
WISCONSIN

Date: 2017-09-23 21:56:28
To: My Senator
From: Nancy Gapinski
State: Wisconsin
Email: [REDACTED]



Statement to submit to:

Hearing to Consider the Graham-Cassidy-Heller-Johnson Proposal

Monday, September 25, 2017

10:00 AM, 215 Dirksen Senate Office Building

From:

Nancy Gapinski
[REDACTED]

Glendale, WI [REDACTED]

My name is Nancy Gapinski and I live in Glendale, Wisconsin. Our son Ben is 10 years-old and he is a great Scout who takes the Scout Oath seriously promising, "to do my best to do my duty to God and my country, to help other people, and to obey the law of the Pack." His teachers, scout leaders, and coaches all comment that Ben tries his best. He volunteers his time in the community and prays for the sick and for his friends each night. He appreciates the special education supports he has at Glen Hills Middle School to help get his "mind and body ready to learn each day." Ben sees it as his duty to help other children by sharing how Medicaid therapy services helped him, because he wants them to get the help they need too. He values his friendships and his family; he supports the Pack. Ben has autism.

Prior to receiving early intervention (birth-to-three) services, intensive in-home autism treatment services, and special education services in the local public elementary school, Ben did not respond to his own name, frequently body-slammed us, ran off when out in the community, and barely spoke. He didn't call me mama or have an effective way to express his needs, wants, and thoughts. Now he is performing grade-level work in an inclusive regular education classroom, is active in Cub Scouts- with a dream to become an Eagle Scout one day. He runs cross country and plays the bass in the school orchestra. He has friends over to play Minecraft and he and his sister, Zoe, bicker over things like who gets to sit where and whose turn it is to pick the movie to watch. Seven years ago my husband and I had no idea whether Ben would be able to do any of these things.

We will be forever grateful for the help Medicaid funded for Ben. We could not afford \$52,000 per year in therapy or even with employer-sponsored insurance, the out-of-pocket insurance obligation of \$8000 per year for 3 ½ years. Our mortgage was underwater enough that we could not sell our home to meet his needs- we looked into it. Like thousands of other parents trying to meet the health and developmental needs of their children, Medicaid was our last resort.

Ben is no longer a Medicaid participant but he benefits from the infrastructure that Medicaid provides in schools through reimbursement for nursing and therapy costs (\$60 million in Wisconsin alone). We don't know what supports Ben will need as he grows into an adult, but want to be sure that if he needs support to live in an apartment or maintain a job that these supports are available to him and to other people with disabilities across our nation. Right now they are available through Medicaid Home and Community Based waiver services.

Like Ben, you also have taken an oath, your oath of office: "I do solemnly swear that I will support and defend the Constitution of the United States against all enemies, foreign and domestic; that I will bear true faith and allegiance to the same; that I will take this obligation freely, without any mental reservation or purpose of evasion, and that I will well and faithfully discharge the duties of the office on which I am about to enter. So help me God."

I ask that you also take your oath seriously. You will not "well and faithfully discharge the duties" of your office if you vote "yes" to the Graham-Cassidy-Heller-Johnson Proposal. In scout speak, you won't be protecting the Pack. We, your constituents, need for you to protect the most vulnerable- children, frail elders, people with physical, developmental, intellectual, and mental health disabilities, and people with addictions. We need you to protect our access to essential health care, regardless of our ability to pay or our pre-existing conditions. We need you to protect our jobs and our economy, 1/6 of which will be impacted by this bill. If you won't listen to us then we need you to take the advice of the 75 different expert organizations that have spoken out against this bill.

Please set aside partisan politics and any magical thinking that somehow the states can do more with billions less in funding. Remember Ben and remember your oath of office and vote for the health and safety of our country. Vote no to the Graham-Cassidy-Heller-Johnson Proposal and make it clear that you will protect Medicaid- swear to it.

Date: 2017-09-21 17:32:05

To: My Senator

From: abigail tessmann

State: Wisconsin

Email: [REDACTED]



Medicaid benefits me and others in a variety of ways. For me personally though, it provides me the ability to live independently as an adult with a disability. I rely on Medicaid for support workers, supported employment, shelter, daily needs - groceries and personal care. However, If you and your teammates across the aisle together decide to decrease the Medicaid funding across the USA or state(s); I suspect I will end up moving home to live with my parents or a shelter of some kind and with that mentioned my ability to function on my own as a independent will decrease.

Date: 2017-09-24 09:00:47
To: My Senator
From: Theresa Barnes
State: Wisconsin
Email: [REDACTED]



Dear Senators Johnson and Baldwin,

We beg you to vote No to this new bill being introduced to cut health care benefits! We know how very important Medicaid is because our son has benefited and continues to need the supports he receives from the programs funded by Medicaid.

Sixteen years ago our son was born with Down syndrome. We had no idea what was in store for us. The host of health concerns made known to us made our heads spin. When a family's awaited newborn arrives, excitement and celebrations fill the room. Phone calls announcing the birth are made, family and friends rush to the hospital to welcome the newest addition. Not true for a family who gives birth to a baby with a disability.

We found out Lukas had Down syndrome in the delivery room. The feelings of angst and fear were high. We soon were given information about the Birth -3 program funded by Medicaid.

For the next three years we had supports from physical, occupational and speech therapies. This Medicaid funded program is essential to any family who has a child with a disability.

We beg you to vote No on the proposed bill thousands of Wisconsinites depend on. Medicaid saved lives and money.

