VIRGINIA

Date: 2017-09-21 18:28:59
To: My Senator
From: Kim Crawley
State: Virginia
Email: [redacted]

My son, Isaac is a Medicaid recipient (EDCD waiver). He is 8, and he is trach and GJ tube dependent. Medicaid is his secondary policy, he has health insurance.

Many people don't seem to realize that insurance doesn't pay for everything. The nursing services that keep Isaac safe and alive are not covered by insurance, Medicaid pays that. Many of the medications Isaac receives are not covered by insurance, Medicaid pays for them.

Without Medicaid I would not be able to work, and would likely lose my home.

Isaac is a typical 8 year old - he loves video games, YouTube videos and bike riding. Medicaid makes a normal life possible for him.

The Arc.

Date: 2017-09-23 11:41:30
To: My Senator
From: Ellen Soehngen
State: Virginia
Email: [redacted]

Unfortunately, my son, Stephen Soehngen, will not need Medicaid anymore because he passed away on September 7th after a 9 1/2 year battle with TBI suffered as the result of a car accident when he was just 15. Many people think that they will never need Medicaid because they work and they and their family are healthy and have insurance. The truth is that in the blink of an eye, that can change. Stephen was healthy, bright and active. He ran Cross Country and took IB classes in High School. He planned to spend his junior year abroad studying somewhere in South America. He had a gift for languages. In the blink of an eye, he could no longer speak at all. In the blink of an eye, he could no longer eat his favorite foods or sing or dance or run or even walk. He needed around the clock nursing for the rest of his life. After 5 years at VCU both inpatient and at Children's Hospital TCU, Stephen came home to live out his remaining time. Without Medicaid, my family would have been bankrupt and unable to care for my remaining son who also has special needs but does not have Medicaid. Stephen certainly would have never come home to live out the rest of his life. How can an average middle-class family pay for medical needs like Stephen's without Medicaid? For nursing needs around the clock? Even with the very good private insurance which Stephen had for all his life?

Date: 2017-09-21 18:04:52
To: My Senator
From: Rachel Higgins
State: Virginia
Email: [redacted]

The Arc.

Hi my name is Rachel higgings

I amoslt a 30 year old adults I had know choice to get optima health this year it stared Augs frist of this year I do not like this new changes I wish I could have back medicad but I can not for my doctors I may need to get a spiceal kind of ok to see them for next year yes medica doe matter please bring it back to those how had it .

Thank for you time

Rachel higgings

The Arc.

Date: 2017-09-22 21:28:20
To: My Senator
From: Joe Bassett
State: Virginia
Email: [redacted]

My Families Story:

My wife and I were firmly in the middle class for years. She was a teacher and I work for a Custom Home Design Build Firm. My wife's insurance was provided through her work and we could easily afford to pay premiums for a group policy offered through my job.

It was just the two of us and with no kids we were very comfortable financially. Saving for retirement, traveling whenever we had time etc.

11 years ago we decided to adopt a child and were blessed to become parents of beautiful 10 day old boy whom we named Riley.

We had saved enough money for my wife Cathey to take a few years off from work while we raised Riley.

Cathey had some pre-existing conditions and we quickly learned that getting insurance for her was "very expensive". All we could afford was a high deductible - catastrophic insurance policy.

When Riley was 1 1/2 years old we started noticing that he was not developing language and social skills as expected. My wife having been a special education teacher quickly realized that Riley was likely Autistic. When he was 3 years old we got an official diagnosis.

The next year or so was spent trying to sort through and understand what if any services we could tap into to help us start working with Riley and help him start learning how to overcome these extreme deficits in communication and social skills. There were no books or how to guides to turn to. It was not a pleasant time and I would not wish it on anyone.

At about the same time as this was occurring, my company could no longer offer a group policy because some of the members had health issues and the premiums were skyrocketing.

Suddenly I had to find insurance for all three of us: my wife with pre-existing health conditions, my son with autism and myself (fortunately I have been healthy my entire life). Very quickly I was looking at insurance premiums that were far exceeding my monthly mortgage payments to provide catastrophic health insurance with very high deductibles.

We finally learned that Riley was entitled to receive funds and insurance through Medicaid. This has been a godsend to our family. First of all it was a major reduction in health insurance costs for us (even though our premium was still higher than our mortgage for just Cathey and I). Second of all it provided us with funding to hire attendants and respite care givers to aid us with the unending amount of work that we needed to be doing with Riley to give him a chance to become an independent adult.

Riley has had some health issues that have required us to seek out and travel to various specialists. All of this would have been out of pocket if not for Medicaid.

Riley has made good progress so far and our family is still intact in large part due to the funding available to us through Medicaid. Riley does not sleep well and we have stayed in constant and severe sleep deprivation. Having folks who could provide occasional respite care has been a life saver.

Due to Riley's severity of Autism, my wife has been unable to go back to work. This has become quite a financial hardship for us. We are no longer firmly within the middle class. Thankfully the current health care bill was passed and our still catastrophic insurance is much more affordable thanks to the assistance we get through Health Care .Gov

So as you can see our family has a real vested interest in the changes that are being proposed.

I am strongly opposed to any changes that would weaken an already underfunded Medicaid program. My son deserves a chance to become a contributing and independent part of his community.

I am strongly opposed to any changes that would make health care even less affordable than it already is.

My question to you: If you were in my position would you favor the current proposal?

I doubt it.

Sincerely, Joe Bassett

Father of a child with Autism and husband to a wife with health problems and pre-existing conditions.

