PENNSYLVANIA

The Arc.
Pennsylvania

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Senate Finance Committee Hearing
"Graham-Cassidy-Heller-Johnson Proposal"
September 25, 2017

Written Statement from The Arc of Pennsylvania

The Arc of Pennsylvania stands with The Arc of the United States and the many other organizations opposed to all proposals that reduce Medicaid funding and specifically, the bill authored by Senators Lindsey Graham, Bill Cassidy, Dean Heller and Ron Johnson. This legislation jeopardizes the health care of thousands of Pennsylvanians, including people with disabilities. For 68 years, The Arc of Pennsylvania has worked to ensure that children and adults with developmental disabilities including autism and intellectual disability receive the supports and services they need, are included in their community, and have control over their own lives. This bill jeopardizes all that we have worked for and achieved over the past 68 years.

This proposal while shifting significant responsibility onto states; institutes a block grant that expires in 2026. Our recent experiences in Pennsylvania have led us to be wary of block grants. They are often espoused to offer flexibility however much of the flexibility offered is already available in the current system and the block grant actually translates to cuts in funding. The block grant in the Graham-Cassidy proposal is a significant cut in Medicaid funding to Pennsylvania.

The Arc of Pennsylvania is concerned about the ability of block grants to adjust when there are changes in needs, such as natural disasters, health care epidemics, or economic recessions. With a capitation, legislation, often challenging to pass, would be necessary for Medicaid to provide additional financial help when the need in Pennsylvania increases. Pennsylvania's data demonstrates that our population is aging and the acuity of people receiving disability services is becoming more severe over time. Certainly, this past year's hurricanes and the national opioid epidemic have made states more aware of the critical role of Medicaid.

The Arc has a long history of promoting pre-natal care and we especially promote the avoidance of drinking alcoholic beverages during pregnancy. We are very concerned that states would have options regarding the coverage of essential benefits including pre-natal care. Understanding the established scientific research regarding the benefits of early pre-natal care and the impact of addiction treatment on developing fetuses, we strongly request reconsideration of your plan and require states to provide this essential health benefit coverage.

In Pennsylvania, our Early Intervention program, serving children birth through five years of age, significant portions of special education, and our entire adult system for people with disabilities all rely on Medicaid funding. Cuts to Medicaid impact 722,000 people with disabilities in Pennsylvania. It is estimated that Pennsylvania alone will lose $15 billion in federal funding by 2027 if Graham-Cassidy is passed. This will result in an extreme shift in funding to our state budget. Our state legislature would be tasked to replace this funding or be forced to cut services, reduce payments, or completely eliminate coverage for some of our most vulnerable citizens. Our legislators will be tasked with very difficult decisions - who is most deserving of health care? Our children? People with disabilities? People in a mental health crisis? Those with addictions? Working age taxpayer adults with disabilities? Our seniors? Our worry is that children born with disabilities will not receive the critical services they need at an early age and that adults with disabilities will be relegated to large congregate facilities if they receive services at all. The Arc of Pennsylvania

The Arc

Date: 2017-09-21 19:43:49
To: My Senator
From: Penney Clark
State: Pennsylvania
Email: [redacted]

My daughter Ashley Clark has many medical and mental health disorders. Her life would be even more negatively impacted if she would lose or have reduced Medicaid coverage. Though we,her parents, are willing, we would not be able to afford the high cost of her care. Please help Ashley and her family by voting NO on the Graham-Cassidy Bill. People like Ashley need a voice to hear them. Do not repeal the affordable care act until you have something that can provide for those who are willing but unable to provide for themselves.

Penney and John Clark

The Arc.

Date: 2017-09-22 14:01:16
To: My Senator
From: Charlotte Pletcher
State: Pennsylvania
Email: [redacted]

To Whom it May Concern:

I have worked in the field with folks with Developmental Disabilities/Intellectual Disabilities for the past 34-years.

Part of my job duties is supporting folks with I/DD in their community with medical appointments. These folks have come to rely on Medicaid to pay for their medical needs. The folks I support are on a very limited income and cannot pay medical bills out of pocket because of this. It would be a hardship for them.

These folks did not ask to be born with a disability that leaves them unable to work, so that they could have otherwise, had access to health care coverage through their employer.

There are a lot of folks with I/DD that do not have the mental capabilities needed to learn a job skill. And those that do have jobs, still earn below poverty level wages.

We closed the institutions, where health care was provided. This was a great thing that the institutions closed!!!

We put folks in the community, where they deserve to live a life as anyone else that does not have a disability would. Please do not take this essential program away from them.

Folks that have a I/DD have a right to Medicaid.

I have worked hard all of my life and have paid taxes, and as a taxpayer, I feel that some of this tax money could go towards helping folks who need Medicaid.

I'm sure many other tax payers across the state of Pennsylvania, feel the same way.

Sincerely,

Charlotte R. Pletcher

Date: 2017-09-23 13:07:16
To: My Senator
From: Marilyn Long
State: Pennsylvania
Email: [redacted]

The Arc®

We have a lovely young daughter, who is one of our triplets born at 26 weeks gestation. She was diagnosed with spastic quadriplegic cerebral palsy at 8 months old. She is medically complicated and has spent a large portion of her 25 years of life at doctors offices, hospitals, undergoing surgeries, therapies, blood tests, finding appropriate equipment (DME) and medical supplies, etc.

We happen to be a family of productive and contributing citizens, who pay our taxes and have been lucky enough to have had private insurance for the last 25 years to help defray the costs of our daughters medical care. (BTW, we contribute significantly to that private insurance through payroll deductions each week) She also is eligible for Medicaid , and she uses that insurance to cover those expenses not covered by private insurance (which are becoming more and more as private insurance cuts what they are covering to reduce the amount of claims they have to pay).

I would like to give you an example of a recent medical expense that she incurred:

My daughter is non verbal and has been experiencing some "events" that so far, no doctor has been able to explain. WE have spent months going to various specialists, hospitals, being tested both inpatient and out patient, and no answers to date. This is not only very time consuming, but also extremely expensive. Most recently, her issues have been exasperated with the addition of very high blood pressure. When this started, we called our Primary Care Doc and she told us to go to the ER, because her blood pressure was so high, she was at risk of stroke. The medical professionals at the ER were very thorough in their testing, trying to get to the root of the problem. We were there for 5 hours, her blood pressure did come down, but we left with no conclusive reason for the issue. We continue to systematically rule out "root causes" with testing, while trying to manage these particular symptoms with BP meds, which to date, have not been effective. When I went on her hospital portal, I looked at the bill for our 5 hour visit to the ER, and it was over $25,000. Thank goodness we have insurance to cover this "small" expense, but come May, when she turns 25, she will no longer be able to be a dependent on our insurance policy, and will have to rely 100% on Medicaid to cover her extraordinary medical expenses. If Medicaid were not an option, she would most certainly not live a full life. This ER visit is one small example of the extraordinary cost of her medical care.

What seems hypocritical to me in this political system of ours is that , we have politicians espousing "WE CHOOSE LIFE", when the debate around legalized abortions is raised, however, these same politicians are those who are advocating to cut Medicaid, which would end up with the same result, cutting short a life that could be saved if they had the resources to afford the appropriate medical care. When we found out that we were having triplets, we were required to participate in a genetic counseling session, where we were strongly encouraged to consider "selective reduction". This was due to the statistics that demonstrated the risk of birth defects in multiples. We chose life at that time, but it is disheartening to me that at this point, our government is going to turn it's back on the most vulnerable population of citizens to "balance the budget" or afford tax breaks to those who can care for themselves, and effectively shorten the life of these individuals.

It is not only the moral and ethical thing to do , but it is our civic duty to care for the citizens of our country who cannot care for themselves, through no fault of their own. Rather than put this burden on the backs of these vulnerable citizens, our politicians and government officials should be spending their time and our money on investigating and closing the loopholes that allow Medicaid fraud, as well as fraud and waste in other government spending, which would allow those who really need the Medicaid funding to continue to receive it.

I would be happy to expand on any of our story if anyone would be interested.

Thank you.

Date: 2017-09-23 11:15:39
To: My Senator
From: Linda Baker
State: Pennsylvania
Email: [redacted]

Our twin daughters are now 28. 27 years ago we were the first family in Columbia county to apply for & receive Medicaid based on each girl's income, not our own. What a blessing having Medicaid has been for each of them, & us. Costs of orthotics, equipment, therapy aides, & medicines have all been covered. Their physical therapy, occupational therapy & speech therapy were all covered by Medicaid throughout their school years. Our youngest who is wheel chair bound with cerebral palsy & has developmental delays as well as intellectual delays from neurolical damage receives the consolidated waiver. The waiver is tied to Medicaid. How will u protect the integrity of the waiver if Medicaid is changed?

Both of our adult daughters are wonderful early intervention successes. Each one lives on her own, the eldest has a job, & they enjoy continuing to strive to reach their potential. They need your continued support to be productive citizens. Thank you for your time & support.

Date: 2017-09-22 15:37:19
To: My Senator
From: Cassie Naron
State: Pennsylvania
Email: [redacted]

The Arc.

My name is Cassie and I work full-time in order to support my family. I often work numerous hours of overtime in order to limit the help from the federal government we do receive. The only help we receive is through the funds that assist with paying for medications my son and husband both take.

PLEASE do NOT make any further cuts to Medicaid. My family needs it and depends on it. One of my husband's medications would cost $7000 per month. I only make about $12/hour despite having a master's degree which I worked hard to obtain. I have worked part-time while working full-time in order to make ends meet.

PLEASE think about the situation as if this was your family member and what you would do if you could not afford to pay for my medicines. What would you do if the government said they could not help you pay for medicine that would save my life?