Sincerely,

The Barnes Family

Milwaukee, WI

Date: 2017-09-22 14:34:10
To: My Senator
From: Mary Jo Foye
State: Wisconsin
Email: [REDACTED]



My name is Mary Jo Foye. I live in Muskego with my husband and three sons, ages 19, 18 and 15. My oldest son, John, has severe cognitive and physical disabilities and is medically fragile. He requires 24/7 skilled care. He has an extremely rare genetic disorder and because of this he requires a tracheostomy for breathing, a feeding tube for nutrition and a wheelchair for mobility. He communicates using nonverbal and augmentative communication assistance and requires 1:1 personal assistance and skilled care for accessing school and the community. He has 10 specialists that he sees for his medical care, including pulmonology, cardiology, nephrology, hematology, orthopedics, to name a few. He is on multiple medications to manage his respiratory status, GI, blood pressure and other issues. He receives therapies. He is involved with Special Olympics. He loves going to social functions including The Night to Remember Prom for young adults with special needs. He is currently transitioning into an ongoing community based program that will help to give him a meaningful and happy life. We are hoping this includes a mix of social and community activities as well as volunteer or paid employment as a companion for older people with Alzheimer's or dementia.

His medical care, skilled and personal care, medications, therapies, day programs and activities are currently covered by the Family Care Program which is funded by Medicaid. We have worked with Family Care to provide a meaningful life for John. It hasn't always been easy. Both my husband and I have had to cut back on work and career goals with decreased hours, income and insurance coverage, relying on the market place for our own health insurance. We have had to fight and work to get coverage for needed equipment and therapies. We frequently visit an equipment lending facility in Waukesha to get equipment and supplies that are not covered. Family Care has worked well with the funding they have, helping us get what we need to support John. The Affordable Care Act has worked very well for the rest of our family.

The bill to cut Medicaid programs in Wisconsin is very concerning to our family and our many friends who use Medicaid programs for themselves or their loved ones with disabilities. Estimated cuts to WI are \$1 billion over the next ten years. John and so many others need supports funded by Medicaid. Medicaid pays for his school therapies, medical supplies, medications and support his adult life including his no one can reassure us that cuts won't impact him. It truly seems unreasonable to me that anyone could assure us that a \$1 billion cut would not impact people like John who can have very costly and essential supports - especially since Wisconsin has already moved to managed care for Medicaid. There simply isn't much "fat" to cut: certainly not \$1 billion worth.

I have no idea where we would be without Medicaid.

That's why what is happening thousands of miles away in Washington, DC this week is so personal to families like mine. The debate over whether to call it a "cut" or a "slowing of growth" or "reduced reimbursement" does not change the fact that multiple non-partisan experts predict that Wisconsin and all other states will receive significantly less federal monies for Medicaid over the next ten years. Wisconsin specifically stands to lose \$2,909,000,000 (or nearly \$3 billion) by 2027 and \$29 billion by 2036.

Families like mine are tired of the rhetoric.

Wisconsin did not take the Medicaid expansion dollars, we have been extremely efficient with our Medicaid funding, we have eliminated waiting lists for adults with disabilities (and propose to do the same for children in this state budget.) We are a leader in the nation. Why are we being punished in the bill being pushed through the U.S. Senate?

Reducing federal Medicaid funding permanently will not help Wisconsin continue to innovate and meet the needs of our state residents. It will not protect optional services like therapies for children, autism services, Katie Beckett or prescription meds.

Families like mine have seen the impacts of even minor decisions meant to cut costs in Medicaid that end up hurting people or reducing their quality of care.

This bill will have far reaching negative effects on the lives of so many. Not only will it severely negatively affect John's life but without the caregivers and supports he receives my husband and I would need to assume that roll and It would affect our ability to work outside of the home, send our other children to college, pay for our own health care...the ripple effect is wide and negative.

Vote NO on Graham-Cassidy

Thank you for your time,

Mary Jo Foye

[REDACTED]

Muskego, WI

[REDACTED]

Date: 2017-09-21 18:02:29
To: My Senator
From: Lisa Pugh
State: Wisconsin
Email: [REDACTED]



My daughter, Erika turned 18 this past summer and it got me thinking about her life as an adult with a disability. Erika's birth was a shock to our family. I remember the day clearly, that little red-headed baby who the nurses wanted to keep a close watch on overnight for some reason. They knew something about her we did not. And a week later we found out she had two holes in her heart and a rare genetic disorder that would mean should would live with a lifelong significant disability. We faced heart surgery and dealt with feeding tubes and therapies early on.

The news of our daughter's diagnosis is not what a new parent wants to hear, but 18 years later I can say not only that our daughter brings us joy but that she enriches our lives and that of many others in our community.

The one thing that has been a constant in our life since Erika's birth was the promise from medical professionals and others that there was help and hope. Erika has benefited significantly from Medicaid-funded programs in Wisconsin like Katie Beckett, intensive autism services, children's long-term support waiver, occupational, speech and physical therapy, durable medical equipment (communication devices, personal supplies), prescription medications.

I have no idea where we would be without Medicaid.

That's why what is happening thousands of miles away in Washington, DC this week is so personal to families like mine. The debate over whether to call it a "cut" or a "slowing of growth" or "reduced reimbursement" does not change the fact that multiple non-partisan experts predict that Wisconsin and all other states will receive significantly less federal monies for Medicaid over the next ten years. Wisconsin specifically stands to lose \$2,909,000,000 (or nearly \$3 billion) by 2027 and \$29 billion by 2036.

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Wisconsin did not take the Medicaid expansion dollars, we have been extremely efficient with our Medicaid funding, we have eliminated waiting lists for adults with disabilities (and propose to do the same for children in this state budget.) We are a leader in the nation. Why are we being punished in the bill being pushed through the U.S. Senate?