Date: 2017-09-22 20:38:05
To: My Senator
From: Angela Scarpa-Friedman
State: Virginia
Email: [redacted]

My son was diagnosed with autism when he was 23 months old. He is now 16 years old and has made great strides to learn to speak, communicate, self-regulate, and control his behavior. Although he still has challenges in all these areas, his progress was largely due to services he was able to receive from Medicaid. He received a Medicaid EDCD waiver in elementary school, and was just recently switched to the DD waiver. The personal attendant and respite care services he received were critical to keeping him safe, as he tended to wander off and was at risk of elopement. His personal attendants and respite care providers over the years not only kept him safe, but taught him invaluable skills about care, compassion, identity, and living with the inherent challenges of autism. They became his teachers, confidants, and mentors. By looking after him, they also provided the opportunity for my husband and I to take some much-needed breaks. Taking care of ourselves was also needed in order for us to take better care of him. All-in-all, medicaid services were essential in providing the care and intervention that helped my son develop into the mature teen he is today, and he is looking forward to applying for college in acouple years. The services he will be able to receive with the DD waiver will be even more important now that he has to target independent living skills and transitioning to college and then employment. He has come a long way, but he still needs support in order to permit him to become a fully participating adult. I hope that other children with autism will have these services available to them so they, too, will be able to benefit and live the lives they were meant to live.

Date: 2017-09-21 18:57:00
To: My Senator
From: Catherine Gagnon
State: Virginia
Email: [redacted]

Megan's Story

We are the parents of a daughter with autism. For the past 17 years Megan has worked at an electronic assembly company. While this is not the most glamorous job, Megan takes pride in her work. Like most parents of any young adult, we are happy she is a productive member of society and not just sitting at home watching TV!

This past year, we purchased a condo for Megan so that she would have a safe, familiar place to live at such time Jim and I are unable to care for her. Because Megan doesn't have the ability to live alone she has a "companion" who is there to help her cope with the challenges of daily living. Her living arrangements and her employment are possible because Megan receives a Medicaid subsidy.

If the ACA is repealed or is revised in such a way that it cuts and caps Federal Medicaid funding, it is very likely Megan and the disabled colleagues with whom she works will lose their jobs. Megan also will be unable to live in the condo because the life support she requires also will be unavailable. This is particularly worrisome because over the longer-term Jim and I will no longer be able to provide that support.

I realize you are very busy but I am asking you to take a few minutes to make a phone call to your senator. Please ask them to reconsider the changes being proposed for the ACA – in particular the changes to Medicaid. This is not a partisan political issue, rather it involves providing protection for our most vulnerable citizens. The changes to ACA that are being contemplated may not affect you but the proposed Medicaid revisions will have a very adverse effect on many disabled people who cannot speak for themselves.

“A Nation should not be judged by how it treats its highest citizens, but rather its lowest ones.”

~Nelson Mandela

Thank you.

Catherine Gagnon

The Arc®

Date: 2017-09-22 19:46:54
To: My Senator
From: Cathy Wild
State: Virginia
Email: [redacted]

How much time do you have? How can I put into words how much my daughter needs Medicaid and how we can not make it without it. Karley was born 17 yrs ago, 1 month early, no warning of her diagnoses before birth. Karley was born with a rare breathing disorder called Congenital Central Hypoventilation Syndrome also known as Ondines Curse. There are only 1,000 cases of this rare syndrome nationwide at the time of her birth 17 yrs ago there was only 500 cases workd wide. People Born with CCHS do not take one breath on there own when the fall asleep and only shallow breaths while awake. The signal that goes from Our diaphragm to tell us to beeath makes no conncetion when My Daughter falls asleep, when she sleeps the signal stops with no way to fix it. Karley requires 24/7 ventilator support. Karley also cannot regulate her temperatures , has trouple with her Blood pressure, and heartrate. Karley has a pacemaker that prevents her from heart pauses and sudden death. Karley also was born with Hirschsprungs Disease 13% of the Kids with Her rare breathing disorder have Hirschsprungs disease. Karleys entire non-functioning Colon and part of her small intestine was removed at 18 months because of the hirschsprungs disease. Karley has a feeding tube feed 20 hours a day, no formed stool, Hypoglycemia because of her short gut, that causes seizures and injections such as glucagon, juice and frequent Accu checks to regulate and monitor her Blood Sugar. Karley also has Ehlers Danlos Syndrome which is a connective tissues disorder that makes her joints hyper mobile and loose putting her at Risk of falling, dislocations and breaks. Karley also has epileptic seizures from the left, right and back of the brain, she is autistic, non-verbal and was diagnosed with crohns in 2008. She is currently hospitalized at this cery moment since saturday for her crohns disease. She has bronchectasis and asthma being treated like a cystic fibrosis patient with Tobi nebs, chest vest and vita cough. She has 2 ventilators, 2 suction machines, pulse ox and heart monitor, oxygen tanks and concentrator, ETCO2 monitor, aerogen nebulizer over 16 medications a day and 11 breathing treatments a day, her incontience requires her to have frequent diaper changes usually between 11-12 diapers a day which requires ointments to prevent skin breakdown. Karley is currently on the ID (Community Living waiver) she requires 24 hours of private duty nursing a week because of her complex care. Karley has a port o cath for crohns infusion meds and also to keep her hydrated with fluids. In Karkeys first few years of life she used well over 1 million dollars in medical care and equipment. Cutting medicaid out of the lives of children/adults like Karley will cost the state much more if these children could not be cared for in the home and had to be placed in facilates due to cost of caring for them. Karley has alot of medical over the counter cost that are not covered by medicaid.. Medicaid, Waivers, Mental Health Supports, Durable Medical Equipment and Medical supplies, Pharmacy, assistive technology, OT, PT, Speech, handicapped equipment and home modifications all of these things and more are needed to care, provide for our special kids. Please dont take these services away by taking away our kids Medicaid Insurance and Waivers through mental health and Social Services. Our lives as parents are hard enough, harder tban I can out on paper or make u understand unless you are in our shoes. Im asking you to think of our children and adults. My contact number is (804)338-6780. Thank you.

Date: 2017-09-21 21:53:44
To: My Senator
From: Brenda Nowlin
State: Virginia
Email: [redacted]

The Arc.

