MISSOURI

Date: 2017-09-22 11:54:21

To: My Senator

From: Amanda Anderson

State: Nebraska

Email:



Medicaid is way more than health care. For my brother with developmental disabilities is is everything. Medicaid funds the staff that care for him and teach him new skills so he can be as independent as possible. Medicaid funds his vocational program which helps support him to work multiple small jobs tailored to his strengths and needs. Medicaid supports my brother to have value in society, and lead a meaningful life. It is way more than medical care. It is everything. To place a cap on Medicaid is inhumane. Everyone has different needs. For some the Medicaid funding and the skills taught through Community Living and Day Supports programs do lead to greater independence, and thus less funding is used.

Please consider who this impacts the most, and do the right thing. This is more than politics, these are people's lives. This isn't the way to save money.

Amanda Anderson

Date: 2017-09-23 23:19:17

To: My Senator From: Heather Jenkins

State: Nebraska

Email:



I am 40 years old and I have a sister with developmental disabilities that is 37. Our parents died 9 years ago. My parents thought they would just live forever to take care of my sister. Allison has for the last 9 years been essentially on her own. I watch her finances and also have to fight for social services for her. She was able to work part time and live on her own. Two and a half years ago my sister fell and broke her ankle taking out her trash. She was taking out the trash after starting a fire in her microwave by cleaning it with various cleaners. When she was in the hospital, she was diagnosed with Mytonic Muscular Dystrophy. Through tests that occurred over the following months this muscular dystrophy was determined to be the reason for her developmental disability. When we had to reapply for Disability Services through the state of Nebraska Medicaid.

Allison has now been moved to an Extended Family Home. We are private paying for it because of the waiting list for residential services. There is a 5 year waiting list and Allison has only waited 2.5 years. When she fell she moved into a nursing home because she couldn't walk and had to have round the clock care, because of the strain on Medicaid dollars already in Nebraska, she was a 35 year old stayed in that nursing home until I found her a way out. She was awarded day services after I fought the state for funding for her through DD services.

I fear for my sister daily. I fear that cuts to Medicaid will doom my sister back into a nursing home. I fear for others like her, but honestly I am concerned about her. She is now happy. She lives with a family and goes to a day program. She works with this day program and earns money for her to buy simple things that she needs or wants. Being a part of the program has changed Allison since she can no longer drive or participate in gainful employment. By participating she is working with staff that understand her disabilities and also with other individuals of various abilities. Cutting Medicaid is not the answer our country needs, at least not in cutting people with disabilities.

Date: 2017-09-21 22:30:37

To: My Senator From: Brenda Smart State: Nebraska

Email:



My son is 30 years old and Autistic. He has residential and day services. He is totally dependent on staff for his daily needs 24/7 Bathing, cleaning, cooking, eating taking medication, outings etc. He has anxiety and gets overstimulated easily with noise or with crowds. He is dependent on Medicaid for his services and staff. He is blessed with some amazing staff that don't get paid nearly enough for what they do, but do It for the love and compassion for their clients. It would be very detrimental to his well being if there are cuts or caps on Medicaid. My husband unexpectantly passed away this year the day after his 55th Birthday. I no longer have his income and I am working fulltime to support myself and have health insurance. Therefore I am not able to care for my son. There are many people with disabilities that are dependent on Medicaid for their well being and no longer have family. I know too well that I am not guaranteed tomorrow, should the Lord call me home. I would like to have some peace in knowing that there is a system in place for my son and his best interest should that happen. I am pro life and appreciate the support of many senators who claim to be, but find it very hypocritical when they vote pro life, but want to take away the programs that support those same babies that are born with disabilities and grow into adults that need those services. I would of like to address you in person instead of writing this letter, but unfortunately I cannot take the time off of work. I appreciate your consideration when voting on these important issues that have an impact on many lives. Thank you, Sincerely Brenda Smart

From:

Joanna Browning

Sent:

Thursday, July 20, 2017 7:42 AM

To:

Nicole Jorwic

Subject:

Medicaid Matters to Me

My 2 year old son Jacob has Myotubular Myopathy, an extremely rare genetic neuromuscular disorder that is characterized by weakened skeleton muscles. Jacob is extremely medically fragile and his care is very complex. Jacob receives 16 hours of nursing care/day. He requires respiratory support (BiPAP) through a mask overnight and during his naps to assist with the inflation of his lungs. Jacob has an intense respiratory management-protocol, which takes about 1-hour-2-times/day. Jacob has a very weak cough and therefore, secretions that block his airway are difficult for him to remove on this own. He is monitored 24/7 by a pulsox to monitor his heart rate and oxygen saturation. Jacob has a difficult time swallowing and requires frequent suctioning of his own secretions. He is fed primarily through his Jejunum, and is fed continuously approximately 20 out of the 24 hours per day.