Reducing federal Medicaid funding permanently will not help Wisconsin continue to innovate and meet the needs of our state residents. It will not protect optional services like therapies for children, autism services, Katie Beckett or prescription meds.

Families like mine have seen the impacts of even minor decisions meant to cut costs in Medicaid that end up hurting people or reducing their quality of care.

My worst fear for Erika's adult life is that the Medicaid supports meant to help end up only being enough to afford a very small life. A life where I, her Mom, am her only caretaker because I can no longer work outside the home; where she has no friends or young adult activities because there is no transportation in her plan; she has no supports to get a job where she can contribute something; she has cheaper and cheaper personal supplies that may meet her medical needs but reduce her dignity.

This is the stuff about decisions being made thousands of miles away that keep Moms like me awake at night.

Lisa Pugh,
[REDACTED]

Stoughton, WI [REDACTED]
[REDACTED]

Date: 2017-09-22 09:45:17
To: My Senator
From: Marion Holmberg
State: Wisconsin
Email: [REDACTED]



My name is Marion Holmberg and I live in Waukesha. I am the mother of three young adults with intellectual disabilities, my daughter Meara is 21, my son John is 18 and my daughter Lia is 16. Like all young adults, they strive for independence and full inclusion in the community. Like all parents, I want to see my children strike out on their own, have good jobs and contribute to society. In order to fulfill these goals, my family needs a little more help than most. For my children independence means having the right kind of help and supports that enable them to work and live safely.

Medicaid programs such as the Wisconsin IRIS (Include, Respect, I Self-direct), Forward Health and Children's Long Term Supports are a lifeline for our family. Not just do they help with ongoing medical and behavioral health needs, but they also provide the means for my children to work and live in the community. Currently my daughter Meara is employed part time at one of the local school districts. She works in the kitchen doing dishes. She needs a job coach to make sure that she is able to do her job correctly; job coaching is funded through Medicaid. In the afternoons, Meara volunteers at a variety of places accompanied by her supportive homecare worker. Her supportive homecare worker is paid through Medicaid. Although she still lives at home, her dream is to eventually live in an apartment by herself. For this she will need extra help to stay safe and healthy. Again those are the types of supports that are funded through Medicaid.

Without Medicaid, no job, no volunteer opportunities, no support for independence. Without Medicaid, no employment for the job coach, the supportive homecare worker, the respite providers and on and on. Without Medicaid, my husband and I become the sole caregivers. No Medicaid, no opportunity, no independence, no support for families.

The Graham-Cassidy-Heller-Johnson proposal will have a devastating impact on people with disabilities, who rely on Medicaid for their very lives. Without adequate (and cost effective) care in the community, many will be left with no alternative but some type of costly institutional setting. I worry about the future for my children, myself and my friends who rely on these programs. Peoples' lives are at stake here! That seems a high price to pay for a hollow political victory.

Issues as complex as Medicaid and healthcare need careful study and bipartisan collaboration. The American people depend on you to do the right thing. My family depends on you to do the right thing!

I beg you from the bottom of my heart:

- Please oppose the Graham-Cassidy Bill and do not vote to move this bill out of the Finance committee
- Please oppose ANY cuts to Medicaid.
- Please work in a bipartisan fashion to increase access to affordable, accessible health care and long term services and supports

Sincerely,

Marion Holmberg

Janene/ Katrynna

My daughter needs Medicaid! Without it I wouldn't be able to afford her medications to treat her schitzophrenia! I wouldn't be able to afford the blood work that is required every few weeks and I definitely couldn't afford the doctors and hospital!

Medicaid is a service so many people need and for my daughter it helps her have a positive and wonderful life by keeping her stabil.

Without it I can't imagine how her quality of life would be!

Katy is Medicaid



Nancy Gapinski - wisconsin

~~Center costs \$1052. I never want her to go back there because even one day spent there, also~~

I am the volunteer legal guardian for my friend Lisa who has severe autism and uses the Medicaid HCBS Waiver Family Care for care management services and to meet her 24-hour supervision and support needs to stay safe. She lives at an adult family home that does a great job helping her stay healthy, volunteer, and participate in activities in her community. I have known Lisa for 20 years, first as her county care manager and now as her friend. She does not have any family, who can provide the support she needs. Prior to her move into the adult family home, Lisa was institutionalized due to self-injurious behavior. One day at Winnebago Health Center costs \$1052. I never want her to go back there because even one day spent there, also has a high emotional cost. Her adult family home provider cannot afford a rate reduction as they already struggle to hire direct care staff given the current reimbursement rate. Some of her care providers also likely qualify for Medicaid themselves as their earnings are so low. I don't think Lisa would be happy living with my busy family and our unpredictable schedule, so I don't know what I would do if the adult family home provider could not serve her due to rate cuts. She is one of the most vulnerable people I know and Medicaid is truly her last resort. Please vote "no" to the BCRA. I don't want to see cuts or caps to Medicaid.

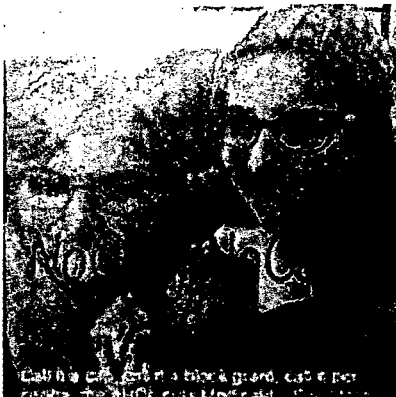
Jenny Benjamin - wisconsin

[REDACTED]

Please vote no to the BCRA. I don't want to see cuts or caps to Medicaid. My elderly mom needs Medicaid to have her care needs met so she can stay in her home and out of a nursing home.