Leaving a job in the nineties, facing COBRA prices I went without health insurance until recent years. I had not been to doctor for checkup, etc., until the last few months. I would not have known I was diabetic if I had not become eligible for Medicare. I also certainly would not have been able to buy these medications I recently started taking, and still had to not buy some. It was so high even with Medicare.

I am well aware the problems we have with healthcare are much due to large companies refusing to pay for injuries they know they are responsible for. My injuries long ago were denied, even though a supervisor was right beside me when I was injured. That threw my medical payments back onto my regular health insurance. Multiply my situation by multiple injured employees denied, and the cost is phenomenal to private insurers. I am surprised we are not hearing this problem measured into the equation.

Healthcare for all will do away with most problems in our healthcare system.

The Arc.

Date: 2017-09-21 22:09:01
To: My Senator
From: Michael Jaworek
State: Virginia
Email: [redacted]

to whom it may concern in government,

my son lee is 27 yrs old now. he is a brilliant painter and has had a painting shown on cbs sunday morning and two shows in our state capital. he is on the autism spectrum and also has ptsd. without the help of medicaid,he would not be functioning, PERIOD. the assistance with prescriptions,living quarters, aides,etc has been CRITICAL and ESSENTIAL to his quality of life and being able to contribute what he can as a member of society. medicaid has enabled him to

get thru life and not have to be warehoused and kept like a zombie on drugs. instead, he has added to the grace of living. check out his website and artwork, www.leejaworek.com.

if his aid is taken away, i do not know that he will be able to survive, much less thrive.

don't do it.

if he were YOUR child, would you?

michael jaworek

falls church,va

Date: 2017-09-24 13:59:34
To: My Senator
From: Paul Williamson
State: Virginia
Email: [redacted]

The Arc.

Our daughter kaitlyn is had Medicaid and the services associate of Medicaid for about eight years starting from the age of about 3. Through her Aba Therapies and other Associated services she has made great strides in learning how to handle her sensory disorders. We could never have afforded the services that she requires without Financial assistance of some sort before we had the services of a an attendant I was forced to stay home and we became a single paycheck family. Those that are disabled need folks who can speak for them so that they can get the services that they deserve without the need for institutionalization, without assistance Medicaid help my daughter live in the home and get the services she needs I'm not sure that we could support her in the home.

Date: 2017-09-22 17:24:04
To: My Senator
From: Stacie Mikels
State: Virginia
Email: [redacted]

My letter to whoever will listen regarding the proposed Medicaid cuts. It's not a republican or democrat thing... it's an American thing....it's my family and it's pretty important!

To whom it may concern,

My daughter, Noelle is absolutely a miracle! Born at 24 weeks gestation, 9 years later she is still oxygen dependent and uses a g-tube for nutrition. Without Medicaid, my family would not be able to care for her at home! Medicaid provided us with the services she needed to learn how to walk, talk and be a fully functional individual! Her lungs may need a lot of help, her gut sometimes has issues and we travel out of state for the best medical care...but her smile will charm anyone!

She still has a lot of needs, just ask her and she'll tell you. However, this thriving kid would have never happened without Medicaid! In order for her to continue to thrive, our family NEEDS her to be able to continue services. The care she needs is expensive, without Medicaid... she would most likely not be able to stay home with her family! These proposed Medicaid cuts would destroy our family! Please help! Also, we are die hard Washington Capitals fans.... and we'd really like a Stanley Cup this season, can you do anything about that?! ;)

Stacie Mikels: Front Royal, Va.

Date: 2017-09-21 21:48:45
To: My Senator
From: Kelly Miller
State: Virginia
Email: [redacted]

The Arc.

My oldest has Cerebral Palsy autism and Epilepsy he needs Virginia Medicaid for his Seizure meds, therapies and Neurologist appts. Without his medication he could start having 200+ seizures again it pays for braces for his legs to help him walk.

My youngest have a chromosome disorder 17Q12 duplication Syndrome it causes severe developmental delays which he needs therapy for weekly medicaid pays for his braces so he can walk,and his seizure medication. My children's lives matter

Date: 2017-09-21 19:58:26
To: My Senator
From: Kathy Lewis
State: Virginia
Email: [redacted]

The Arc®

My son who has autism and is 23 years old would not have much of a life without Medicaid. With his Medicaid he can attend a day program that teaches him everyday task that we all take for granted such as washing and folding laundry. Loading and unloading a dishwasher. Learning to go out into the community to participate in volunteer work and learn to socialize and interact with community. Please don't take away my sons chance at living life to his fullest that he is capable of. Please, please! Respectfully, Kathy Lewis, mom of Jeremy Tyler Lewis

Date: 2017-09-24 11:44:04
To: My Senator
From: Katia Luedtke
State: Virginia
Email: [redacted]

Our youngest son was born with a ultra-rare genetic disorder caused by a random mutation in a very important gene. At the time of his diagnosis, we were the 3rd family in the US to be diagnosed with this condition, Snyder-Robinson Syndrome (SRS). SRS is a serious and life-limiting disease that impacts multiple bodily systems including the nervous system (seizures, intellectual disability, developmental delay), bones (severe osteoporosis), and many other systems that we are just learning about.

After receiving his diagnosis four years ago, my husband and I are working tirelessly to find a therapy or a cure for his condition. We created a foundation to fund scientific and medical research into SRS in the hopes of helping not only our son but others who are or will be diagnosed with SRS. The study of SRS could also shed light on more common diseases like cancer, ALS and Alzheimers because it is the only known disease that in which an enzyme present in every living organism isn't functioning properly. We are working with scientists and researchers across the country and other families with SRS around the world and are making amazing progress.

I also work tirelessly to help my son become the most independent and healthy that he can be. I have taken him to more specialists and doctors and procedures than one could imagine. I have spent the last 10 years taking him to therapies to help him be able to walk, to talk, to be able to feed himself. He attends our community school and is thriving for a person with SRS. He is happy, he is loved, and he loves people and makes them laugh with his incredible sense of humor.