Despite these obvious challenges, Jacob is a sweet 2 1/2 year old with a love and determination for life! He loves spending time with his family, especially big brother, and enjoys drawing, working on his flashcards, and watching Sound of Music. He steals the hearts of everyone he meets with his sweet spirit and smiling eyes. For a child that faces challenges daily, he has no limits in his ability to love and inspire all that have the benefit of knowing him. This little boy will do BIG things to make this world a better place.

The benefits that Jacob receives through MO Healthnet and St. Louis Arc are LIFE GIVING. Please take Jacob's story into consideration when reviewing any changes to health care reform. Please Do NOT allow cuts to Medicaid services that are crucial for people with disabilities like Jacob. Please Do NOT allow states to opt out of requiring health plans to cover basic health care and keep it affordable for people with preexisting conditions.



From:

Nicole Jorwic

Sent:

Wednesday, July 19, 2017 5:33 PM

То:

Nicole Jorwic

Subject:

Missouri

Dawn Zeterberg



Nicole T. Jorwic, J.D. | jorwic@thearc.org Director, Rights Policy, The Arc



1825 K Street NW, Suite 1200, Washington, D.C. 20006 T 202.783.2229 x322 T 800.433.5255 | F 202.534.3731 thearc.org | Donate | Facebook | Twitter | YouTube

For people with intellectual and developmental disabilities



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From:

Jim Ward

Sent:

Wednesday, July 19, 2017 5:30 PM

To:

Nicole Jorwic

Subject:

How Medicaid impacts my life: Missouri

Dear Sir or Madam,

I am the parent of a nineteen year old son with an autism diagnosis (Asperger's Syndrome). We are walking through the steps of what his future is going to be. Medicaid is going to be an important part of that funding picture. I would like to think my son can "get it together" and lead a productive life. Unfortunately, I don't believe that will really happen. I will not be around to take care of him forever. And currently, I have to pay for him to live in a motel because my wife will not let him live in our home. For the time being, that's the best situation for him, because the only alternative I can figure is living on the street, and I don't want that to happen.

We are in the process of filing for Medicaid, and we are hopeful to get approved and pursue a living situation that will be favorable for my son.

That's how Medicaid impacts my life. Thank you for your time and consideration.

Respectfully submitted,

James T. Ward, P.E., LEED AP
Senior Mechanical Engineer | Project Manager



Rock Hill Mechanic Corporation

From:

Jim Jordan

Sent:

Wednesday, July 19, 2017 3:00 PM

To:

Nicole Jorwic

Cc:

Jim Jordan Missouri

Subject:

Attachments:

RIMG0416.JPG

I am a single parent of a total care son who has trisomy 9 mosaicism. Mother and my wife died of leukemia when Aidan was 7 12 years ago. Aidan has been in St. Louis Children's Hospital (SLCH) since June 21 (a couple days out then back again twice) with seizures. The only way to stop the seizures once they start is with IV loads of rescue drugs in the hopsital. We hope to be released July 21 with a new home plan and anti seizure drug regimen.

Aidan is 19.5 years old and is the recipient of a community waiver through Missouri Dept of Mental Health and is on Medicaid (MO Healthnet)

I want to work and hire care providers (PA's) through self directed support. Aidan still attends public school and summer programs (when not in the hospital). If it were not for the waiver and self directed support, I could not work.

Aidan has spent about a full year of his life in SLCH (most of it in the ICU) and has exceeded the lifetime limit. I have family insurance through individual purchase since my employer is to small to offer group medical insurance. I keep medicaid secondary to help keep the costs to Missouri lower. This year he has already met all the deductibles so medicaid is not paying anymore and the insurance company is covering 100%.