Beth Swedeen - wisconsin
[REDACTED]

My daughter Cara is 24 and was a chromosome deletion resulting in physical, intellectual, and mental health disabilities. Last year she also experienced extreme heart failure. With the support and healthcare from Medicaid, she has several jobs in the community from which she pays rent and her household expenses. She is living with a roommate in her own apartment and is now managing a lot of her healthcare herself. All of her success is dependent on optional support in Medicaid that simply cannot continue at their current levels if this senate bill is past and Medicaid cost containment takes place. Her whole life will crumble apart and her health and safety are at risk. People with disabilities and their families have many practical and financially responsible ideas for containing the cost curve in Medicaid but we have not been part of this Conversation. Please please slow down the speeding train, listen and work with us, and move to a reform in healthcare that will truly benefit all and ensure supports for those who need the most and women's lives are at risk without a careful approach. Beth Swedeen, [REDACTED]
[REDACTED] Madison, WI, [REDACTED]

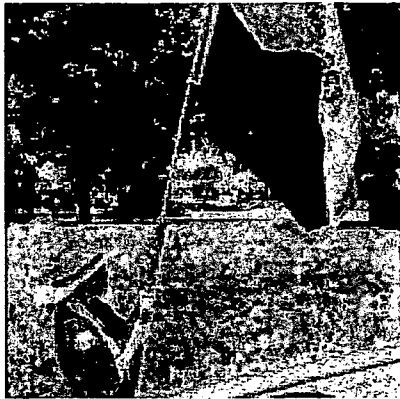


Daniel Gapinski - Wisconsin

[REDACTED]

Our son, Ben, age 10, has an autism spectrum diagnosis and we used Medicaid Home & Community Based Children's Long-term Support waiver funds in addition to our employer-sponsored insurance for him to receive intensive autism treatment. We also utilized Medicaid card services for appointments with specialists, MRIs, EEGs, and medication. When he started autism treatment, he did not respond to his own name, frequently body-slammed us, ran off when out in the community, and barely spoke. Now he is performing grade-level work and is active in Cub Scouts, school orchestra, swim team and computer club. He has some close friends and even went for a sleep-over. We will be forever grateful for the help Medicaid

provided. We could not afford \$52,000 per year in therapy or even the out-of-pocket insurance obligation of \$8000 per year for 3 ½ years. Our mortgage was underwater enough that we could not sell our home to meet his needs- we looked into it. He no longer uses Medicaid but benefits from the infrastructure provided through the Medicaid school-based services funding his public school district receives. We don't know what supports Ben may need in the future so that he can live and work in the community. We want to know that the Medicaid safety net will be there. Please vote "no" to the BCRA and please protect Medicaid.



Nancy Gapinski - Wisconsin

Nancy. [REDACTED]

My mom, Evelyn Benjamin, pictured here with our son, Ben who has autism. She has congestive heart failure (with a pacemaker defibrillator) and other chronic health conditions and she needs support with food preparation, personal care, housework, medication, frequent medical appointments, and transportation because she cannot drive because of limited vision following a stroke behind the eye. These are considered Supportive Home Care Services in the Medicaid Home & Community Based Waiver program- IRIS. She uses a walker but has fallen more frequently recently and now has a lifeline she wears when home alone. Depending on how she is feeling, I don't leave her alone for very long. This has affected my ability to work outside the home. I have a part-time job that I can perform mostly from home but I even had to reduce my hours with that job to meet her needs. We exhausted my mom's savings when we were caretaking for my dad for 7 years following his major stroke; I think that this happens to a lot of elderly surviving spouses. We are committed to keeping my mom out of a nursing home, but I don't know how we would do it without help with my mom's high medication costs and some financial support to meet her care needs. Mom reluctantly applied for Medicaid so that we could continue to support her at home. She sobbed when meeting with the county worker for the assessment saying, "I worked hard my whole life and I never thought it would come to this." Medicaid was our last resort and it has made a huge difference.



Kim Beloin, Ph.D. - Wisconsin


Dear Senators Johnson & Baldwin,

Please vote "No" to this latest version of a Senate Healthcare Bill. This Bill, just like the last will be devastating to children and adults with disabilities.

My husband and I adopted a sibling group of 4 from Wisconsin's foster care system. They are ~~now young adults. Two of our daughters require Medicaid to live and work as safely and~~ independently as possible. They are productive, working citizens who live in their community with long-term care support. Our daughters need Medicaid-funded long-term supports for job coaching, transportation to their jobs, healthcare and other basic daily needs.

Your vote will determine if our young adult daughters can continue to work and live safely in their community. Without Medicaid, they will need more costly institutional care which will cost the public even more money and result in less productive and independent lives for these two young women.

Our young adult children pay attention to what is happening in their government and they never miss an opportunity to vote and let their voices be heard. They will be watching to see how you vote. Represent them well and do what is right for our most vulnerable, yet productive citizens with disabilities.

Cordially,

Kim Beloin, Ph.D.

Nicole Jorwic

From: Gradiva Couzin [REDACTED]
Sent: Monday, July 17, 2017 4:58 PM
To: Nicole Jorwic
Subject: Medicaid Matters to me - Wisconsin

Dear Lawmakers,

Medicaid in Wisconsin matters to me. My mom is a resident of Franksville, Wisconsin and has been fighting stage 4, grade 3 ovarian cancer since 2011.

My mom worked hard all her life and - like many others - she lives modestly and is not sitting on a huge pile of money. A nursing home would eat through her savings rapidly. If she ever needs long term care, Medicaid will be a crucial safety net.