This help is essential to me and millions of people who are doing their best to take care of themselves but need some help in order to make ends meet. Thank you for your time.

Date: 2017-09-22 15:28:03
To: My Senator
From: James Naron
State: Pennsylvania
Email: [redacted]

My name is James and I have been on medicaid to help me pay for my medications since I was diagnosed with insulin-dependent diabetes in 2000. I am unable to work because of a culmination of medical issues resulting from not being diagnosed sooner.

My wife works full-time in order to support our family. She has worked numerous hours of overtime in order to limit the help from the federal government we do receive. The only help we receive is through the funds that assist with paying for my medically necessary medications I take. Without each and every medicine I am on, I would eventually die a slow and literally painful death. I would require ongoing medical appointments as well as expensive hospitalizations due to never-ending medical problems as a result of not having my life-saving medicines.

PLEASE do NOT make any further cuts to Medicaid. I need it. Other people like me that might not write in need it. I worked until these medical problems started and do not choose to have these issues. I would work if I could but I am physically unable to do so. PLEASE think about the situation as if I was your family member and what you would do if you could not afford to pay for my medicines. What would you do if the government said they could not help you pay for medicine to help me?

This help is essential to me and millions of people who are doing their best to take care of themselves but need some help in order to make ends meet. Thank you for your time.

The Arc.

Date: 2017-09-22 15:16:34
To: My Senator
From: Thomas Naron
State: Pennsylvania
Email: [redacted]

My name is Tom and I have been on medicaid to help me pay for my medications since I graduated from high school four years ago. I am high-functioning autistic and work part-time at a convenience store to pay for my cellphone and basic hygiene items. I worked with a job coach and applied for over a hundred jobs before I finally landed a job.

I offer to pick up shifts at my workplace at every opportunity, but because of my autistic tendencies I am not able to work full-time. I need the financial help I get from Medicaid in order to pay for my medicine. I depend on it in order to afford my medications. I have to take my medications every day in order to function at the level I do. I have tried on my own to be independent of any medications through "medication holidays" where I did not take my medication for extended periods of time. I was not successful and found myself feeling depressed, anxious, and unable to focus or to perform simple everyday living tasks that I would otherwise be able to do,

PLEASE do NOT make any further cuts to Medicaid. I need it. Other people like me that might not write in need it. I work hard doing as much as I can in order to support myself, but I do need help because I do not qualify to be on my parent's insurance plan. PLEASE think about the situation as if I was your son and what you would do if you could not afford to pay for my medicines. This help is essential to me and millions of people who are doing their best to take care of themselves but need some help in order to make ends meet. Thank you for your time.

Date: 2017-09-22 11:07:13
To: My Senator
From: Madilina Sink
State: Pennsylvania
Email: [redacted]

My sister lives in a group home in New Jersey. About 25 years ago I fought to get her out of the institution that she was placed in as a teenager. It took 5 years and now she is what I thought was safely living in the community in a group home. She is now 70 years old and her medicaid and her home is at risk. Some would say that maybe a nursing home would be appropriate for someone of her age. That is not necessarily the case for all. She has all of her mental functions as she would have related to her cognitive abilities. Coming from an institution (which has left her with many mental and physical scars) and going from a home (her home is how she sees it) to another institution (which is what a nursing home is) would kill her spirit and defeat all that she has worked toward. She would die quickly. She would be depressed and saddened by the move. Since medicaid is becoming such an issue it sometimes seems easier for agencies to let the nursing homes deal with it the medicaid and send people with disabilities there. She is legally blind, has seizures and cognitive disabilities yet she could tell you her whole life story. She remembers her past like it was yesterday. Please don't take away her medicaid or limit her access. As it is now she pays out of pocket for doctors and hospitals that she never paid before. It is ok because at least she is getting the medical care she needs. Please don't make it worse. Don't take her life. She has been through enough already.

Date: 2017-09-22 08:46:35
To: My Senator
From: Alison Kandrovy
State: [redacted] PA
Email: [redacted]

This is not to say that life has come easy. When I was 8 months pregnant with little to no issues, we were told out of the at our last routine visit that Riley would be born dead. What I thought was a routine ultrasound turned out to be the start of our journey into our new normal. The very next day we visited a high risk OB who told us that diagnosis was completely wrong and that our baby had a form of hydrocephalus. Riley was born on July 24th, 2014 and had his first surgery at 4 days old. He was in the NICU for 26 days at Children's Hospital of Philadelphia. Four days before being discharged we were told that it was L1CAM syndrome, the root cause of his severe hydrocephalus (AKA x-linked hydrocephalus). It was the talk no parent should ever have to go through and it was one of the worst moments of our lives.

Riley has had four major surgeries total, two on his brain and two in his stomach area. He has a g-tube and hearing aids as well as multiple diagnosis's that commonly go along with L1CAM syndrome. He has cortical visual impairment, bilateral hearing loss, hypertonic diplegic cerebral palsy, and as they call poor weight gain in children "failure to thrive."

I'd be lying if I told you there weren't multiple tears, anger, guilt, frustration, and even despair when things were really bad. They say "what you don't know won't hurt you" but I find the opposite of that to be true. Not knowing if you are going to bury your child sooner rather than later is probably one of the worst things you could feel as a parent. Upon our arrival home from the hospital after Riley was born, one of the first things we were asked was if we had a funeral home picked out for him. I sincerely hope none of you have or ever have had to go through such a question with a newborn baby.

In addition to St. Joseph's, Riley has additional services who help him as well such as Hospice of the Sacred Heart in their PATH program. This is a program for those young and old who essentially "graduate" from hospice and are still followed by social workers to ensure all is going well. Riley graduated from hospice shortly before his first birthday and we've been with PATH ever since. It is always fun when they visit and they enjoy seeing Riley grow and thrive. We are also involved with PA. Elks Home Service with his wonderful LPN Tanya who checks in with us to visit Riley and make sure we are getting everything we need and they serve as wonderful advocates for Riley. In addition to these services and being involved with Wayne County Early Intervention, Riley is part of Wayne County Office of Behavioral and Developmental Programs, through which he has an Individual Supports Plan. He is with the Bureau of Blind and Visual Services which provide him with unique opportunities for visual therapy toys,and he was even in their own fashion show last year which was coordinated by one of their own clientele. Riley is also with American Society for Deaf Children, which is an organization that provides access to videos for early learners through high school, as well as for parents and teachers with topics such as ASL story telling, training, deaf culture, academics, children's literature, and much more. Riley is involved with Lekotek, a lending library for therapy toys, through United Cerebral Palsy with the director of Lekotek Sally McColloum, Summit Music Therapy with Cheryl Mozdian, who I truly believe has brought out so much of his voice. We're with Parent to Parent of Northeast PA, an organization that helps in making connections with other families of the same disease or condition as your child, Hands and Voices an organization for children ages 0-3 for parental support for deaf children, which we were with for a few months before Riley turned 3 but I made some wonderful connections in that short time. Women Infants and Children otherwise known as WIC, which provide Riley with monthly vouchers for formula, food, as well as check ups and he has a fabulous medical team at Penn State Hershey Medical Center.

Riley is now 3 years old and was not supposed to make it to 2. All of these things listed above is because he has Medicaid. Without the help of Medicaid, Riley's life would have ended much earlier. I beg all of you in this financial committee, please do NOT cut Medicaid, put a cap on it, or anything else. His medical daycare where he is thriving and receiving therapies, is made possible by Medicaid. His multiple surgeries and specialists and team of doctors at the hospital would not be possible. Riley is alive because of Medicaid. There are countless other children and adults out there who rely on this service in order to lead fulfilling lives. It is not worth it to cut this program only to satisfy political needs and favors. Think of the people this will truly affect and hurt in the long run. My son will NOT pay for this lack of empathy that Senators Bill Cassidy and Lindsey Graham cease to have. If it were one of their own children or themselves, they'd have an entirely different view. I invite them to come spend a day with myself, my son, and tour his daycare. They may learn more about Medicaid in just a few hours than they have in their entire political careers. PLEASE PLEASE PLEASE do not cut or cap this. Save my son's life and that of so many others. He doesn't deserve a lesser quality of life because of the almighty dollar that is decided by people who will never meet him or have any impact on his life. I invite you to contact me to discuss this matter further if it helps anyone understand how important Medicaid truly is.

The Arc.

Date: 2017-09-22 21:49:44
To: My Senator
From: Lisa Kogan
State: Pennsylvania
Email: [redacted]

Dear Senators,

My name is Lisa Kogan and I have two sweet sons with autism, Danny (11) and Ryan (14). Medicaid has helped our family by providing home and community based wrap around therapy services here in Pennsylvania. Medicaid has helped pay for our sons outpatient dental surgeries. Medicaid helps our family by providing special education services to their local public schools.

Please vote no on the Graham-Cassidy bill. Please protect Americans with disabilities. Please work together on a bipartisan solution to improve health care for all.

Thank you,

Lisa Gart Kogan

Date: 2017-09-21 20:34:46
To: My Senator
From: Mary-Jo Tucker
State: Pennsylvania
Email: [redacted]

The Arc.

I have a 23-year old son, Nathaniel, who has autism and intellectual disabilities. I have great concerns about Graham-Cassidy impact to Medicaid and how it impacts my son. I cover him with my insurance and Medicaid covers what it does not cover. Nathaniel takes expensive meds to address his anxiety and impulsive behavior. He also is sick more than his typical sister. He also requires visits to specialists (neurologists, psychiatrists, cardiologists, etc.)