As it is, we already pay a huge deductible for my husband's employer-based insurance and large out-of-pocket expenses for his therapies as they are not covered by our private insurer, because he was born with his disease. Although my son has a Medicaid Waiver, it is a temporary one and he has been on the waiting list in Virginia for 7 years for the ID Waiver.

If this bill passes, with a lifetime cap on benefits, our family could quickly become bankrupt. The cuts to Medicaid will threaten his back-up insurance, and would mean that our son may not have access to health care in a crisis. Without access to proper medical care, his life is in jeopardy if he has a major medical event. Additionally, without Medicaid to enable him to continue to live in the community, he would likely be institutionalized.

This is not the future I envision for my son. I realize that his disease may threaten his life, but I do not understand why Senators Graham and Cassidy and others who would vote to pass this bill would want to do so. Would they wish this on their child or grandchild?

This bill threatens everything we are working towards to save and/or improve his life.

Thank you for your work and in understanding the significant and cruel impact this bill would have on people like my family.

The Arc.

Date: 2017-09-22 06:55:30
To: My Senator
From: Bethany Sizemore
State: Virginia
Email: [redacted]

My name is Bethany Sizemore and I live in Mechanicsville, VA. The Graham-Cassidy Bill would be devastating to my family. Me and my husband have a 4 year old son, Carter, who heavily relies on Medicaid. He had a subdural hematoma when he was only one month old which has severely impacted his life. He has hemiparesis in his left side, seizure disorder, developmental, speech and cognitive delays. He is one of Medicaid's recipients and he utilizes every aspect of it. He is one of the many Medicaid recipients whose life will change drastically if this bill is passed. The Graham-Cassidy Bill would devastate my family. Please do not pass this bill and put a cap on my son's quality of life.

The Arc.

Date: 2017-09-22 22:46:14
To: My Senator
From: Amy Bravo
State: Virginia
Email: [redacted]

My husband Frederick Bravo, United States Air Force Major Retired, and I are writing to express our opposition to the Graham-Cassidy Bill.

Our son, Anthony, was born in 2012 with Trisomy 21 (Down syndrome) and other special needs. Anthony has been able to receive the specialized medical treatments, equipment, and therapies he needs to reach his fullest potential thanks to the CCC Plus Medicaid Waiver (formerly the EDCD Waiver). Anthony is a social and happy little boy and the light of our lives. He attends preschool three days a week with an aide, uses ASL to talk and is beginning to use verbal communication; he is learning to self-feed; and is learning to use scissors. All of this is happening thanks to the services we receive through Medicaid.

Anthony is doing well now thanks to the services he receives through Medicaid, and we are grateful, but having Trisomy 21 requires that he have a lifetime of care and support.

If the Graham-Cassidy Bill is passed, it would threaten the availability of these invaluable services for Anthony, others with disabilities, and the elderly, now and for the future.

We very much appreciate your time and consideration.

PLEASE vote NO to Graham-Cassidy.

Date: 2017-09-22 04:57:06
To: My Senator
From: Lori Shapiro
State: Virginia
Email: [redacted]

I am disabled from Birth,and I rely on Medicare & Medicaid ,to access health care ,Rx & In Home support staff. This bill is nothing short of malicious ,and any senator who would vote for it ,should lose their access to health care !

The Arc.

Date: 2017-09-23 20:45:54
To: My Senator
From: Regina and Joe Petrecca
State: Virginia
Email: [redacted]

For the past 15 years our disabled daughter has been bounced from one transitional Group Home to another. Finally, at age 40, she recently received a Medicaid Waiver that enabled her to get permanent housing in a Group Home that is safe and appropriate for her developmental disabilities. We are both almost 80 years old and finally thought that we no longer had to worry about her welfare after we had passed away. The Medicaid cuts in the proposed Graham-Cassidy Bill will have a devastating effect on our disabled daughter's life. We beg you tp search your conscience and reject the Graham-Cassidy Bill.

Regina and Joe Petrecca

The Arc.

Date: 2017-09-21 17:25:46
To: My Senator
From: Lori Levy
State: Virginia
Email: [redacted]

My daughter is 21. She has Down Syndrome/autism/visual impairment. If is were not for medicaid funding for Day Support Services I would not be able to work. Rachel would not have a full life as she would not be afforded a job coach who is currently helping her access employment. To me, it is that simple. Please do not make any cuts to medicaid that will hit our most vulnerable citizens the hardest.

Sincerely,

Lori Levy

The Arc.

Date: 2017-09-21 18:18:20
To: My Senator
From: Syrita Lewis
State: Virginia
Email: [redacted]

I am a single mother of 2 special need teenage boys. My story didn't start that way. I was married and decided to start a family. My first son came into this world born with ventricular septal defect. His heart was respaired at 11 month old. During that time I got pregnant with my second son. My first son was always small and always delayed due to us thinking it was his heart. Once repaired he started growing more, gaining weight but he still wasn't meeting mile stones. We just figured through opinion of pediatrician, cardiologist that he was development delayed. I did the research and took him a school for developmentally delayed infant children. In the midst of that I had my second son who was healthy no defects and 9pounds 7ounces . Everything was fine until the pediatrician noticed as well he wasn't meeting all of his mile stones. I had genetic testing done and found out I was a carrier and the boys had Fragile X syndrome. What in the world did that mean? It's is an intellectual disability. It is genetic in the x chromosome. I was not inducted into parent hood like tv. With the giggle baby in the diaper commercial. This was work. This was a new level of parenting. Crash course. Love for your child like you never knew could have. I use all of their medicaid services. Mental health, positive behavior supports, in home, respite, medical. Without these services there whole life would be affected. They have been given this diagnosis and have to function in this world. Least we can do is fight for them. My kids and like them are always going to exits.

The Arc.

Date: 2017-09-22 18:41:09
To: My Senator
From: Rosemary Seltzer
State: Virginia
Email: [redacted]

My daughter is one of the 12,000 Virginians currently on the waitlist for a Medicaid waiver. These are all people who are eligible for services but not receiving services. Virginia ranks at the bottom of all the states for providing services for people with disabilities. My daughter is fortunate to have the EDCD waiver which provides respite for our family. Without it, we would not be able to keep her at home.