Aidan medicaid is essential and as he is an adult and I have full guardianship, we need this support in order for me to remain a productive member of society and give back to society as an educator.

Jim Jordan

From:

mary cagle

Sent:

Wednesday, July 19, 2017 11:20 AM

To:

Nicole Jorwic

Subject:

Medicaid

I pray they don't do away with Medicaid. We live in the State of Missouri which is bad to begin with but pray for my many friends who have children in Group Homes families with parents in nursing homes and for my son who is 59 years old and hopefully will have a group home to go when we pass away. My husband and I are both 85 yrs now and in bad health. We are all in a HMO but how will taking Medicaid away effect this. MORE THOUGHT NEEDED because all will feel the effects except the rich....especially then the hospitals have to downsize because of money. PLEASE THINK THROUGH

From:

Chris Bagnell

Sent:

Monday, July 17, 2017 4:33 PM

To:

Nicole Jorwic

Subject:

Missouri

Medicaid enables the most vulnerable individuals in our society to obtain the services and supports that they desperately need. Current Medicaid funding needs to be protected and most definitely not reduced.

From:

Harker, Christine

Sent:

Monday, July 17, 2017 9:16 AM

To:

Nicole Jorwic

Subject:

Medicaid Matters to my Family

Dear Legislators:

Please understand that Medicaid is a success story in American social programming: paying for Medicaid is what we all, as taxpayers and members of a compassionate society do for one another. For years I happily paid taxes that I knew supported the program--because looking after our neighbors is what civilized societies do.

Then I and my family became one of them: when my daughter was catastrophically injured in a multiyear crash at 4 days of age, our lives changed dramatically. I have health insurance through my employment, but the 20% uncovered expenses would have crippled our family were it not for Medicaid. Medicaid has made the spinal surgery that saved her life possible. If we had not had that assistance, at some point in the years of surgeries--which are thankfully now over as far as we can see--I would have to have made a choice between being housed and giving my child a chance at a painfree life.

These are the very real stakes of Medicaid. Please reconsider very carefully before you vote in favor of any reduction in this program: the eyes of the nation are on you. It is up to you whether you stand w compassion or with corporate greed.

sincerely, christine harker

From:

debbie jenkins

Sent:

Monday, July 17, 2017 9:13 AM

To:

Nicole Jorwic

Subject:

MISSOURI

My name, KEVIN JENKINS and have CEREBRAL PALSY with Seizures utilizing a WHEELCHAIR full time. Of course, Medicaid is an important element in my life to remain healthy and independent.

Please make sure you support ME and many OTHERS that depend on MEDICAID and MEDICARE.

Regards,

Kevin Jenkins

From:

Denis Doelling

Sent:

Sunday, July 16, 2017 11:26 PM

To:

Nicole Jorwic

Subject:

Missouri - Medicaid

Dear Senators:

Please do not pass the AHCA bill! I am the parent of two adopted young-adult children both with developmental disabilities. In addition one has a cognitive impairment affecting communication and the other has mental and physical health problems. One has consistently worked part-time for a few years; the second has had difficulty working. Both depend on Medicaid.

Please keep the ACA with Medicaid as is. Thank you.

Carol Doelling Glendale, Missouri

From:

Suzanne Klevorn

Sent:

Sunday, July 16, 2017 10:05 PM

To:

Nicole Jorwic

Subject:

Greetings from Missouri- Don't Cut Medicaid

Dear Senators,

Please do not pass this healthcare bill which is more than a repeal of Obamacare. It is a complete restructuring of the Medicaid program as we know it. I am contacting you on behalf of my grandson who has a genetic disorder call Fragile X Syndrome. He benefits from the Medicaid payments to schools to pay for speech and occupational therapies. He has some behavioral issues due to his sensory processing and executive function deficits. We are receiving in home behavior therapy from Medicaid. Without these helpers coming into our home, my grandson would have to be in an institution. I worry about his future if you decrease funding when the costs of healthcare are increasing. Please do not pass this bill or give Medicaid to the states in block grants. Missouri is not growing and will not be able to support the many people who need help. Thank you for your consideration and please think about the most vulnerable citizens in our country.

Sincerely, Sue Klevorn St. Louis, Mo.