Nathaniel has a lot with which to deal. But, he is a fighter. He keeps trying in world that he struggles to understand and in which to find a place. Because he is different, he has been bullied, spit on, and at times shunned. As a result, he has a lot of anxiety, but he keeps trying to find his place in this world to be a citizen and add value to this country. He comes from a long line of patriots. Both of his grandfathers fought in World War II. One as the commander of a mine sweeper and one who was in the Infantry and who, at some points, had to string communication wire ahead of the allied front lines to prepare for next day's battle. Two of his great grandfathers fought in World War I. Nathaniel has their determination and courage. But, because of his disabilities, he had to rely on help from his fellow Americans – help in the form of Medicaid funding to help cover his medical expenses as well as Medicaid waivers to pay the helpers who enable him to hold a job and to be in the community.

Pennsylvania stands to lose $8.3B in medicaid funding in the Graham-Cassidy Bill. How can our state fill that gap?

A loss of $38B impacts the state's ability to provide health insurance and waiver services to the most vulnerable American citizens (including my son) which translates to cuts in coverage. Please support Americans like my son and do not support Graham-Cassidy.

Date: 2017-09-21 16:21:48
To: My Senator
From: Mike Marsh
State: Pennsylvania
Email: [redacted]

The Arc

Our daughter is legally blind, non-verbal, with CP and spastic-quadriplegia. She is about to have major surgery to try to keep her bones from separating more which would make it nearly impossible for her to get around.

We know that she has been as successful as she is because of early intervention and services provided at school under medical assistance (OT, PT, O/M, VT, SpT) We also know that she would be a shell of who she is if she were relegated to a state center for people with intellectual and developmental disabilities. We know that such centers are many times more expensive and do not provide good outcomes for people.

I don't understand how the PA legislature and Congress can keep coming back to people who need support and threatening to cut their lifeline. I don't understand how smart people who run our country fail to see that when I have to spend time writing a note like this, I am not producing revenue for my company and driving the economy forward because I am worried about my daughter's welfare. How does it benefit the economy when parents have to quit their jobs or make decisions between productivity, happiness, and a better life or supporting their loved ones?

Government is probably too big.... but it should stand for those who can't stand for themselves. Make people who abuse the system and find loopholes pay rather than threatening the lives of people with intellectual and developmental disabilities.

I'm really disappointed in the way these conversations keep going

-mike marsh

The Arc.

Date: 2017-09-21 18:18:50
To: My Senator
From: Deborah Arcoleo
State: Pennsylvania
Email: [redacted]

Please DO NOT allow these deep cuts to Medicaid. My 21-year old daughter has Down syndrome and relies on Medicaid waiver funding for her part-time Home & Community Habilitation aid. I work full-time and am single, so this aid not only ensures that my daughter Emily is safe and not alone, but is also teaching her valuable life skills for independent living, such as cooking, cleaning, shopping, managing money and using public transportation. Emily's Medicaid waiver funding also provides her with invaluable Job Support services: a job coach who is helping her learn the job skills she needs in dining services. Emily relies on Medicaid for all of this, plus her health insurance. We waited over 6 years to get the first (smaller) Medicaid waiver; the Consolidated Waiver will take much longer due to insufficient funding. Medicaid is critically important for adults with intellectual disabilities to remain living in their homes and to work and be productive members of their communities. Whatever issues there are with the ACA, please do NOT gut Medicaid. My daughter cannot live her life without it.

Date: 2017-09-22 17:19:01
To: My Senator
From: Jaqueline Humes
State: Pennsylvania
Email: [redacted]

The Arc.

I was born and diagnosed with down syndrome at birth. Somehow my mother believed to go with the Pro Life Movement and accept taking care of me because she felt God's love. From the moment I was born, my problems started. A chord wrapped around my neck, jaundice, and down syndrome. Great. My mom was so sad as I was sent to neonatal care. While in that nursery, a doctor pulled her aside into the utility room. "Do you want me to push her aside and just let her go?" My mom was appalled.

"No", she replied shocked at the mere suggestion. Go take care of my child. If it were not for Medicaid, I would have died without insurance from jaundice. : Maybe I could have died that day, and saved people who don't like unperfect people a lot of grief. But I was a sweet and happy child, and brought my mother much joy! My father was in shock and my brother...well, someone told him his first sibling was a retard.

Many people were employed due to my coming into the world. Thru the Child Link in Philadelphia, I had a therapist at 6 months who taught me how to sit up and roll over. My speech therapist came and helped me blow bubbles and try to babble. A special education teacher played with me. My mom was sick from depression. Medicaid gave her an antidepressant to keep pushing me in the coach. A lot of people were making money because of me. Did I boost the economy or bankrupt the government. I don't know. Nurses came while I was dying of jaundice. Should they have let me die?

My name is Jaqui and I may not be perfect, but I have a lot of love to give to people who accept me.

I am willing to work and volunteer in society to help other people who are abandoned and hopeless if the world will give me a chance.

My education was at public school. I was there because of the IDEA act, but in the end it was a pretty bad idea. I was very sick at school from mean kids bullying me and beating me up . I was very very sick and refused to go back to school. My mom homeschools me.

Government workers are employed because of me. They are overworked and underpaid and they still try to help me achieve a normal lifestyle. Doctors made too much money while treating me because they overcharged for a visit. $600. a visit because society says I'm too fat. The dentist made a lot money too and coeerced my mother into pulling out my teeth. They never grew back. I don't care. When I was 17 I had too many skin disorders from stress. School was killing me. But my mother would not let me die. She was at the hospital every month trying to get the help I needed. Oh, by the way, my father had insurance but medicaid subsidized me because I was a disabled person and even though my dad turned his life over from a truck driver to a special education teacher because I was almost killed by a car once and God saved me, he stil has a hard time trying to take care of my needs. I just found out I have polycystic ovarian syndrome. Thyroid disorder. I still need speech therapy, physical therapy, and nutrition counseling. Even though the $600. an hour doctors couldn't help me. I take lots of medicine.

Now Iam not that smart, but my mom told me that a great country takes care of their poor and their sick. Maybe the government needs to stop helping sick people because it is too hard for them to survive. Maybe it is easier to build bombs and have a silent genocide of the feeble and weak, so nobody has to deal with it anymore. But I am sure, cutting Medicaid at this point is the least of your problems.

With liberty and justice for all. I don't think so anymore. Not if you cut medicaid. I will lose my grandmother who is one of the only people who loves me. My life will be more painful. But I am Jaqui, and God blessed me to tolerate much pain in life. I was put here to show you how to love.

The Arc.

Date: 2017-09-22 08:15:15
To: My Senator
From: Susan Caretti
State: Pennsylvania
Email: [redacted]

My son has a rare chromosome anomaly. He uses Medicaid to get his expensive medicine. Without it he would be sitting in his room without the energy or initative to get up and leave the room to do anything. Without his waiver he would not go out into the community with his mentor and meet people and have new experiences. Or learn how to budget his money or learn to grocery shopping . Thank you for opportunity to tell our story.

The Arc.

Date: 2017-09-21 20:53:23
To: My Senator
From: Celia Hoyek
State: Pennsylvania
Email: [redacted]

My daughter is 20 years old and relies on Medical Assistance to cover her health care needs. In addition she will be graduating from high school this year and it will be imperative that she have funding to attend a program. Medicaid is the main source of funding for over 70% of people like my daughter for supports and services they need to live and work in the community. Any proposal that cuts their funding cuts their livelihood, health and life expectancy.

Rather than repealing the ACA we should be ensuring that all individuals with a diagnosed intellectual disability have access to health care and community supports that allow them to live a full and productive life. I have not advocated for my daughter For the past 20 years to see her future threatened by lack of funding for medically necessary services and supports.

The Arc.

Date: 2017-09-22 08:21:58
To: My Senator
From: Theresa Puharic
State: Pennsylvania
Email: [redacted]

As a mother of two sons with disabilities, I am terribly frightened of what might become of them with the cuts proposed in the Graham-Cassidy bill. My boys did not ask for their disabilities but they each handle what they have been given in life with the help of the medical field and services afforded them through Medicaid. The cost of the surgeries/medicine that they have been on throughout the years would have wiped us out had it not been for the help of co-insurance. One of my sons is working now and paying taxes contributing to the services he once received. He does not know what the future holds for his health and might one day again be in need of assistance. I hope and pray that that assistance will be there for him. My other son will soon be entering the next phase of his life. He will always need assistance. Without Medicaid and the systems in place to help adults with intellectual disabilities, I cannot imagine what life will be like for him. I don't know how anyone could live with themselves knowing the hardships they would be placing on the less fortunate and their families. Put yourselves in their shoes before you make such drastic cuts.

The Arc.

Date: 2017-09-21 19:42:14
To: My Senator
From: Lisa Rajakovich
State: Pennsylvania
Email: [redacted]

My daughter, Maria, has Down syndrome. She is 23 years of age and a productive member of our society and has a fulfilling life. She also has a seizure disorder and Graves disease. She depends on Medicaid for her medical needs as well as for her quality of life. With the devastating cuts being proposed to Medicaid we are certain the life as she knows it will most definitely be effected in a negative manner. I also work in a school for children with special needs and I cannot even begin to think of the devastation to their lives and those of their families if these Medicaid cuts happen. It saddens me that our country does not take care of its most vulnerable individuals who bring so much to everyone's lives. Please vote with your conscience and intelligently and compassionately make a decision to vote no.

Date: 2017-09-21 18:08:46
To: My Senator
From: Gerri Mikelski
State: Pennsylvania
Email: [redacted]

The Arc.

My husband and I adopted our grandaughter nine years ago. She has many special needs. If you take away medical assistance you will be murdering her. My husband will only have his work medical insurance till February. He had to retire due to bad health. He is 62 and I am 67. We both have pre existing conditions. What will happen to us especially my granddaughter? She is on many medications for epilepsy, cystic fibrosis, autisim. Her pancreatic enzymes cost over 3000.00 a month.