Sincerely,
G. Couzin

Nicole Jorwic

From: [REDACTED] Lyle Updike [REDACTED]
Sent: Sunday, July 16, 2017 11:04 PM
To: Nicole Jorwic
Subject: Wisconsin
Attachments: J.jpg

Our adult son has Down syndrome and multiple health care needs depends upon Medicaid for his health care, employment, transportation, supported living. Please, save Medicaid!

Nicole Jorwic

From: Jean Robertson [REDACTED]
Sent: Sunday, July 16, 2017 10:10 PM
To: Nicole Jorwic
Subject: Medicaid Matters to Me in Wisconsin

I am the volunteer guardian of two men with Developmental Disabilities. Their parents are deceased. Both men are in their early fifties and require full time supervision. One also needs full time physical care. The funding that allows them to have the care they need comes through Medicaid. A decrease in Medicaid dollars would greatly negatively impact their lives.

Jean Robertson
Fitchburg, Wisconsin

Nicole Jorwic

From: John and Amy Stack [REDACTED]
Sent: Sunday, July 16, 2017 7:18 PM
To: Nicole Jorwic
Subject: Medicaid is critical to our family--- WISCONSIN

To our Senators---

Medicaid is a critical support to my 8 year old daughter's life. Lauren suffered a massive brain hemorrhage when 2 days old and subsequently suffers from severe cerebral palsy and a seizure disorder.

We carry private, employer sponsored health insurance, but having Medicaid as a secondary insurance for Lauren prevents our family from drowning under the massive expenses (copays, deductibles, etc). incurred from having a severely disabled child. Her medication and equipment copays alone would cost (out of pocket) more than \$10,000 a year-- not an amount we can absorb without taking away from our other two children.

My greatest concern lies in what will happen when my daughter becomes an adult. She will not be employable and will depend on Medicaid for continued health care. If services are cut, as outlined in the Senate's current bill, her life would be impacted negatively. Who are we as a society if we don't take care of those less fortunate than us?

I trust you will do the right thing and protect Medicaid for my daughter and other severely disabled American citizens.

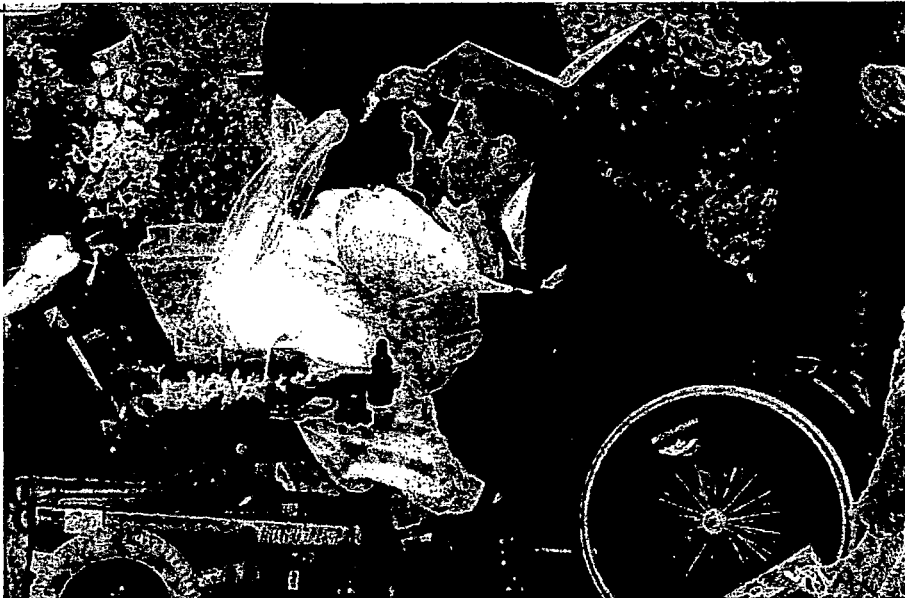
Best regards,
Amy Stack

[REDACTED]
Oshkosh, WI [REDACTED]
[REDACTED]

Nicole Jorwic

From: Stephanie Helle [REDACTED]
Sent: Sunday, July 16, 2017 7:05 PM
To: Nicole Jorwic
Subject: Medicaid Matters to Me - Wisconsin

Hello, I would like to share how Medicaid Home and Community Based Services (HBCS) allow me and my husband Dan to live independently as a married couple. We both have congenital physical disabilities: I have Osteogenesis Imperfecta and he has Cerebral Palsy and optic atrophy which renders him legally blind. We met in college over 15 years ago, got married in 2006, and have been together ever since:



Dan and I both use a number of Medicaid Home and Community Based Services to maintain our independence, including home health care, durable medical equipment, and accessible transportation.

On 09/23/2016, Dan received life altering news. He was diagnosed with Stage 4 oral cancer of the tongue. His treatment included a partial tongue removal and reconstruction, a neck dissection to remove malignant lymph nodes, and 30 radiation treatments. Medicaid Home and Community Based Services were absolutely lifesaving during this time. They ensured that Dan was able to not only access medical care at UW Hospital in Madison, but that he had the necessary supports to recover at home after surgery and radiation. On 05/10/2017, a follow up CT scan showed that the disease is currently in remission.

Dan and I want nothing more than to continue living independently as a married couple, especially now that Dan has been given a second chance at life. We are extremely worried that the drastic cuts to Medicaid which are proposed in the Better Care Reconciliation Act will affect the availability of Home and Community Based Services, as they are optional under federal law. Please vote NO to the BCRA and to any other proposal which cuts and caps Medicaid. Our lives literally depend on your vote!!!