I am so tired of people marginalizing her and others who need Medicaid or coverage under the Affordable Care Act. I was taught that if your were fortunate in life, you had an obligation to give back to the community. All Senators seem to be very fortunate people. Where is your compassion? You are one car accident or illness away from a life like ours.

Stop trying to repeal Obamacare because you hated Obama. This is not what the American people want.

The Arc

Date: 2017-09-21 18:05:12
To: My Senator
From: Stephen Grammer
State: Virginia
Email: [redacted]

My name is Stephen Grammer I'm thirty seven years old. I have CP (cerebral palsy), I live in Roanoke Virginia. I am in a wheelchair and use a communication device to help with public speaking. This allows me to speak to legislators to advocate for people with disabilities. I lived with my mother until the age of twenty two when she become ill, my sister put me in the nursing home called Raleigh Court Health and Rehabilitation center in Roanoke Virginia and I was there for nine years. Also I lived at Salem Health and Rehabilitation for a month during this time frame. While I was in Raleigh Court life was horrible, they made me wear diapers which I didn't need. I was afraid to tell them I had a soiled diapers because they wouldn't change me and if they did they wouldn't put me back in my wheelchair. I always looked at my alarm clock every time I pressed my call button and it would take anywhere from 15 minutes to over an hour for someone to come to my room. Some of the staff would come in my room and turn off the call light without asking what I needed. I had to wait over an hour for some one to come and assist me with the bathroom. If I was in my wheelchair I would go in the hall to tell the CNA's I had to use the bathroom, they would walk the other way without assisting me. I was always the last one to be feed. If i even got a tray, the food was horrible and cold. I was lucky because some of my friends would take me out to eat during the week. What still bothers me to this day is, one of my room mates was a diabetic and they let him bottom out because they didn't feed him. I had to wear ear plugs at night to try to sleep because the residents would scream and knock on the walls. Sometimes the staff was loud or they would buff the floors in the middle of the night. Sometimes I would have to fight the staff to even receive my medications because the nurses just wanted to be difficult or on a smoke break half of the shift. Every other weekend nobody got taken care of because the supervisor wouldn't make the staff do their job. I had a friend come at seven AM every other weekend to get me out of their because the care was so bad. They didn't realize I was in my twenties so they got mad if I went out and came back with alcohol on my breathe even though I had a doctors order for two beers a day. I seriously believe that people get better treatment in prison then they do in nursing homes. I got out of the facility honestly because I reported them to the State. They were doing a State inspection every year and I would always complain about their care. The last inspection I told them my food was always cold and they stayed an extra day to investigate my complaint. Of course Raleigh Court didn't like that so a week later I got a letter from the administrator saying I had thirty days to leave due to alcohol on my breathe which was a cover. The best part was on my last day I told the administrator "Thank you for kicking me out, you made my wish come true.". What is frustrating about the whole thing is that I could of been prevented. I was working with the local CIL to get my own apartment while living at Raleigh Court but people fought with me and CIL about trying to get out which lead into my eviction. After that I moved into my friends house for two years. He had a ramp put on his house through the waiver. I began to do some volunteering and work at Salem's baseball stadium with my communication device, I also took the PIP course. After living with him, he also evicted me so I got my own apartment that was in a bad location. I almost got sent back to the nursing home one winter when it snowed because care givers couldn't get to me so my case manager sent me to the hospital. Now I'm living in a retirement community in my own apartment. The advantages of living in the community are you have a lot more choices as far as what you want to eat and it's warm, you can do what you want without answering to the nurse, and you can sleep in peace without ear plugs. I have been on the news and in the news paper for all of my advocate work for people with disabilities. I am on several boards like the Community Integration Advisory Committee, the Fair Housing Board, the Salem business club, the wavier slot committee, and I'm trying to get on more boards. The disadvantage of living in the community, especially if you use consumer directed services, is trying to find reliable caregivers. I don't have any natural support so my care depends on caregivers. This is extremely hard when they can't work over 40 hours a week. Another disadvantage in my area is public transportation. They stop running at 8:15 PM and don't go on Sunday that's why I had to quit my job at the Salem baseball stadium. Due to the new administration I'm really afraid of returning to the nursing home because of Medicaid and housing cuts. If the government votes for these Medicaid budget cuts I would have to move back into a nursing home which would violate my ADA rights to stay in the community. If I have to go back to a nursing home it would be devastating. Also for the people who are in nursing homes they would probably never have a opportunity for community living due to the lack of funding. This amazes me that the government would rather cut Medicaid forcing people to be institutionalized which will cause the state more in the long run rather then give funds so that disabled people can stay in the community. This is a human and decency issue plus civil rights issue.

Date: 2017-09-21 17:54:23
To: My Senator
From: Lynne Blythe
State: Virginia
Email: [redacted]

My adult son has Down syndrome and relies upon Medicaid to cover his personal care assistance in our home. Without this assistance our family would find it very difficult to maintain him safely in our home. My husband and I are in our 60's and we are hoping our son will receive a Medicaid waiver slot so he can transfer to a community setting prior to our demise (no one lives forever!)

ANY restrictions on Medicaid will cause our son to wait even longer (and he has been waiting more than 10 years already!)

There are more than 12,000 people in Virginia waiting for a Medicaid waiver slot- restricting Medicaid will cause this waiting list to drastically increase and put lives at risk!

Vote "NO" on the Graham-Cassidy bill.

The Arc.

Date: 2017-09-21 19:21:40
To: My Senator
From: Jack Bruggeman
State: Virginia
Email: [redacted]

My 54 year old sister Cathy, for who I am guardian, has profound disabilities and requires 24/7 care for all activities of daily living. She is dependent on Medicaid for both her health care and housing. Any cutbacks, particularly in the expensive No. Virginia area in which she and I live, would be devastating. My sister's care has be the work of two generations of my family. Help from Medicaid has made her's a life worth living. Why would we change a system that works for her and so many people like her with disabilities? Are we not better than this?