That is just one medicine she is on many others. My husband has heart condition, asthma, copd and high cholesterol. As for myself cardiac medicine, asthma medicine and cholesterol.

We both worked all our lives and never expected to be raising a child in our retirement. Our savings is gone from caring for and the cost of adoption.

Please consider all the children being raised by grandparents and other relatives due to the horrors of drug addiction. Please remember most people have preexisting conditions and can't afford high premiums for health insurance.

Date: 2017-09-23 11:56:46
To: My Senator
From: Barbara Blasucci
State: Pennsylvania
Email: [redacted]

The Arc.

My son has low functioning Down Syndrome and is dependent on Medicaid for his community supports and health care. We are a family on a fixed income. My husband is retired and I am home because of my son. Medicaid is his lifeline and enables him to have his medical needs met and to have a meaningful life outside of the home. Please don't cut, cap or block Medicaid in any way. This would hurt my son and our most vulnerable citizens.

The Arc.

Date: 2017-09-23 18:16:27
To: My Senator
From: Liliane Min
State: Pennsylvania
Email: [redacted]

Both as a physician and a mother of a special needs child, I see in my daily life the importance of having universal coverage, as every patient I take care of has a pre-existing condition, and when I get home, I see my own young child, who already meets that criteria. Many of my patients, if they lose their job and their insurance, would need to purchase insurance through the individual market, and before the ACA, many would have been shut out of most plans or unable to afford the premiums. I fear for them if the ACA individual health mandate and the subsidized federal funds are dissolved, as they will be, and left to the states to decide. Regarding my own special needs child, most of his care has not been covered by our own health insurance, but by medicaid. If the medicaid federal funding formula is changed to block grants, it will hit our state PA very hard. PA has one of the best medicaid programs for children with special needs and the state budget will be severely impacted if the federal funding formula is changed from its current form. Many children will either be dropped from the program or have their benefits cut, which will lead to poorer long term outcomes and lead to more costs down the line as these children become adults. I stand firmly against this new Senate bill which seeks to take away the federal protections for my patients and my own child.

Dr Liliane Min

Rheumatologist

Bryn Mawr, PA

Nicole Jorwic

From: [redacted]
Sent: Wednesday, July 19, 2017 11:54 PM
To: Nicole Jorwic
Cc: [redacted]
Subject: How does Medicaid impact our family?

To Senator Pat Toomey-

How does Medicaid impact our family?

Before our son was born, our family (my wife, daughter and I) only visited the doctor for routine annual physical examinations. Thirteen years ago, our son was born with a rare genetic disorder - Willliams Syndrome. He required medical attention from specialists to address several of his health concerns- Urologist, Cardiologist, Ophthalmologist, Genetics doctor, Orthopedic doctor, and his Pediatrician. Each of these specialist visits required we pay high copays. In addition, our son required occupational and physical therapy to address gross and fine motor weaknesses. The weekly therapy sessions also required we pay expensive copays. The therapy sessions have helped our son learn life skills that have enabled him to achieve a significant level of independence. Our son's medicaid insurance covered the copayments for the weekly therapy sessions.

At the time our son was born, my wife had just been laid off from my job. Our son's medical expenses increased our household expenses at a time when our household income had decreased. Our son's medicaid insurance helped ease our financial burden as we addressed his medical concerns.

In addition to covering the copayments for doctor visits, Medicaid covered expenses not covered by our health insurance for our sons leg braces. After years in leg braces (with the help of physical therapy) our son no longer wears the leg braces and only requires orthopedic inserts.

Medicaid insurance helps our disabled son receive the healthcare that he requires. As a result, our son is thriving, which will in turn enable him to become a contributing member of the community.

Respectfully,

Caesar Williams

From: Katrina Williams [redacted]
Sent: Wednesday, July 19, 2017 11:43 PM
To: Nicole Jorwic
Cc: Bonita McCabe
Subject: Pennsylvania - Medicaid Matters to Me

To Senator Pat Toomey-

How does Medicaid impact our family?

~~Before our son was born, our family (my husband, daughter and I) only visited the doctor for routine annual physical~~ examinations. Thirteen years ago, our son was born with a rare genetic disorder - Willliams Syndrome. He required medical attention from specialists to address several of his health concerns- Urologist, Cardiologist, Ophthalmologist, Genetics doctor, Orthopedic doctor, and his Pediatrician. Each of these specialist visits required we pay high copays. In addition, our son required occupational and physical therapy to address gross and fine motor weaknesses. The weekly therapy sessions also required we pay expensive copays. The therapy sessions have helped our son learn life skills that have enabled him to achieve a significant level of independence. Our son's medicaid insurance covered the copayments for the weekly therapy sessions.

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Medicaid insurance helps our disabled son receive the healthcare that he requires. As a result, our son is thriving, which will in turn enable him to become a contributing member of the community.

Respectfully,

C. Katrina Williams

From:	Helen Naab [redacted]
Sent:	Wednesday, July 19, 2017 10:13 PM
To:	Nicole Jorwic
Subject:	PA Senator Patrick Toomey

Dear Senator Toomey,
Please continue to back Medicaid support for individuals with disabilities as part of any changes to the ACA. My brother, aged 56, has Down syndrome, and needs the Medicaid support services he currently receives to ensure his quality of life and support his many health issues.

Discontinuation of any support service my brother receives would result in loss of skills, further cognitive decline, as well as an overall diminished quality to his life. As a most vulnerable member of society, my brother deserves to be cared for, not cast aside, by the leaders of our country. Please work in a bipartisan manner with members of Congress to repeal and replace what needs to be fixed from the ACA.

Sincerely,
Helen Mack Naab

Sent from Yahoo Mail on Android

Nicole Jorwic

From:	Nicole Jorwic
Sent:	Wednesday, July 19, 2017 5:41 PM
To:	Nicole Jorwic
Subject:	Pennsylvania

Colin Buckwalter _ Pennsylvania

[redacted]

Colin spoke at a non-partisan rally in Lancaster, PA on July 28, 2017 on why Medicaid is so important to people like himself and his friends. Below is a copy of the speech, and a link to the video of the speech. We were happy to be among so many people who cared that night. Robin Buckwalter (mother and legal guardian of Colin) [redacted]. Thank you all for all that you do!

Good Evening. My name is Colin Buckwalter. I am 23 years old and I live at the very top of Lancaster County. I went to Cocalico schools for middle school and high school. I also went to Aaron's Acres camp for many years.

Because I have Cerebral Palsy, I use my ECO augmentative communication device to speak with the world. I use my power wheelchair to navigate through life. I am a huge baseball fan. To be honest, I would be home tonight watching my team. But being here is so very important. So I am here with you to come together as community who cares about people.

Medicaid supports people who have disabilities like me. It provides people with communication devices like my ECO and the training to learn how to use them.

This communication device is my voice. The current bill in the Senate will cut 25% of Medicaid. Think about that.

Because of my ECO, I can speak for myself and direct my own care. I can live and participate in my community. I can also use my ECO to interview people for my website. My website will be a back yard travel guide to Lancaster County. I want people to visit beautiful and historic Lancaster county and encourage tourism. This will bring more tourism dollars to Lancaster and possibly bring more money and jobs. I am connected to family and friends because of my ECO. I can meet new people and interview them with my ECO.

My family hears that we will be Ok, that THOSE OthER PEOPLE will lose their benefits, not me. But the truth is no one really knows because the health care bill just came out and there are NO hearings to discuss what it may mean for me, for you, for everyone. We don't know.

How can you pass a bill that affects millions and millions of United States citizens and not talk about what it means to those millions of people?

How can you try to force it through without hearings on the 4th of July? The celebration of American Independence and not having the basic right to have your voice heard….. that just does not go together. That is not the American way.

I went to hear Senator Casey at his town hall on Saturday. I would like to go to a town hall with Senator Toomey, but he is not having town halls to answer questions. So we sent a letter to him instead.

Money that is being cut from healthcare will go to pay for a tax cut for the richest of the rich. It's right there for all the world to see: Take away healthcare so we can make sure that people with money get more money. They could have waited and had another bill. What does that say about Mr. McConnell and Mr. Ryan? They did not even try to hide it. They were in such a rush.

I have a friend who I asked to come to the rally tonight. My friend was afraid to come because they are looking for a job. They are afraid that if they come, someone might see them and then not hire them. They feel they cannot exercise their right to listen or their right to speak because it will be held against them. Think about that.

Me and my family are not public speakers. But when something this important threatens so many peoples' lives, we cannot just sit and do nothing. Please join me in speaking up for people who cannot. Please join me and raise our voices so we may be heard. We all can work together for a better country. I have friends who are Republicans. I have friends who are Democrats. I have friends who have never voted their entire lives. We all need to work together to solve our problems. It is hard work to do that, but that is also the American way. To work hard to find solutions.

At Senator Casey's town hall a man asked a question: In this time when everything seems so crazy, where can we find hope? We find hope from everyone here tonight who didn't stay at home having a hot dinner. Who rolled away from watching their favorite baseball team. Who risked maybe not getting a job. On the 4th of July this year, think about what all those men and women over 200 years ago risked. They decided to stand up for themselves and commit to a new idea and a new country. And then look at your new friends around you tonight and then think: there is hope.