Thank you,

Dan and Stephanie Helle

Nicole Jorwic

From: theresa barnes [REDACTED]
Sent: Sunday, July 16, 2017 4:58 PM
To: Nicole Jorwic
Cc: Theresa Barnes
Subject: MEDICAID CONCERNS - WISCONSIN
Attachments: IMG952770.jpg

Dear Senators Johnson and Baldwin,

Tomorrow our son Lukas turns 16.

We found out at birth that he has Down syndrome. Babies with Down syndrome have very low muscle tone and in order to suck and swallow a speech therapist through the Birth - 3 program, taught us how to feed our son. Medicaid saved his LIFE.

My husband and I depended on Medicaid to provide speech therapy when Lukas turned 3 , it paid for school-based services such as speech and occupational therapy. Because of early intervention and his love of reading, Lukas can now read at a fourth grade level, a tremendous accomplishment for a young man with Down syndrome!

Medicaid provides essential life skills training and opportunities for people with disabilities of all ages. We depend on services funded by the Children's Long-Term Support Medicaid Waiver for Lukas to attend a specialized day camp in the summer, for social skills training, and for a respite provider to give us a needed break.

With his social reasoning being that of a 5 year-old, it is not prudent for us to leave our 15 year-old son unattended for more than a short while. He has called 911 for non-emergencies but would have difficulty responding to actual emergencies. He is at high risk of victimization by predators on the internet; we have discovered him exploring inappropriate sites despite our "family protections" in place. He lacks an understanding of personal boundaries and has violated the personal space of others without recognizing it.

We simply can NOT afford all of the supports our son needs to be safe and to develop the skills he needs to become more independent.

I chose to bring this child, this *life*, into the world. If we are a society that values life, then we need to provide the desperately needed resources to ensure that people with disabilities have the same opportunities that you and I take for granted. MEDICAID provides LIFE support!

Sincerely,

Theresa A. Barnes
[REDACTED]

Milwaukee, WI [REDACTED]
[REDACTED]

Nicole Jorwic

From: [REDACTED]
Sent: Sunday, July 16, 2017 10:52 AM
To: Nicole Jorwic
Subject: Medicaid Matters to Me in Wisconsin

Hello Nicole Jorwic,

My name is Martha Chambers. I was injured in a horseback riding accident 23 years ago and am now paralyzed from my neck down unable to use my arms or legs. I have worked for the past 20 years primarily as an Information and Referral Specialist and also am involved in a leadership capacity on three advocacy groups in Wisconsin. Because of my disability, I rely on Medicaid for my services.

I am very concerned about the impact the new health care bill will have on Medicaid services and more importantly on me and many others who need Medicaid. Right now I am in the IRIS program which allows me to hire highly-trained caregivers to take care of me; who assist me nearly the entire day so that I can get to work, to my advocacy groups or just out in the community to go grocery shopping like any other person may do. Without my caregivers I will lay in bed unable to move. If the changes are too drastic, I could end up in a nursing home which is more expensive than me living on my own with the assistance that I presently have.

Please vote no on the new health care bill. Find a way to keep the ACA. It does work. Myself and many others would not end up in a nursing home. This is not an option for me.

Thank you for listening,
Martha Chambers

[REDACTED]
[REDACTED]
Milwaukee, WI [REDACTED]
[REDACTED]

Sent from [Mail](#) for Windows 10

Nicole Jorwic

From: Gail Bovy [REDACTED]
Sent: Saturday, July 15, 2017 8:21 PM
To: Nicole Jorwic
Subject: Wisconsin - how Medicaid impacts your life

I can tell you that I have had Medicaid in Iowa and when I moved to Wisconsin I do not have it due to the long wait list. As a military veteran the content moving has put me in this position.

Impact: My teen age daughter does not have access to the services she needs because she does not have Medicaid. Her cognitive impairment is very extensive and with out services she has regressed to the point she can not be left alone. Lack of services makes her a safety list for society and her quality of life is very poor. Medicaid helps her live with a purpose.

Any cuts top this program jeopardize her ability to have a purposeful life. Can we really afford the social costs of not doing the right thing?

DO NOT CUT SERVICES - THEY NEED TP BE EXPANDED.

Gail Bovy

Nicole Jorwic

From: Mary Jo Foye [REDACTED]
Sent: Saturday, July 15, 2017 1:44 PM
To: Nicole Jorwic
Subject: How Medicaid impacts your life - Wisconsin



My name is Mary Jo Foye. I live in Muskego with my husband and three sons, ages 19, 17 and 14. My oldest son, John, has severe cognitive and physical disabilities and is medically fragile. He requires 24/7 skilled care. He has an extremely rare genetic disorder and because of this he uses a wheelchair for mobility, communicates using nonverbal and augmentative communication assistance and requires 1:1 personal assistance and skilled care for accessing school and the community. He has 10 specialists that he sees for his medical care, including pulmonology, cardiology, nephrology, hematology, orthopedics, to name a few. He is on multiple medications to manage his respiratory status, GI, blood pressure and other issues. He receives therapies. He is involved with Special Olympics. He loves going to social functions including The Night to Remember Prom for young adults with special needs. We are currently looking for an ongoing community based program that will help to give him a meaningful and happy life. We are hoping this includes a mix of social and community activities as well as volunteer or paid employment as a companion for older people with Alzheimer's or dementia.

His medical care, skilled and personal care, medications, therapies, day programs and activities are currently covered by the Family Care Program which is funded by Medicaid. We have worked with Family Care to provide a meaningful life for John. It hasn't always been easy. Both my husband and I have had to cut back on work and career goals with decreased hours, income and insurance coverage, relying on the market place for our health insurance. We have had to fight and work to get coverage for needed equipment and therapies. We frequently visit an equipment lending facility in Waukesha to get equipment and supplies that are not covered. Family Care has worked well with the funding they have, helping us get what we need to support John.