From:

Betty Sutherland

Sent:

Sunday, July 16, 2017 4:45 PM

To:

Nicole Jorwic Todd Sutherland

Cc: Subject:

Medicaid Matters State of Missouri

To Nicole Jorwic at The Arc of the United States:

My Grandsons, Matt and Zach Sutherland are almost 16 year old. They were born three months premature with cerebral palsy. They are in wheel chairs, cannot dress themselves, require round the clock assistance and an extreme amount of medications. They have had many surgeries and will probably require more. Their parents have devoted their lives to them, they are in my eyes and everyone who know them, super hero's! They, along with a devoted big sister are giving these amazing boys the best possible lives they can provide.

I'm writing to ask what happens when a child with a serious disability grows up? Because in the Senate health care bill, it would keep them out of a per capita cap program as children but then punish them as adults with significant cuts to their programs. Please EXEMPT people with disabilities from this harmful bill.

Sincerely, A very concerned Grandparent Betty Sutherland

From:

Patricia Ciapciak

Sent:

Saturday, July 15, 2017 4:52 PM

To:

Nicole Jorwic

Subject:

Missouri

To: Nicole Jorwic

Thank you for reading this (among many, I hope) email regarding Medicaid and the need for each state to be supported by the federal U.S. government to maintain necessary funding.

I have a brother (age 55) (Down syndrome), and he is currently residing in the Saint Louis Arc/Rainbow Village community of individuals with varying disabilities. This community exists, employing excellent caring staff to help make my brother's life safe, well-nourished, and growing in his life experience.

Medicaid makes this community possible for a population of individuals who need their voices and their needs served by a country that cares about all of its citizens.

Thank you. Sincerely.....Patricia Ciapciak

From:

Joan Frost

Sent:

Saturday, July 15, 2017 1:15 PM

To:

Nicole Jorwic

Subject:

Missouri - Medicaid Story

Please listen carefully to your constituents,

I have a developmental disabled 49 year old sister, Karen. Karen has Down's Syndrome and while she lives in a peaceful and happy internal world, securing care for her has not been easy. Until recently Karen lived with her very elderly mother, who had been her caregiver her entire life. Mom is no longer able to continue Karen's physical care. She needs 24/7 supervision to ensure her safety. She needs, like all of us, social contacts, interesting activities and a sense of engagement in her community. Her Mediciad coverage has assisted to provide this for Karen for many years, at adult day care, now in her group home, in her daily community integration activity program and in providing for her health care needs. Without this support she would be very withdrawn from the world and what a loss that would be for others. You see Karen is a very loving and caring human, she is the watch dog for the other residents in her home. She cares deeply about her family. You may ask why doesn't a family member take care of her? We siblings are like many others, working full time jobs to make ends meet and caring for our own families. We are in the squeezed middle class that cannot afford to quit work to provide a stimulating environment for our sister.

This is one story, there are so many people and families that would be impacted should Medicaid coverage be cut. We have a responsibility as humans to care for each other, do not forget your responsibility!

Sincerely,

Joan M Frost

From:

Marvanne Griffin

Sent:

Saturday, July 15, 2017 12:07 AM

To:

Nicole Jorwic

Subject:

Missouri - Better Care Reconciliation Act- Vote NO

July 14, 2017

Attention Senator Roy Blunt:

The senate republicans are currently working on an awful law called "Better Care Reconciliation Act" which I find to be a very offensive piece of legislation.

You call it "Better Care" but in all respects it is in reality the "Republicans Don't Care Act." You got into office to do what is right for Americans, but have decided you only want to work for the wealthy Americans and let everyone else fend for themselves. I get it...wealthy people have no problems paying for the very best healthcare that big money can buy. Wealthy people don't need the ACA, but wealthy people do "need" more money! When they get to be millionaires then they want to be billionaires. Billionaires don't need the ACA, but they "need" more money, which can be achieved with lower taxes. The appetite for money is insatiable. The republicans appear to be all too eager to throw the less fortunate off of affordable health care. Please take a stand and show some backbone that you are not one of those nasty people who bow to the party line just so you don't draw attention from the republican leadership that has no problem in serving the minority rich instead of the majority that put them in office.

At present our family does not use Medicaid, but I have an autistic son that will likely need some support from Medicaid in the future. The BCRA is designed to gut that program. Please vote NO to the BCRA.