The Arc.

Date: 2017-09-22 15:12:22
To: My Senator
From: Rosemarie Hughes
State: Virginia
Email: [redacted]

My 51 year old son with an Intellectual Disability relies upon Medicaid for living in his four-person group home, going to day support, and participating in activities in the community, as well as for his medical and dental and prescription needs. Without Medicaid his income puts him far below the poverty level. I have no idea what would happen to him when I am no longer living (I am almost 74) or become incapacitated without Medicaid funding.

His story is not unique. Thousands of people with disabilities will be left to either fend for themselves without Medicaid support. We knew what that looked like when people with intellectual disability were institutionalized, and no one wants to go back to those horrible days.

Date: 2017-09-21 19:41:48
To: My Senator
From: Lora Wikle
State: Virginia
Email: [redacted]

The Arc.

Here's our Medicaid story:

My first son Blake, unbeknownst to us, had a stroke in utero and was born with severe cerebral palsy. He is nonverbal and non ambulatory. He gets nutrition by feeding tube and has seizures every day.

I work in the healthcare field and have excellent insurance.

When my second son was born three years later, I cried in the hospital and told the nurses to not send me home because I couldn't take care of both of them.

Medicaid thru a waiver has been our family's life saver. It has allowed Blake to stay in our home and not be institutionalized. It has provided him with skilled nursing that's kept him in better health. It's also allowed him to go to school. It has also meant that his brother has been able to have a normal childhood. I have also been able to work full time and contribute to society.

Medicaid has helped our family a great deal so that we all can have #alifelikeyours.

Please keep up the fight for us.#savemedicaid

The Arc.

Date: 2017-09-22 23:33:52
To: My Senator
From: Kim Jarrett
State: Virginia
Email: [redacted]

Hi my name is Kim Jarrett , I have extensive experiences with Medicaid at the importance of no cuts no caps to the Medicaid program . I have provided residential sponsored placement services for the past 10 years for two gentleman who has intellectual disabilities and significant physical disabilities coupled with mental illness health support needs. Their services rely sole on Medicaid waiver. Both men have no family to care for them and are unable to reside alone. I've been an integral part of advocating and keeping these gentlemen in their family sharing home with my husband and I they have little alternative besides institutional living , group or nursing homes. Cuts and caps will decimate the waiver programs . The Graham Cassidy bill appears more heinous than all others before it . I strongly urge all to vote no and protect our most vulnerable Americans. In addition to what I do for a living and see the independence the community contribution of the gentleman I support I have extensive family and friend first hand knowledge of the importance of Medicaid personally. A niece whom nearly died a few months ago who has Down syndrome developed a blood clot that reguired her to have open heart surgery w a 10% survival rate to leave operating room, she spent 3 months in MCV recovery having 4 surgeries in that time when she almost lost her leg. She is alive and well now but will always have preexisting conditions. Her family would have suffered financial ruin had she not been approved for an emergency Medicaid waiver and fund raisers go fund me accounts because the cost was so astounding, Medicaid saved this family . My good friends 1 1/2 year old granddaughter was diagnosed with neuroblastoma , her medical bills are in the millions , she likely would have died with out Medicaid , Raygan Skye Batton is a beautiful little kindergartener this year and 2 years no evidence of disease . She will always have a preexisting condition. I have many more testimonies of the need , benefit of Medicaid but I will close with saying protect our care protect our fellow Americans s our most vulnerable the disabled, children the elderly , the poor. Fix what's broken and leave Medicaid alone lives depend on it . Kim Jarrett

Date: 2017-09-21 22:31:01
To: My Senator
From: Kasie Ballard
State: Virginia
Email: [redacted]

The Arc®

My name is Kasie, and I am the mother of a seven year old son with Mowat Wilson Syndrome. He is severely mentally and physically handicapped. He has life threatening epilepsy and requires a very expensive seizure medication in order to stay alive. Without it, he would go immediately into Status Epilepticus and his life would be endangered. Just one year ago he went into Status and ended up on life support. We spent a week in the hospital, and believe me, it wasn't the first time. He's had numerous tests, surgeries, and hospitalizations since birth.

Not only does my son rely on his medication to survive, but he requires many therapies and specialist appointments to ensure his quality of life. I am a stay at home mother because he requires my constant attention, even when he attends school. I have to be readily available to rush to him if he seizes at school, but most of the time he is home due to his weakened immune system and constant illnesses. We are a single income family with two small children and I can't imagine the stress that would be put on us without Medicaid. I honestly don't know how we would get by. I would have to work in order to pay solely for his medications, and because my husband works out of town to support us, I don't know the extent to which our children would suffer. I am the only one who can provide comfort to our disabled son, and the only one who recognizes the signs of his seizures. Day cares wouldn't take him, his school can barely manage. Our son's life depends on Medicaid. Please picture a beautiful, smiling, fragile little boy with bright blue eyes and shaggy blonde hair begging you not to tear apart his family. To make them choose between the quality of his life and keeping him alive. We feel so incredibly blessed to have had Medicaid available to us all these years, and have not once taken it for granted. We, like so many families, will face heartbreaking and damaging choices if this bill goes through. Thank you.

Nicole Jorwic

From: [redacted]
Sent: Wednesday, July 19, 2017 10:07 PM
To: Nicole Jorwic
Subject: ARC: Medicaid Letter Writing Campaign - Virginia Parents (Fwd: ARC - 7/17)
Attachments: DOC012 (1).pdf

To: Nicole Jorwic

From: Robert and Helen Wiech

Thank you for the opportunity to express our concerns regarding "Medicaid Matters."

In response to ARC's timely appeal we share the following on behalf of our multiply handicapped daughter, Sarah Wiech. ***Sarah is eligible for Medicaid yet not receiving medical care.*** It's not our fault!!!