The bill to cut Medicaid programs in Wisconsin is very concerning to our family and our many friends who use Medicaid programs for themselves or their loved ones with disabilities. Estimated cuts to WI are \$1 billion over the next ten years. John and so many others need supports funded by Medicaid. Medicaid pays for his school therapies, medical supplies, medications and support his adult life including his skilled and personal care and community based programs. We are concerned about what this significant cut could mean for his future and no one can reassure us that cuts won't impact him. It truly seems unreasonable to me that anyone could assure us that a \$1 billion cut would not impact people like John who can have very costly and essential supports - especially since Wisconsin has already moved to managed care for Medicaid. There simply isn't much "fat" to cut: certainly

not \$1 billion worth. Without the outside support for his care we would have to further cut back on our employment which would have an economic impact on our family and the community.

Thank you for your time,

Mary Jo
Foye

[REDACTED]

[REDACTED]

Muskego,

WI

[REDACTED]

Nicole Jorwic

From: Anne Morgan Giroux [REDACTED]
Sent: Saturday, July 15, 2017 1:38 PM
To: Nicole Jorwic
Subject: No to Senate Bill - Wisconsin

This is my 22-year old daughter Lily working at Noodles and Company, one of her two jobs. Lily has an intellectual disability.

Because of medicaid she can afford her seizure, antidepressant and other prescription drugs. She has a job coach that helps her keep and improve at her jobs (30+ hours a week) so she doesn't get fired. Because of Medicaid she can live independently at her own apartment, volunteer to help others, spend money in her community, and vote.

Ironically, if you cut her Medicaid, then she loses her job and becomes MORE dependent on government assistance through SSI. She also loses her apartment and her spending ability. So besides the moral argument that Medicaid allows her to live a happier, more fulfilling life, there is the economic argument as well. Medicaid cuts and caps do NOT help taxpayers. And they certainly do NOT help our daughter.

Please do what the vast majority of Americans are telling you to do. Vote no on the the senate health care bill.



Anne Morgan Giroux

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Nicole Jorwic

From: [REDACTED]
Sent: Saturday, July 15, 2017 1:35 PM
To: Nicole Jorwic
Subject: Wisconsin

The loss of Medicaid for my daughter would be devastating. She has a part-time job with the help of job coaches. She is developmentally delayed and cannot be left alone. Therefore, she needs the assistance of job coaches to complete the tasks at her job and to continue the volunteering she does in the community. Obviously, she cannot drive, therefore, she needs the transportation of these coaches as well. These activities give her life meaning, a purpose, and she can feel like a contributing member of society. It would also impact her healthcare adversely as she does not have the resources to afford it otherwise and she needs her medication to live. These things are rights of all citizens and do not deserve to be taken away by people who make selfish decisions and have absolutely no idea who they are affecting. It is also unfair to the states to make these decisions as to who lives and who does not. The program that is set up for her is working and should be left alone. Please vote NO on this horrible bill that destroys the lives of far too many.

Nicole Jorwic

From: Kathi Hansen [REDACTED]
Sent: Saturday, July 15, 2017 12:34 PM
To: Nicole Jorwic
Subject: Medicaid Matters to Me (Wisconsin)

Dear Senator,

My 52-year-old sister Barb, for whom I am co-guardian, has Down syndrome and mild Alzheimer's disease, as well as moderate to severe arthritis. She has frequent medical appointments and benefits from health insurance through both Medicare and Medicaid.

The funding she gets through Family Care, a Medicaid program in Wisconsin, helps pay for her room, board, and care at The Dwelling Place, an Adult Family Home. This is critical in allowing her to stay in La Crosse and be active in the community where she has lived her entire life.

Barb's father is 96, has mild Alzheimer's disease, and lives in an assisted living facility. No other family members live closer than 60 miles. Because Barb is able to live at The Dwelling Place, 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.

The proposed changes and cuts to Medicaid put programs like Family Care at risk in Wisconsin. Please consider the lives of Barb and other individuals with disabilities like her who rely on Family Care, IRIS, Community Options, and other programs, to live full and meaningful lives in our Wisconsin communities. Please vote NO on the Better Care Reconciliation Act.

Thank you,
Kathi Hansen
Wrightstown, WI [REDACTED]

Nicole Jorwic

From: Tiffany Glass [REDACTED]
Sent: Saturday, July 15, 2017 11:01 AM
To: Nicole Jorwic
Subject: From Wisconsin - Medicaid matters to us
Attachments: IMG_0129(1).JPG

Hi,

I'm emailing to share our story with the 'Medicaid Matters to Me' effort.

~~My name is Tiffany Glass, and we live in Madison, WI. I have a seven-year old son, Max (photo attached), who has a dual diagnosis of Down syndrome and Autism. He cannot speak, has trouble with eating and drinking, has complex behaviors and risks for medical complexity, and he needs significant support with all aspects of personal care and daily life.~~

His only means of communication is an electronic communication device (shown in the photo). Medicaid provided him with this electronic communication device. Medicaid also assists in providing the skilled personal care assistance that he needs. Max could live well into his seventies or beyond, with life-long needs for high levels of medical, therapeutic, and personal care support. Medicaid is critical to permit these needs to be met for Max and to permit him to continue to live in the community with his family.

I am willing to have senators share our story publicly.

Thanks!

Tiffany Glass

Nicole Jorwic

From: Kim Beloin [REDACTED]
Sent: Saturday, July 15, 2017 8:19 AM
To: Nicole Jorwic; Nicole Jorwic
Subject: Wisconsin - Vote "No" and maintain Medicaid for our citizens with disabilities

Dear Senators Johnson & Baldwin,

Please vote "No" to this latest version of a Senate Healthcare Bill. This Bill, just like the last will be devastating to children and adults with disabilities.