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
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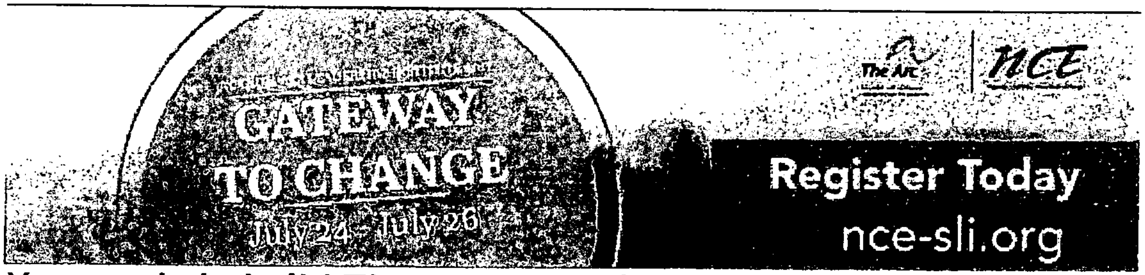
The Arc.
For people with intellectual and developmental disabilities



Nicole Jorwic

From: Prashant Shekhar [redacted]
Sent: Wednesday, July 19, 2017 10:56 AM
To: Nicole Jorwic
Subject: Fw: Call to Action - Medicaid needs your support

Dear Sir/Madam,

Being parents of an Autistic teenage daughter, the Medicaid support really helps provide our daughter varied options including Wrap-around, Speech/Occupational Therapy, Costly Medication(s), Social services at school, Summer Camps, etc.

Hope our elected officials act in the best interest of the constituents.

Warmest personal regards,
Prashant & Sapna
[redacted]

----- Forwarded Message -----
From: The Arc Alliance Action [redacted]
To: [redacted]
Sent: Tuesday, July 18, 2017 1:50 PM
Subject: Call to Action - Medicaid needs your support

Call To Action! **July 18, 2017**

Quick Links

call your Senators and take part in our emergency letter-writing campaign.

Contact Us

The Arc Alliance Website

Dear Prashant & Sapna

Emergency Medicaid Matters to Me Letter Writing Campaign. Please share, write letters and make the calls.

Take a few moments and write a brief message about how Medicaid impacts your life.

Please send those messages in the body of an email to Nicole Jorwic at The Arc of the United States: jorwic@thearc.org.

PLEASE INCLUDE YOUR STATE IN THE SUBJECT LINE OF THE EMAIL.

The Arc of the United States will hand deliver all the printed messages to the Senators from your states later this week. So please act fast, emails must be received by midnight on Wednesday, July 19th, to be printed.

Major Recent Events

Health Care/Medicaid - Senate Releases New Healthcare/Medicaid Discussion Draft, Concerning Provisions Largely Unchanged NEED YOUR ACTION

On July 13, the Senate released a new discussion draft of the Better Care Reconciliation Act (BCRA). The Senate was unable to secure support to pass the bill before the July 4 recess and Majority Leader Mitch McConnell (R-KY) and Administration officials continue to work hard to convince at least 50 Senators to support the bill. To address strong criticism regarding the impact on people with disabilities, the new draft includes $8 billion for a four-year home and community based services demonstration for rural states. This woefully inadequate one-time fund is much smaller than the $19 billion cut from the enhanced federal match (which is not time-limited) in the Community First Choice state option. Additionally, the draft bill still includes per capita caps, which, when combined with cuts to Medicaid expansion, will result in reductions in Medicaid spending by 35% by 2036, compared to current law. Additional changes include allowing insurers to sell plans that cover fewer services, increased funding to address the opioid crisis, and maintaining the Affordable Care Act's high-income payroll tax and investment income tax. In a statement, The Arc warned that the new draft continues to pose a severe threat to people with disabilities. Senate Majority Leader McConnell has announced that a vote on the BCRA will be delayed for at least a week. Advocates should continue reaching out to their Senators and organizing against the BCRA. Please call your Senators and take part in our emergency letter-writing campaign.

Budget & Appropriations - L-HHS-Ed Appropriations Bill Advances

The House of Representatives continued advancing several funding bills for Fiscal Year (FY) 2018 which begins on October 1. On Wednesday, the House Appropriations Committee released its draft bill for the Departments of Labor, Health and Human Services, and Education (L-HHS-ED) which includes the vast majority of discretionary disability-related programs and passed it out of subcommittee the following day. The bill provides funding of $156 billion, a $5 billion (3.1%) cut from FY 2017 levels. The Department of Education has the most significant cut of $2.5 billion (though IDEA programs received a small increase), while the Department of Labor would face a $1 billion cut and HHS faces around $500 million in cuts. See summary here. Line item figures are expected to be made available soon. A markup by the full House Appropriations Committee is planned for July 19.

Education - Bill to Improve Higher Education for Students with Disabilities Introduced in the House

On July 12, Representative Mark DeSaulnier (D-CA) and eight co-sponsors introduced H.R. 3199, the Improving Access to Higher Education Act. This bill would amend the Higher Education Act to improve college access and completion for students with disabilities. The Arc supports this comprehensive legislation that would provide students and institutions with improved training, greater resources, and expanded services, and includes improvements to the Transition and Postsecondary Programs for Students with Intellectual Disabilities.

Social Security - Trustees Release 2017 Annual Report; House Holds Hearing

Last week, the Social Security Board of Trustees released "The 2017 Annual Report of the Board of Trustees of the Federal Old-Age and Survivors Insurance and Federal Disability Insurance Trust Funds." The 2017 report finds that, in 2016, Social Security took in roughly $35 billion more than it paid out (in total income and interest). Social Security's reserves were $2.85 trillion at the end of 2016. The Trustees continue to project that Social Security's combined Trust Funds can pay all scheduled benefits through 2034, at which point the Trust Funds would be able to pay approximately 77 percent of scheduled benefits. The Trustees also find that Social Security Disability Insurance Trust Fund can pay full scheduled benefits through 2028, after which the fund will be able to pay about 93 percent of scheduled benefits. This is 5 years longer than projected in the 2016 Trustees Report, due to declines in applications, awards, and the number of people receiving Social Security disability benefits. Additional key points about the Trustees Report are available from the Consortium for Citizens with Disabilities Social Security Task Force.

The Social Security Subcommittee of the House Committee on Ways and Means held a hearing on the 2017 Trustees Report. The witness was Stephen C. Goss, Chief Actuary, Social Security Administration. Visit the Committee web site to view testimony and archived video.

Education - Department of Education Issues Final Rule Eliminating the R-Word from Its Regulations

The Department of Education released its final rule eliminating the r-word from its regulations and replacing it with "intellectual disability" or "intellectual disabilities." This rule does not make any change to the meaning of the regulations, but rather brings them in line with Rosa's Law, the 2010 law which eliminated the term from all statutes under the jurisdiction of the Senate Health, Education, Labor and Pensions Committee.

Announcements

Rights - July 17-21 is National Disability Voter Registration Week

According to a Rutgers University research report, people with disabilities and their families accounted for 25% of the electorate in 2016. Yet, people with disabilities register and vote at rates that continue to lag behind voters without disabilities.

Let's change that! This is National Disability Voter Registration week - and it's time to Register! Educate! Vote! Use your Power! Join the REV UP Campaign and use this quick and easy link to Register to Vote Now!

Already registered? Make sure your friends and family are registered too!

Here are helpful resources:

- Organizations by state that provide voting support to individuals with disabilities.
- Ten Tips for Voters with Disabilities

Thank you for your supporting National Disability Voter Registration Week!

Education - Report Shows Most States are Not Meeting IDEA Obligations

The U.S. Department of Education found that only 22 states deserved the "meets requirements" designation for the 2015-2016 school year. All other states were placed into the "needs assistance" category. The findings come from an annual mandatory assessment of state compliance with the Individuals with Disabilities Education Act (IDEA). The ratings are based on how well states meet their obligations to serve students with disabilities ages 3 to 21.

Address postal inquiries to:
The Arc Alliance Foundation
3075 Ridge Pike
Eagleville, PA 19403
Powered By

From: John Koethe [redacted]
Sent: Wednesday, July 19, 2017 8:42 AM
To: Nicole Jorwic
Subject: Medicaid matters to my family

Dear Senator Toomey,
Here is why Medicaid matters to my family- My son Kevin was born with Down Syndrome. He is now 29 years old and works in the community thanks to Medicaid funded programs. Without the supports of Medicaid, he would be at home instead of a valuable part of the work force. I would be home supporting him instead of teaching children how to read. Medicaid funded programs help the most vulnerable like my son. Make the right choice and continue to support Medicaid.
Sincerely,
Marie Koethe

Sent from my iPhone

Nicole Jorwic

From: Lareau, Annette [redacted]
Sent: Wednesday, July 19, 2017 12:59 AM
To: Nicole Jorwic
Cc: Lareau, Annette; Freeman, Samuel
Subject: Medicaid

To Our Political Leaders:
Our son is severely autistic. He cannot understand money. He earnestly wants to be an old man. He cannot be left alone, since he cannot get out of the house. When he gets upset, he hits people.

Medicaid is crucial to his survival. The threat to Medicaid is terrifying.

As it is now, the people who work in his group home are paid extremely low wages for very difficult work. The proposed cuts would be very harmful.
I strongly urge you to protect and defend Medicaid to help our most vulnerable.

Yours,
Annette Lareau-Freeman
[redacted]
Philadelphia, PA 19119
[redacted]

Nicole Jorwic

From:	Anne Whitehead [redacted]
Sent:	Tuesday, July 18, 2017 3:46 PM
To:	Nicole Jorwic
Subject:	PA Medicaid Matters to ME Urgent Letter

To my Senator of PA,

~~I have a seriously disabled daughter who was born with multiple medical~~ problems and mental retardation. She developed serious mental health issues resulting from the same syndrome she was born with. Velo Cardio Facial Syndrome. She is permanently disabled.
It has impacted her entire life's ability to stay alive, stay out of the hospital for prolonged periods of time, learn any information, control her emotions and hallucinations. Needless to say, her issues have the same impact on our family.
I have my own multiple medical and psychiatric issues and am permanently disabled.

We would both not be alive without Medicaid to pay our medical and psychiatric bills.

We would never be able to purchase health insurance since we are totally disabled.

