept would be destroyed. Past forced change(s), not to her liking or understanding, have created major trauma to her overall functional level and ability to socialize with others. Consistency and predictability are not just nice but necessary!– LynnDee

COULD NOT DO IT WITHOUT SERVICE.—Rhonda

They allow me to remain safe and healthy. –MaryAnn

As care providers, we keep our clients in a family home and out of an institutional setting so they can live more fulfilling lives and be active members of their communities.—Billie

My son is able to attend school. He is able to have access to his medications and therapists. –Jennifer

I have a parent who is physically disabled. She lives in a group home. They help her with all of her ADL'S. She has medicare which helps her pay for a lot of her medical expenses. But it doesn't cover everything, so I have to help her out sometimes too.—Samantha

I am a caregiver for the mentally ill. And we need ur support!– Nanci

The care my daughter receives ensure she is as healthy and happy as can be. It gives me piece of mind that she will have a good live should something happen to me and I am not here to care for her. Her care allows her to live an independent happy life.— Cheryl



My son John, is 35, with Downs Syndrome, and Juvenile Diabetes (insulin dependent) requires sheltered workshop, transportation and medical help. I provide the daily care, making appts, glucose testing etc.—Linda

I am a respite care provider, daily living skills coach, and a personnel care worker. All of my jobs are paid for through these services. If they are taken away. I loose my job. I am a single mom, and this is very concerning.—Erin

WHITEWATER

I am a caregiver. I help a person get out of bed, eat, scratch their head, blow their nose, wipe their eyes, wash their face, drink water, go to doctor appointments, take their medications, take their blood glucose, bath them, dress them, make phone calls, assist them with paper work, comb their hair, brush their teeth, help them evacuate stool, clean them up...etc...My job is to do everything for a person I can to help them live a normal as possible life on a daily basis, and to maintain a healthy, safe, clean environment, while giving these cares.—Kathy

Without them I could not live independently.—Amy

Wouldn't be able to work without it.—Chris

Gets me my medications.—Pamela



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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