We have been swept up into a frenzy of parents begging for services beginning with education which never came to fruition -- to SSI, diverted to caretakers -- to Medicaid, without medical treatment-- culminating in a pursuit for safe, available, and appropriate group homes. Where does the begging end and do the services begin.

What good is Medicaid if you can't get medical care???

Contrary to the way we have been treated, we are not and never were charity patients on the dole.

We have elaborated on the attachments.

Sincerely yours,

H. Wiech

R. Wiech

[redacted]

---------- Original Message ----------
From: ODS02266CPC [redacted]
To: [redacted]
Date: July 19, 2017 at 8:46 PM
Subject: ARC - 7/17

Nicole Jorwic

From:	Nicole Jorwic
Sent:	Wednesday, July 19, 2017 5:38 PM
To:	Nicole Jorwic
Subject:	Virginia

Jen Majors

[redacted]

I rely on Medicaid to pay for my Medicare premiums. I am Disabled and unable to work so I have a limited amount of money every month from SSI, and seeing different doctors and therapists can cost a lot of money, so not having to worry about having the money for that and premiums really helps my sanity.

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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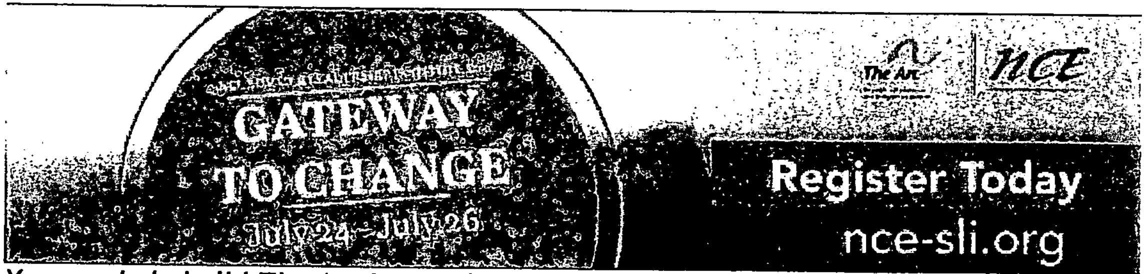
The Arc.
For people with intellectual and developmental disabilities



Nicole Jorwic

From:	Bethany Keener [redacted]
Sent:	Monday, July 17, 2017 4:14 PM
To:	Nicole Jorwic
Subject:	Virginia Senators: Save Medicaid

Dear Senator Kaine and Senator Warner,

I know both of you are already working hard to save Medicaid and I appreciate what you are doing. I wanted to write a quick note to add my voice to the many around the country who are asking their representatives to stay strong in this fight.

I want to tell you about a few of my friends who rely on Medicaid. There's H., who carried both my sons on her lap in her wheel chair when they were babies and toddlers. Her word recall is limited ... until you put on Michael Jackson. There's C., who was the first person I went to when a dear friend lost her mother to cancer. He hugged me and cried with me, unashamed of pain and vulnerability. There's F., a man of few words but many dance moves, always ready for a party to start and the last one to leave.

They are human; limited perhaps in physical and intellectual capacity, but not limited in love or potential.

Keep fighting, for them, for all of us.

Gratefully,

Bethany Keener
22204

Nicole Jorwic

From:	Lynn Welch [redacted]
Sent:	Monday, July 17, 2017 4:01 PM
To:	Nicole Jorwic
Subject:	Virginia

Hello,

My 19 year old daughter has an undiagnosed genetic condition that results in an intellectual disability. While my daughter struggles with certain cognitive tasks, she is sharp as whip when it comes to understanding her social situation. She knows she is different. She knows there are many things in life that will not follow for her as they do her brother and sister such as a high school diploma, a college degree and driving a car. Yet, despite these realities that separate her from her typical developing peers, her greatest need is just like most of us and that is to belong. She longs to belong to a work force community where she can contribute her skills and be part of something larger than herself. Yet, she will need support to do so.

Our daughter will age out of Fairfax County in a mere 2 years. We are deeply frightened by the proposed cuts to Medicaid. Where will she go? What will she do? We have already been through a period where our daughter harmed herself because of a poor fit in schooling where our daughter did not feel accepted. That has all changed through much counseling and carefully planned structured days. Our family has been through so much to bring our daughter to where she is today. We know our daughter has much to offer.

I do too. I have worked in FCPS system as a teacher for over twenty years working with some of our most vulnerable students. I have a skill set acquired by much hard work, patience and persistence. I love my job and it has been my pleasure to work extremely hard for my students.

Yet if programs fall to the wayside due to lack of funding, I will have to relinquish my position. That tears me apart. It pains me to no end to think of stopping my work. It would not be a win for my daughter either because her independence level would decrease as I would be providing all her care. There is no doubt in my mind, my daughter would regress.. So a cut to Medicaid would be a lose-lose to our family and the community at large.

Please do not let this happen. Please help us by keeping funding in tact for Medicaid to fund programs for those with disabilities to have a meaningful life.

Thank you,
Lynn Welch
Fairfax, VA

Nicole Jorwic

From: Lauriemagic [redacted]
Sent: Monday, July 17, 2017 3:36 PM
To: Nicole Jorwic
Subject: Letter writing campaign-Virginia

My son is 22. He is DD, ASD, and he has MH issues. He has finally gotten a waiver after being homeless, hospitalized, in trouble with the Law and much more. He has NO substance abuse issue. Due to his Dual Diagnosis he is incapable of taking care of himself. Is he does not get the needed services he will end up being hospitalized or incarcerated which will be a much greater expense than his current waiver. I will most likely outlive me by a good 30 years or more. He needs the appropriate services to live in the community and not in an institution. Please don't cut Medicaid for our most needy people who can not fend themselves.