We would never be accepted by commercial health insurance because of our catastrophic medical costs that occur every single year.

We would run out of lifetime maximum benefits.

YOU CANNOT CUT MEDICAID BENEFITS !

Keep in mind also- the dollar amount per year (+100,000.00) that I SAVE THE GOVERNMENT by having my daughter live at home every year. She is now 35years old. I do not place her in ASSISTED LIVING PAID FOR BY THE STATE.

Anne Whitehead

From: Beverly Denmark [redacted]
Sent: Tuesday, July 18, 2017 3:14 PM
To: Nicole Jorwic
Subject: Better Care Reconciliation Act (Health Care Matters to Me)

Hello Senators,

I'm very distressed over the changes you intend to make in our present healthcare system,The Affordable Care Act. I am employed and I healthcare through my employer, however most of the population serviced by my agency will be very unfavorably affected by the Better Care Reconciliation Act, you, Senators, will use to castrate The Affordable Care Act. I ~~am asking you to take a more humane point of view, one that may not be popular among your fellow Senators, but it~~ will certainly appease the millions of voters who are just as distressed as I am about them losing their health care. Take a more humane point of view Senators, and vote to continue your support for the millions, with whom health care does matters. Don't make changes to Medicaid that will ultimately result in someone's death.

I am from the state of Pennsylvania, I am a registered voter and I will support a health care system that does not eliminate a person's dignity, and does not disregard a person's need for quality and choices for health care. To me, and most certainly millions of others, Health Care Matters.

Sincerely,

Beverly Denmark
Skill Trainer
Registered Voter

From: Kathleen Nevel [redacted]
Sent: Tuesday, July 18, 2017 2:24 PM
To: Nicole Jorwic
Subject: PA - Medicaid/Health Care Changes

Senators,

My brother is a Medicaid/Health care consumer due to his mental and intellectual disabilities. He is Down Syndrome and a kind-hearted, loving person.

Tom lives in a group home community and relies on Social Security and Medicaid for his basic living and health care needs. His disabilities prevent him from working in a for-pay environment.

Please do not reduce funding for these programs for persons with mental and intellectual disabilities, as Americans and people of humanity we have a responsibility to care for those who cannot take care of themselves.

Thank You

Kathleen Nevel, Ph.D.

Nicole Jorwic

From: Noah W Rinehart [redacted]
Sent: Monday, July 17, 2017 7:27 PM
To: Nicole Jorwic
Subject: Why Medicaid Matters to Me - PENNSYLVANIA

i have down syndrome and a spinal cord injury. i'm 24 yrs and i'm single and live with parents. Medicaid matters to me and my family because it helps me gain independence and the skills that need to be successful in my life. Without medicaid i might NOT have nursing to help me with my limitations and medical needs. Without it i may NOT have the medical supplies i need to maintain my health and well being. In society it well help me and others get medical help from nurses and doctors to keep us free from disease and illness. As we go though our lives ALL different people not including me need help to understand that we all have to help our self's and our community to use what we have to prove so that people can make a difference. All of us have jobs to make money and taxes so we can keep health and to have doctors and nurses to keep us from going to the hospital.

Noah Rinehart

From: The Arc [mailto:info@thearc.org]
Sent: Monday, July 17, 2017 9:15 AM
To: [redacted]
Subject: Emergency Medicaid Matters to Me Letter Writing Campaign - Deadline Extended to Wednesday!

Emergency *Medicaid Matters to Me* Letter Writing Campaign - Deadline Extended to Wednesday!

The Senate is set to vote soon on the latest version of the Better Care Reconciliation Act. The latest revisions to the bill do **NOT** change the devastating cuts to the Medicaid program that over 10 million people with disabilities rely on to live and work in their communities. The time is now to take action and tell your Senators why ***Medicaid Matters to You and Your Family***.

Take a few moments and write a brief message about how Medicaid impacts your life. Please send those messages in the body of an email to Nicole Jorwic at The Arc of the United States: jorwic@thearc.org. **PLEASE INCLUDE YOUR STATE IN THE SUBJECT LINE OF THE EMAIL.** We will hand deliver all the printed messages to the Senators from your states later this week. So please act fast, e-mails must be received by ***midnight* on Wednesday, July 19**, to be printed.

We want to show strong support for Medicaid from all over the nation, but we are particularly looking for letters from the following states:

- Nevada
- West Virginia
- Alaska
- Louisiana
- Ohio
- Arizona
- North Dakota
- Kansas

After you finish your letter, call your Senators and tell them to vote no!

Unsubscribe

Nicole Jorwic

From: Clare Luzuriaga [redacted]
Sent: Monday, July 17, 2017 6:55 PM
To: Nicole Jorwic
Subject: From Pennsylvania

Our 17 year-old daughter suffers from a rare genetic condition. She has grand mal seizures that wipe her out once a week or so, she can't walk unassisted, she has extreme intellectual disabilities, wears diapers, can't take care of herself in any way. Last year, she nearly died from septic shock but thank god was saved by the skilled staff of philadelphia's Children's Hospital's PICU. Without the support of Medicaid, we would be completely lost. Not only does it provide her medical care, it also allows her to have a regular home health aide to help with all the complex care and attention she requires at home.

On top of all this, my husband was diagnosed with Stage IV cancer two years ago. And, needless to say, life got even more difficult at home.

This threat of repeal of healthcare by Republican senators threatens the future of our daughter and my family. It's cruel and worthy of a medieval society to intentionally deprive a helpless population of the very care they need. And, as we know, without that care, many disabled people would end up in institutions, costing the state a lot more money than allowing them to be at home does, so it doesn't even make economic sense.

I work full-time and do the best I can to take care of my family. Please think of the millions of families like ours whose lives are under needless threat for the sake of political posturing by republicans.

Thank you for sharing our story

Clare Luzuriaga
Havertown, PA

Sent from my iPhone

From:	Bonita McCabe [redacted]
Sent:	Monday, July 17, 2017 2:53 PM
To:	Nicole Jorwic
Subject:	Pennsylvania - Why Medicaid Matters to Nicole and Deborah
Attachments:	IMG_5913 (1).JPG

Good afternoon:

Thank you for taking the time to read our email but we wanted to share with you that we have a beautiful daughter, who is going to be 21 years old, and has a diagnosis of Intellectual Disability and Autism. Bonita also has a sister who is 51 years of age and has a diagnosis of Intellectual Disability with Mental Health issues.

Bonita's mother worked very hard with her sister, Deborah, when she was young and as a result, she is able to live with supports in place and is also able to work with supports. Her mother was a true advocate for her sister not only her earlier years but also when she graduated for school at the age of 21.

Bonita learned a lot from her mother when she was younger and knew that she would be facing many challenges after our youngest daughter was diagnosed. Nicole, we call her Nikki, was identified as a child with Autism at 26 months of age and started receiving services shortly thereafter. The services were not what one would expect but with parent training we were able to work on those targeted skills at home and in the community. Having Medicaid allowed us to not only supplement with additional (Speech, Occupational Therapy, Physical Therapy and Wrap Around) services but it also allowed our school district to recoup some of the costs which allowed them to provide those services necessary.

Now our daughter has graduated high school and the next step is her receiving waiver, which requires that she have Medicaid. Keep in mind that we only recently applied for Social Security so she has absolutely no income at this time. Once she receives Social Security (not sure what will happen with Social Security down the line) she wouldn't be able to afford to live on her own simply because she needs some supports. In order to receive Waiver (PFDS or Consolidated), she needs to be enrolled in Medical Assistance (Medicaid) and without it she wouldn't be able to get those necessary supports to keep her at home. If Medicaid gets stripped how will my daughter, and all of the other individuals who have Medicaid, receive those necessary supports and for some children medically necessary, through each phase of their lifetime?

We have friends whose children require extensive care and don't have the resources to privately pay or even pay a co-pay on top of all of their other expenses. What will happen to these children?

Please take a moment to think about what you would do if you were in my shoes, what would you ask for or need? If your child was hurt and needed long term care, how would you make ends meet without losing your house, your job or tapping into your retirement accounts?

We appreciate your time and hope that you will think of not only our family but all of our friends families and maybe you have a family friend who needs Medicaid. We hope you don't mind but we attached a picture of our beautiful daughter, who attended the Night to Shine, in February 2017.

Best,
Robert and Bonita McCabe
Very proud parents and sister!!

Nicole Jorwic

From: Christine Bradley [redacted]
Sent: Monday, July 17, 2017 11:08 AM
To: Nicole Jorwic
Cc: [redacted]
Subject: Pennsylvania - Why Medicaid Mattered for Me

Hello. I am 22 years old, and I live in Willow Grove, PA. When I was born, I wasn't breathing. I spent 10 days in the neonatal intensive care unit because I had bad seizures from the lack of oxygen.

When I got a little older, I was diagnosed with mixed receptive expressive language disorder, which means it is difficult for me to speak clearly, and what I'm trying to say doesn't always come out. I also have severe auditory processing disorder, which means I comprehend speech slowly. I was diagnosed with a coordination disorder, too. So, it's difficult for me to write. I also have dyslexia, which made learning to read very challenging. Finally, I have cortical visual impairment, which means my eyes don't see everything clearly.

Because of my disabilities, I received speech and language therapy, occupational therapy and some physical therapy when I was in school. I had access to assistive technology. These were provided through Medicaid's school based access program.

So, *thanks to Medicaid*, I can read and I can write.

Thanks to Medicaid, I can speak up for myself.

Thanks to Medicaid, I gained the skills I needed to work, earn a living, and have the chance to support myself.

Thanks to Medicaid, I now have a full-time job as an Administrative Assistant at Quality Progressions in center city Philadelphia.