In the future how about trying to work with the democrats on fixes with the ACA instead of pushing an ultra right agenda. United We Stand, Divided We Fall. The way I see it, America is falling fast with the current government actions.

Thank you, Stephen Griffin

From:

Mary Basler

Sent:

Friday, July 14, 2017 6:30 PM

To:

Nicole Jorwic

Subject:

Missouri

How Medicaid has affected our lives: without Medicaid our 19 year old son would not be able to live as independently as he does. Medicaid is absolutely necessary for people with intellectual disabilities. They deserve to live with dignity. Our country needs to help those who can not take care of themselves. Please vote NO on the senate health bill reform. Thank you. Sincerely, Mary Basler

Sent from my iPhone

From:

Dawn Duer

Sent:

Friday, July 14, 2017 5:26 PM

To:

Nicole Jorwic

Subject:

Missouri opposition to Medicaid cuts

I am writing on behalf of my niece, Ainsley, who at thirteen years of age still functions as is more typical of a two year old. She needs assistance with nearly every daily task, such as dressing, eating, and hygiene. Just recently, her parents have applied for a Medicaid waiver, which would provide access to Personal Care Assistance by individuals who would have the time and focus to help Ainsley learn to care for herself.

About a month ago, we learned she was finally approved and granted access to the supports that the Medicaid Waiver can provide our family. While as a family we celebrate getting these services, given the pending legislation and Medicaid cuts, I now understand this is going to be a lifelong battle for us, as Ainsley's family members, to advocate for her since she cannot advocate for herself.

Please oppose any legislation which includes cuts to the Medicaid program. It will result in funds and services being taken away from those who cannot speak for themselves.

Sincerely, Dawn Duer, Ainsley's aunt

From:

Laurie Orso

Sent:

Friday, July 14, 2017 4:26 PM

To:

Nicole Jorwic

Subject:

Medicaid matters Missouri

To whom it may concern

Please help us keep funding for Medicaid!

I am a devoted mother of 2 young children.

My older daughter has Autism and we have so many needs to see psychiatrists get therapy etc, and Medicaid programs pay for all her needs , giving her much improvement and support!

Our lives are hectic and I can't work full time to get benefits and insurance.

Medicaid keeps me and both my daughters healthy and looked after.

Our lives would be impossible to carry on in a normal balanced way without it!! We are so grateful for it and grateful for our country to look out after us all !

Please help Sincerely Laurie Orso Mother - St Louis MO

Sent from my iPhone

From:

Jen Bierling

Sent:

Friday, July 14, 2017 4:20 PM

To:

Nicole Jorwic

Subject:

Missouri - Medicaid Matters to Me

I do NOT support the current version of the Better Care Reconciliation Act with cuts to Medicaid for those with disabilities!

Here is why:

In a time before I had a personal interest in Medicaid, I too, thought this was an easy area to save money or to target in order to lower taxes. Just hold people accountable - make them get jobs, for gosh sake. Why do we let people live off the government? I work hard, why doesn't everyone? We should make them work.

Fast forward to today. I am now the mother of a beautiful 13 year old daughter who has developmental disabilities. Ainsley has changed me in more ways than I could ever imagine. I have never been big on asking for help. I'm still not great at it. But, to build a life for Ainsley - to help her to learn to care for herself and gain more independence We. Need. Help. Ainsley deserves help.

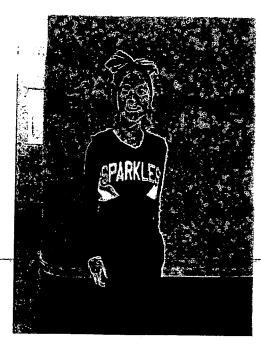
What I have now come to understand is that programs like Medicaid are here to support our most vulnerable citizens. People like Ainsley who have disabilities which make them unable to fully care for themselves or live independently. At 13 years old, Ainsley requires assistance dressing, bathing, using the bathroom, navigating a parking lot without running front of a car, you name it. Imagine caring for, and running after, your two-year-old for 13 straight years. I love her with all my heart, but frankly, it's exhausting. And this is lifelong for Ainsley; the need does not magically end when she turns 18 and is deemed an adult.