My husband and I adopted a sibling group of 4 from Wisconsin's foster care system. They are now young adults. Two of our daughters require Medicaid to live and work as safely and independently as possible. They are productive, working citizens who live in their community with long-term care support.. Our daughters need Medicaid-funded long-term supports for job coaching, transportation to their jobs, healthcare and other basic daily needs.

Your vote will determine if our young adult daughters can continue to work and live safely in their community. Without Medicaid, they will need more costly institutional care which will cost the public even more money and result in less productive and independent lives for these two young women.

Our young adult children pay attention to what is happening in their government and they never miss an opportunity to vote and let their voices be heard. They will be watching to see how you vote. Represent them well and do what is right for our most vulnerable, yet productive citizens with disabilities.

Cordially,

Kim Beloin
Kim S. Beloin, Ph.D.

Nicole Jorwic

From: mwoods2.mw [REDACTED]
Sent: Saturday, July 15, 2017 7:27 AM
To: Nicole Jorwic
Subject: Wisconsin

My 8 year old grandson is on the autism spectrum. It has been difficult to get him into ABA therapy because of the shortage of openings. But thank God for the wonderful PUBLIC school he attends. His teachers and aides have made a tremendous impact on his abilities. Please vote no for the extreme cuts to medicaid.

Sent via the Samsung Galaxy S® 6, an AT&T 4G LTE smartphone

Nicole Jorwic

From: Erin Anderson [REDACTED]
Sent: Friday, July 14, 2017 8:53 PM
To: Nicole Jorwic
Subject: Wisconsin

Our story: We are a middle-class, two-income family. For years, our family was penalized for having two incomes by our employers. We either had to pay an expensive monthly premium penalty to put our family under one plan, or carry two separate high-deductible plans — two premiums, two deductibles, two out-of-pocket maximums, etc. We had to weigh the odds — we're healthy, don't go to the doctor much, don't smoke, etc. This spring was the first time where we were able to get our family covered under a single plan. It felt too good to be true. But, that's just one part of our story.

About 4 years ago, we were surprised to be expecting our third child. A few weeks into the pregnancy, we had test results that showed there might be problems. Later test results proved our daughter has Down syndrome. Scared and emotionally rocked, we decided to continue the pregnancy and support our beautiful daughter. I required high-risk prenatal care. Then, we learned she would need life-saving surgery shortly after her birth. We made changes so that I would deliver at Froedtert and she could receive care at Children's Hospital. I needed weekly monitoring of the pregnancy and expensive prenatal tests to ensure her health.

After she was born, she had surgery at 4 days old and spent 1 month in neonatal intensive care. Additional life-long diagnoses followed. We spent thousands to cover this cost, but she is worth every penny.

Having a child with a permanent disability profoundly changed our lives, mostly for the better, but to say we didn't need help would be dishonest. She needed multiple therapists — physical therapy, occupational, speech — every week to learn the simplest things, like holding her head, eating without choking, and so much more. We applied for and received Katie Beckett Medicaid to help with the costs. She had her second surgery at just 9 months old, so that she could breath better while she slept.

When she was just over a year old, we had a huge blow. She was having rare seizures that threatened her development and life. The treatment was to give her a course of steroids for several months. We learned to give her the injections ourselves and to become her nurse at home, administering tests, and ensuring her safety on a dangerous medication. The medication cost \$35,000 per vial — she needed 6 vials to complete the course of meds. We had to fight and argue with the for-profit insurance pharmacy to receive the medication, since they tried to ration it because of the cost. This taught us to be our daughter's advocates.

Additional diagnoses followed; additional surgeries followed; altogether, her medical costs have approached if not exceeded a million dollars, and she is not yet 4 years old. Without our private insurance, without Medicaid, we would be financially ruined. Changes to Medicaid — block grants, cuts, caps — will affect her future care. Changes to health care — lifetime maximums, pre-existing condition coverage — will have a profound effect on her health. We need our government to fight for her. In our opinion, it is immoral to take away these supports. It devalues her life worth.

Erin S. Anderson | Internal Communications Senior Coordinator

[REDACTED]
[REDACTED]
[REDACTED]



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Nicole Jorwic

From: Christi Whiting [REDACTED]
Sent: Friday, July 14, 2017 5:37 PM
To: Nicole Jorwic
Subject: Wisconsin-Medicaid Matters to Me and My Family
Attachments: Cary Advocacy Letter--Wisconsin.pages

Thank You!

Nicole Jorwic

From: Mary Swifka [REDACTED]
Sent: Friday, July 14, 2017 2:24 PM
To: Nicole Jorwic
Subject: Wisconsin Medicaid Impacts

My husband and I have a 19 year old son who has an intellectual disability. What does he want in life? Everything any other 19 year old man wants: a job, to move out of his parents' home, to have a social life in his community with his friends. But he will always need supports to realize his dreams. That's why he is enrolled in the IRIS program, which is funded by Medicaid dollars.

~~IRIS will provide a job coach to help him at work, caregivers who will make sure he's safe in his home, transportation to work, appointments and church, all at a cost that's significantly lower than nursing home care.~~

We are frightened at the prospect of an 800 billion dollar cut to Medicaid. Draconian cuts of this magnitude will only hurt people. A health care bill should help people, not hurt them.

We urge Senator Ron Johnson and Senator Tammy Baldwin to vote "NO" on the Better Care Reconciliation Act.

Regards,
Mary Swifka & Dean Sauers
New London, Wisconsin