PLEASE save Medicaid so kids with disabilities like me and my friends with Down Syndrome, cerebral palsy, Autism, and other differences have an equal opportunity to be successful.

Thank you!

Peter O'Halloran

From: Donna Johnson [redacted]
Sent: Monday, July 17, 2017 10:03 AM
To: Nicole Jorwic
Subject: PA

Dear Senate,

Please do not vote for the devastating cuts to Medicaid! People with developmental and intellectual disabilities rely on the funding by Medicaid to cover their medical needs. Often these individuals are on several expensive medications or need expensive therapies to help them live and work in their communities.

Thank you for voting no to the Medicaid cuts!

Donna Johnson
[redacted]
Meadville, PA [redacted]

From: Roseann Polishan [redacted]
Sent: Sunday, July 16, 2017 11:24 PM
To: Nicole Jorwic
Subject: Medicaid Matters to Me and My Family in Pennsylvania

I have a son with autism and intellectual disability. He is now 13 years old. He needs developmental doctors, behavioral health services, special education, speech therapy and occupational therapy to help him become the best he can be, but even so he is going to require assistance his entire life. It takes him a long time to reach goals that are simple for others, such as learning to bath, recite his name and address and do simple chores. Services that will help him to be a productive member of society and transition out of school into an assistive work program and the crucial mental health services and medication he needs are all covered by Medicaid. We are very worried that these programs will be cut if funding to Medicaid is block granted or capped per person. This is his lifeline. Please vote No!

Thank you
Roseann Polishan
[redacted]

Nicole Jorwic

From: Melissa Murphy [redacted]
Sent: Sunday, July 16, 2017 8:46 PM
To: Nicole Jorwic
Subject: PA (Medicaid story)

Dear Sens. Casey and Toomey:

Medicaid matters to my family. I have a wonderfully charming 6 year old daughter named Rose. She happens to have Williams Syndrome, a rare, spontaneous, genetic syndrome that causes a host of medical and learning challenges, including a serious heart defect.

We have private insurance; my husband and I both work (ironically, my husband works at a pediatric hospital and I am a career federal employee). Medicaid covers the significant portions of Rose's frequent heart echos that my insurance won't cover. It pays for her hearing aids that my insurance won't cover. It subsidizes a small portion of the 9 weekly therapies she receives.

Do we really live in an America where a little girl born with a bad heart and who is hard of hearing can't get cardiac care and hearing aids?

Melissa Murphy
Wynnewood, PA

Sent from my iPhone

Nicole Jorwic

From: Kathryn Novogratz [redacted]
Sent: Sunday, July 16, 2017 5:17 PM
To: Nicole Jorwic
Subject: PA medicaide

Dear Senator Toomey:

The Senate is set to vote next week on the latest version of the Better Care Reconciliation Act. The latest revisions to the bill do **NOT** change the devastating cuts to the Medicaid program that over 10 million people with disabilities rely on to live and work in their communities.

My son is 17 years old and suffers from Schizencephaly, seizure disorder, and Intellectual Disability. Medicaide keeps my son alive as well as helping him stay in my home. I and my daughter also rely on medicade. I'm a 56 year old single mom that works temporary jobs that offer no medical insurance or benefits. Because of my age, finding a job that offers benefits has proved to be a struggle. I've been without benefits for over a year.

Please vote NO on the Better Care Reconciliation Act. Should this bill become law, my family and I will be forced to go to Emergency Rooms at hospitals for even the most mundane ailments. Please revise the Affordable Care Act and make it a single payer system like all other civilized nations. Thank you.

Kathryn Novogratz
[redacted]
Northampton, PA [redacted]

From: Margaret Richardson [redacted]
Sent: Sunday, July 16, 2017 11:53 AM
To: Nicole Jorwic
Subject: Medicaid Matters to Me in Pennsylvania

Medicaid matters to our family because our son has a disability and may never be able to live independently. He is an only child and his dad and I will not live forever. Medicaid services are his safety net. I have friends with kids that are Downs, have cerebral palsy, or are blind. What is to become of them? We all face the same types of challenges.

And in this day and age, who does not know someone touched by the opioid epidemic? Though the new senate version has more funding, it takes Medicaid services for many to benefit from that funding.

If you have one ounce of humanity, you will vote "No" on this bill.

Margaret Richardson
Wexford, PA

From: DAVID SKRIPKUNIS [redacted]
Sent: Sunday, July 16, 2017 11:08 AM
To: Nicole Jorwic
Subject: Medicaid

To Whom It May Concern:

I am the mother of a 30 year old lady with severe autism. She has been a Medicaid recipient since 1992. During that time, it has helped defray the cost of medical expenses including emergency room care, doctor's visits, surgeries, prescriptions and other services. It helped pay for her anti-seizuer medication which was around $200 a month. Once, after surgery, she wasn't able to keep the medication down and had what's known as a break-through seizure. She had to be transported to the hospital in an ambulance on oxygen. She was unconscious, barely breathing, and her heartrate was extremely weak. Without Medicaid, I would not have been able to afford the services that kept my daughter alive. Today, she attends a day program five days a week where she not only recieves much needed therapies, but gets to socialize with others. Without it, her quality of life will greatly decrease because we can not afford the $23,000+ it would cost to send her.

The Medicaid expansion has also allowed my adult son to purchase insurance through the exchange for the first time in four years. If the expansion is rolled back, he stands being without insurance once again.

I have talked to my Senators and Representatives begging them to not do this. Senator Bob Casey has made it very clear he will not vote for any health care bill that cuts Medicaid. Senator Pat Toomey on the other hand, keeps denying that it is being cut. He will not even acknowledge those of us who are his constituents.

As a mother, I thank you for collecting these emails of support for Medicaid. I hope they make a difference.

Sincerely,

Debra Skripkunis

Exeter, PA

From: Ralph Salerno [redacted]
Sent: Sunday, July 16, 2017 8:44 AM
To: Nicole Jorwic
Subject: Pennsylvania

Mr. Senator,

My name is Ralph Salerno and my wife Donna Salerno is on retirement disability from the V.A. Medical as a R.N. after working there for 21 years. She has end stage renal failure and recently received a kidney transplant which we are very grateful for, but Donna has difficulty breathing at night and is in need of oxygen to be able to sleep. The oxygen is paid for by medicaid and without that coverage we would not be able to afford the cost. Please do whatever you can to make sure my wife will not lose coverage of medicaid which pays for her oxygen.

Thank You,
Ralph Salerno
[redacted]
West Pittston,Pa.
[redacted]

Nicole Jorwic

From: Deborah Arcoleo [redacted]
Sent: Sunday, July 16, 2017 7:55 AM
To: Nicole Jorwic
Subject: Save Medicaid Please (PA)

Medicaid is critical for my adult daughter with Down syndrome. She relies on Medicaid waiver funding for the job coach who is helping her find a job and who will help train her and guide her once she gets a job. She also relies on her Medicaid-funded home & community aid to help her with cooking and cleaning so that she can live on her own. Her health care needs are modest for now, but Medicaid is her sole source of health care.

I also have an uncle with Alzheimer's who is in a nursing home and he has depleted the entire nest egg he worked so hard for his entire life. Now he is on SSI and Medicaid to pay for the nursing home. With our aging society and more seniors developing dementia, how in the world do we take care of them if you cut Medicaid?? How do adults with intellectual disabilities live on their own or with their families without the support services Medicaid provides? This is a life or death decison, please do not gut Medicaid.

Deb Arcoleo
Lancaster, PA

From: Ellen Thompson [redacted]
Sent: Sunday, July 16, 2017 1:16 AM
To: Nicole Jorwic
Subject: Pennsylvania

As a parent of a son with disabilities, the draconian cuts proposed to medicaid would significantly reduce his healthcare, adult program, transportation, respite allotment, community recreation and monthly supplies. Now is the time to vote for HR 676 Medicare For All Act. Thank you, Ellen Thompson

Nicole Jorwic

From: Barbara Blasucci [redacted]
Sent: Saturday, July 15, 2017 6:41 PM
To: Nicole Jorwic
Cc: Barbara Blasucci
Subject: Pennsylvania

Please don' t cut or cap Medicaid. My son Joshua has low functioning IDD and relies on it for his community supports and health care. He is non verbal and needs help and guidance in his daily needs and goes to and adult program which is his social life and educational program. Medicaid is his lifeline. Please think of the most vulnerable. They rely on this for their lives. We need to work together for a health care plan that includes everyone.

From: Nancy Muha [redacted]
Sent: Saturday, July 15, 2017 5:25 PM
To: Nicole Jorwic
Subject: Medicaid in Pennsylvania

My son is 37 with Downs Syndrome, autism, depression, anxiety and self-abuse. He requires numerous expensive medications, therapies, and 24 hour support to keep him safe and healthy. He has been hospitalized several times and requires very frequent medical appointments. Without his Medicaid coverage much of this would be impossible and hospitalization would be more frequent.

My husband and I are in our seventies, and it has become apparent that soon we are no longer going to be able to care for him at our home. Medicaid is now paying for aides to help us care for him. We are now looking to find a suitable group home where his needs will be met. All of this is very dependent on his Medicaid coverage and Consolidated Waiver Money.

We are begging you not to take this away his benefits with a new health care bill that hurts people that cannot help themselves.