About two years ago Ainsley's father and I embarked on a journey to apply for the Sara Lopez Medicaid Waiver for Ainsley, which would provide access to Personal Care Assistance by individuals who would have the time and skill set to help Ainsley learn to care for herself. It was hard admitting just how developmentally behind she is; it breaks your heart as a parent. But, We. Needed. Help. A couple months ago, we learned she was finally approved and granted access to the supports that the Sara Lopez Waiver can provide our family. I want to celebrate getting these services, but given the pending legislation and Medicaid cuts, I now understand this is going to be a lifelong battle for us, as Ainsley's family members, to advocate for her since she cannot advocate for herself. One step forward, one step back.

I want and NEED you to understand that Medicaid is not an enabler for any of us to lay on the couch all day. It's an enabler for our family to give Ainsley the care she needs while still being strong and productive members of our community. The help we get from Medicaid Waiver services allow myself and Ainsley's dad to keep working. To live a full life. To be good role models to both Ainsley and our typically developing son, Alex. And, frankly, to pay our taxes which help fund countless priorities at the state and federal level. But most importantly, we are able to ensure that Ainsley has the care she needs to keep her safe. Because that is a full time job.

I ask that you think hard about Ainsley and people like her living with disabilities, when voting on the current version of this bill. Even if children are protected in the proposed legislation, what happens when those children become adults? They will fall off a cliff. The individuals taking the brunt of the impact of the cuts to Medicaid are not the ones who we should be hurting when trying to fix our healthcare system.

We need to find another way.



Best Regards, Jennifer Bierling (Ainsley's mom) St. Louis, MO

From:

Constance Scheppers

Sent:

Friday, July 14, 2017 3:50 PM

To:

Nicole Jorwic

Subject:

The importance of Medicaid in our lives

Hello

I wanted to take a moment and let you know how important Medicaid is in my life and my daughter's life.

My daughter has disabilities that she was born with and these disabilities affect her daily life skills. We live in the St. Louis Mo area and have no family members to rely on to help us.

My only other child passed from complications of treatment of leukemia 5 years ago. I have no other support, I am single and am personally preparing for a hip replacement and back surgery. I cannot physically handle caring for my daughter at this stage of my life. The ISL services are essential to our quality of life and if we did not have the ISL I cannot imagine how we would survive. Our ISL is supported by Easter Seals and I am very grateful for this service every single day. I know I cannot do it alone.

I am also grateful that Medicaid helps with medical bills for her medical care. Her income is her disability check. She is unable to work at the sheltered workshop any longer due to anxiety issues. We (my daughter and I) would be unable to pay her medical bills without Medicaid's help.

I have tremendous respect for the fact that our state recognizes that there is the social need, a social responsibility, to help those who cannot help themselves any more than what they already do on their own. By giving assistance and support, our state shows their responsibility and respect for those who will never have the chance beyond this to better themselves. The state has a duty to help those in need. These citizens who receive help from Medicaid have a better quality of life with this help and society functions better as a whole with citizens assisted in daily living requirements.

Thank you for listening and taking our concerns seriously. Cutting funding to Medicaid in any way risks the lives and quality of life for folks with disabilities and that will be to the detriment of us all.

Thank you.

Sincerely, Constance M. Scheppers

Ballwin MO

From:

Hendricks, Lesley A. (EHQ)

Sent:

Friday, July 14, 2017 3:39 PM

To:

Nicole Jorwic

Cc:

Mark Keeley

Subject:

Medicaid MISSOURI

Without Medicaid, my 25 year old son with learning disabilities and mental impairments would be unable to have his full time personal assistant funded by a Missouri Medicaid waiver program. Additionally, he would be left home alone most of the day time hours as I work full time. I am also a full time student as this is my senior year at Lindenwood. Therefore, as I further my education, my son is able to have ample time with his PA and will not be home alone during the day. This Medicaid Waiver program saves the state an extraordinary amount of money because this funding keeps a person such as my son, with disabilities, from being institutionalized which could cost taxpayers a LOT more money.

Medicaid is my son's healthcare insurance as well. Without such programs like full Medicaid for healthcare, people like my son will likely go to ERs or 340b healthcare facilities for their healthcare needs which cost the government and taxpayers billions each year. THINK ABOUT IT!!!!!!

I ask that you look at the big picture when thinking about making cuts to Medicaid which will affect millions of people, our most vulnerable of the US population!!!!

Lesley Hendricks