Nancy and Bob Muha
[redacted]
Pittsburgh, Pennsylvania [redacted]

From: [redacted]
Sent: Saturday, July 15, 2017 5:14 PM
To: Nicole Jorwic
Subject: Medicaid Matters to You and Your Family - Pennsylvania

Medicaid is the reason that my son is currently a sophomore in college. When he was five years old, he was diagnosed with aphasia due to uncontrolled epilepsy during sleep. He required speech therapy. Our private insurance, prior to the ACA, would only cover 60 consecutive days of speech therapy per incident. We are very fortunate to live in Pennsylvania where children with disabilities can qualify for Medicaid regardless of their parent's income. Medicaid paid for 30 sessions of speech therapy each year. He had wonderful services through Children's Hospital of Philadelphia and Moss Rehabilitation. In addition, he received speech therapy at school. Medicaid also supported those school services through the PA School Based ACCESS program. My son is now an honors student at Cabrini University studying accounting. He will likely find employment with healthcare upon graduation. However, this would not have been possible without the support of Medicaid.

Beatrice DeAngelis
[redacted]
Chalfont, PA [redacted]

Nicole Jorwic

From: JULIE GERHART [redacted]
Sent: Saturday, July 15, 2017 9:48 AM
To: Nicole Jorwic
Subject: PA Why Medicaid Matters To Me

Dear Senator Toomey & Other Senators Considering the BCRA Bill:

My name is Julie Gerhart-Rothholz, and I am mom to Evan, who is 6 years old and has Down syndrome.

I know you consider Medicaid to be a numbers game. But before you reduce my child to a number, please consider this: When Evan was born, we were encouraged to apply for Medical assistance, which would allow Early Intervention to bill for services. We were told it would also cover copays and expenses not covered by primary insurance. But for some reason, Medical assistance wouldn't enroll my child until the beginning of the next calendar year.

We were told we needed to take our son to see a cardiologist. The health care professionals he'd seen early on did not hear a heart murmur, so they thought it would be a check-the-box appointment and we'd be dismissed. We decided to go before Medicaid coverage was available for our son.

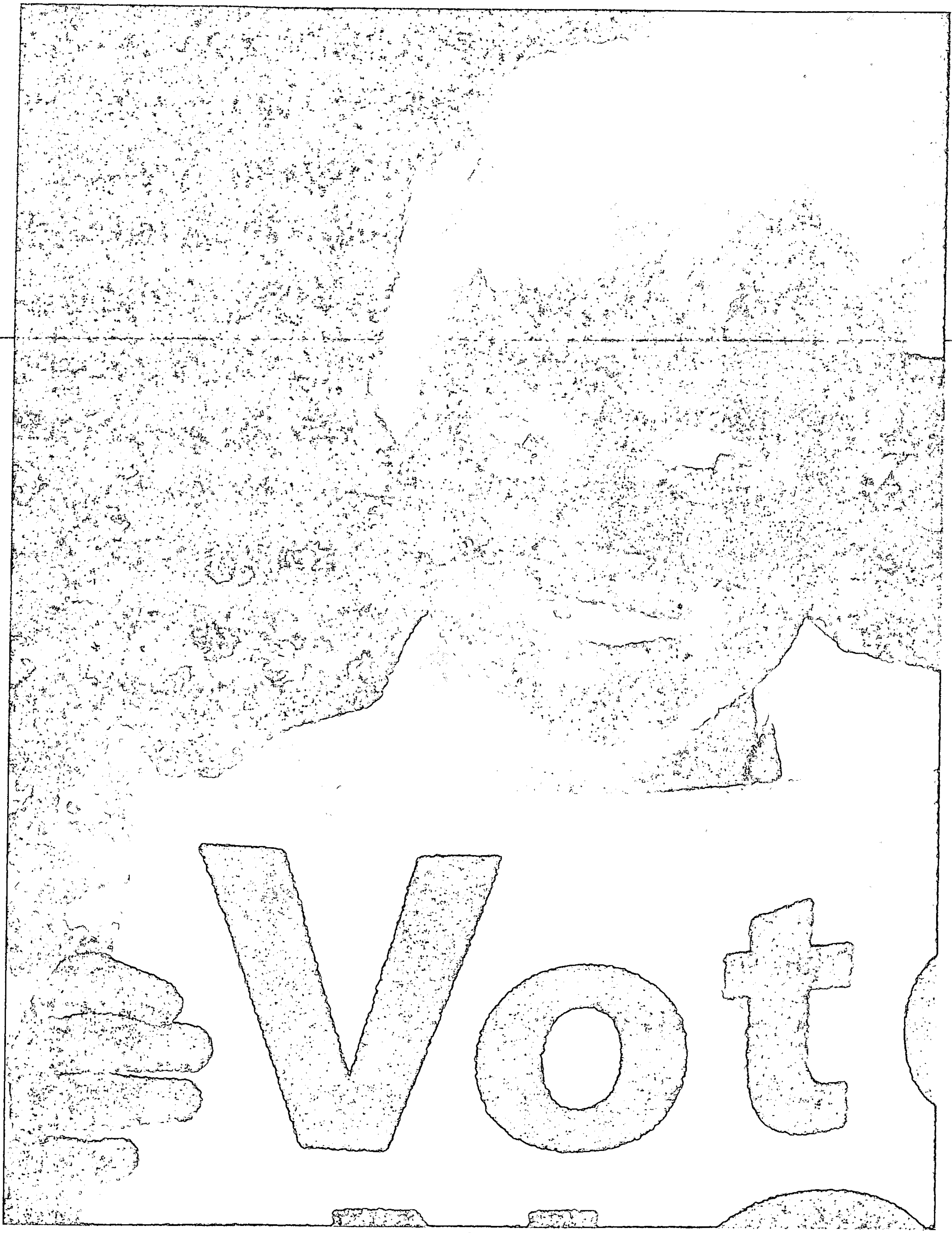
As soon as the cardiologist listened to his heart, I knew something was wrong. He heard a faint murmur. We needed an EKG and an echocardiogram.

I work for a wonderful company with good insurance coverage. But the out-of-pocket expense for that appointment was nearly $900. That was before increased cost sharing. And that's just one of my son's specialists.

We're now facing an era where health plans may be able to deny coverage for pre-existing conditions. Health plans will surely view my son as a pre-existing condition. Will they cover him and the thousands in PA with disabilities who are covered by a primary insurance and by Medicaid?

If primary insurance companies begin denying coverage for all those with disabilities, Medicaid will become the primary payer, and with block granting, there will be fewer dollars available to support the thousands of people and millions of dollars that will be needed to cover increased Medicaid spend. PA is already struggling with its budget, and Medicaid block granting would deal a devastating blow and force some unacceptable choices related to coverage & services.

I worry that my son is going to become part of a horrible reality show where he will have to compete for the healthcare and other services that will help him become a healthy, successful, independent taxpayer and voter. Please vote no to the bill. Don't vote your constituents with disabilities off the island.


Vot

Your constituent,
Julie Gerhart-Rothholz

Sent from my iPhone

Nicole Jorwic

From: Rebecca Sparling [redacted]
Sent: Saturday, July 15, 2017 6:39 AM
To: Nicole Jorwic
Subject: Medicaid matters in PA

Hi Nicole,

My name is Rebecca Zukauskas. I live in Kingston, PA. My daughter Amelia, 4, is autistic, and many of her services are paid by Medicaid.

My husband and I work full time and have private insurance, but this insurance doesn't cover her additional speech therapy sessions or her therapeutic support service worker. Without Medicaid, we might not be able to access these services.

We are fighting to save Medicaid for our daughter and the other disabled children and adults across the country.

Rebecca Zukauskas

Sent from my iPhone

From: Sarah Mullins [redacted]
Sent: Friday, July 14, 2017 8:28 PM
To: Nicole Jorwic
Subject: Save Medicaid

As a physician and a mother of a disabled child, I want to express how important this coverage is to provide school based services that address independence. If children do not receive early intervention, they never stand a chance to contribute to society and gain independence as adults. The burden to our system would be increased from our current situation.

Sincerely,
Sarah Mullins M.D.
Lincoln University PA

From: Louise Link Saruk [redacted]
Sent: Friday, July 14, 2017 5:17 PM
To: Nicole Jorwic
Subject: Why Medicaid Matters to Me -- In Pennsylvania

For the past quarter decade, Medicaid has mattered a great deal to me. My household included a father-in-law suffering from Alzheimer's disease and son, with severe autism. Without Medicaid, I have no idea how we would have managed. We did our very best to care for both of them by ourselves. We kept my father-in-law at home until the local police brought him back for the third time and basically, asked us what we thought we were doing by keeping him at home. They weren't happy with us that they had to pull him out of a ditch into which he had fallen when he wandered off, or respond to our frantic call that he had slipped out in the night and we couldn't find him. Without Medicaid to keep him in a nursing home, what would we have done -- stay awake all night every night or locked him in his room without access to a bathroom (god forbid a fire...).

Similarly, what are the prospects for my son, who is now cared for by Medicaid services? Fully disabled, he will never be able to care for himself. He will never be able to earn a living. We would like to help, but although, my husband is a good earner, all of our money has been spent caring for our loved ones to this point. There have been countless therapies and medications. We are now officially of retirement age, but we can't. And we certainly, cannot provide for our son, much as we may wish to.
Don't repeal the ACA. We cannot afford as individuals, or as a nation, to slash Medicaid funding.

Thank you.

Louise

Louise Link Saruk
[redacted]
West Chester, PA [redacted]

Nicole Jorwic

From: Betsy Miller [redacted]
Sent: Friday, July 14, 2017 12:23 PM
To: Nicole Jorwic
Subject: Pennsylvania

The proposed Medicaid cuts are greatly disturbing to my husband and me. We are the parents of an adult daughter with autism and intellectual disability. She works at a sheltered workshop four days a week and on the fifth day, she is at a day program. We see how vulnerable she and her co-workers are. To neglect people such as these in order to save money elsewhere is shameful.

The Arc speaks for my family and those like us. Please listen to the Arc. Please have a heart for fragile people, those unable to speak for themselves and to defend themselves.

Elizabeth A. Miller
[redacted]
Mechanicsburg, PA. [redacted]

Sent from my iPad