Magically yours,

Laurie Curry

Nicole Jorwic

From: [redacted]
Sent: Monday, July 17, 2017 11:20 AM
To: Nicole Jorwic
Subject: Better Care Reconciliation Act (Virginia)

Our son Brad relies on Medicaid funding for his intellectual, behavioral and physical disabilities. Medicaid funding is **not** some minor aspect that, if lost, will not seriously affect Brad's well being. Medicaid funding is a matter of **life and death** for Brad. Please vote **NO** on the latest version of the Better Care Reconciliation Act, because the latest revisions to the bill do NOT change the devastating cuts to the Medicaid program that people with disabilities rely on to live and work in their communities. Thank you.

Nicole Jorwic

From:	Suzanne A. Shepherd [redacted]
Sent:	Monday, July 17, 2017 10:13 AM
To:	Nicole Jorwic
Subject:	Virginia

I am currently employed by an agency that provides much needed long term care services to individuals with intellectual and developmental disabilities. If the cuts outlined in the new Senate healthcare bill become a reality, there are many people in the Northern Neck and Middle Peninsula who will lose the very few services that exist in this area such as residential care and day support. These individuals are used to being shunned and mistreated by society, it is my job to ensure that they can have a reprieve from the indignities that they have faced most of their lives and live out their days in relative contentment. Please do not make my job impossible, please think about the lives of the nameless groups you may see on outings at your neighborhood park or store. Those people have names and stories; they deserve a chance at happiness and safety, please vote no to the senate healthcare bill and fight for the rights of these individuals to continue receiving the funding that is their lifeline.

Thank you,
Suzanne Shepherd

--
Suzanne Shepherd, MA, QMRP
Program Supervisor
MPNN CSB Community Options
[redacted]

Not everything that is faced can be changed, but nothing can be changed until it is faced. -James Baldwin

From: Annette Porter [redacted]
Sent: Monday, July 17, 2017 9:26 AM
To: Nicole Jorwic
Subject: Medicaid Cuts- Virginia

Medicaid Matters to My Family and Friends!

I am a volunteer with a group of seven adults who are physically disabled who live in a group community in Falls Church, Virginia. Medicaid is vital to their care in providing aids who will provide personal care assistance. These adults are unable to walk or do anything for themselves, yet their minds are intact. Cutting Medicaid would reduce their personal care hours and cause the home where they live, Merica House, to fold. Merica House is unique in the state of Virginia in that the personal hours for each individual were able to be grouped allowing for those hours to be divided among all seven adults, 24 hours/day, 7 days/week! They cannot survive without the Medicaid provided to them!

In addition, my son's fiancé (age 29) has her mother, who has Alzheimer's disease, living with her. The mother is on Medicaid and is allowed personal care hours in the home. With Medicaid cuts, the mother's personal care hours would be affected, requiring more out-of-pocket costs from my son's fiancé. She is already living day to day on a limited salary and would be forced to make other, more limiting, living arrangements for her mother. This would reduce the quality of care being given.

Please do not reduce cuts to Medicaid as it makes a huge difference in the lives of those less able in our society!

Annette Porter
[redacted]
Vienna, Virginia [redacted]

Nicole Jorwic

From: Fern Garner [redacted]
Sent: Monday, July 17, 2017 9:24 AM
To: Nicole Jorwic
Subject: Provider in Virginia

As a provider of residential support to a profoundly mentally disable man, I strongly disagree with the Republican plan to dismantle and defund Medicaid. Without a system of support, paid for by Medicaid, my client and many others like him would end up being returned to an institution. Please protect these vulnerable citizens.

Nicole Jorwic

From: Brandi Horton [redacted]
Sent: Sunday, July 16, 2017 4:10 PM
To: Nicole Jorwic
Subject: VA-Medicaid Matters to Me

Please share my letter and this photo of my amazing son, Wayne with senators as they try to make up their minds about Medicaid and the future of healthcare. I am sorry to miss the rally this week, but I am traveling for work.

Best,

Brandi Horton
Arlington, Va

Medicaid is essential to my family. Our oldest son, Wayne, has been diagnosed with a half dozen afflictions since he was born, all resulting from a rare genetic disorder, a microdeletion at chromosome 6p24. We rely on Medicaid to pay for expensive private therapies, expensive "premium" medications (as my insurance company calls them), expensive specialists, durable medical equipment and the only source of childcare we have--a certified nursing assistant who comes to our home every day. Without Medicaid, one parent would need to quit their job to care for our son and we would have even less money to pay for all of the things he needs to succeed in life. You can read more of our story in this essay published in The Hill on Sunday, July 16: http://thehill.com/blogs/congress-blog/healthcare/342066-the-safety-net-catches-more-than-congress-realizes?rnd=1500206173

Wayne is full of need, but he is also full of love and life. He charms everyone he meets and has so much to give back to society as long as Congress doesn't give up on him.

Sent from my iPhone

From: Frederick Hoover [redacted]
Sent: Sunday, July 16, 2017 3:47 PM
To: Nicole Jorwic
Subject: Virginia Medicaid Matters to My Family

Dear Senator,

I am writing to let you know how important Medicaid is to my family and my son, Mike. Mike is 22 years old . He had severe Autism , Epilepsy and is non verbal. Medicaid pays for all his prescription medications which improve the quality of his life. Medicaid also pays for his Adult Day Support.. HereMike learns important life and daily living skills. Day support also enables my husband and I to continue working outside the home. In the future when my husband and I age, we are hoping Medicaid will be there to help provide an independent living situation or group home for him to live in. We are terrified that he might end up in an institution if Medicaid services are cut. Medicaid is so vital to so many in the disabled community. Please think of all these good people and their families who will be hurt if Medicaid is cut. Please vote NO! thank you so much!

Fred and Beth Hoover
[redacted]

From: Sharon Schoeller [redacted]
Sent: Sunday, July 16, 2017 1:28 PM
To: Nicole Jorwic
Subject: Virginia

Dear Senators Warner and Kaine,

I know that you do not support the current Senate health care bill, but hope that my information may help you to document the tragedy that will occur if the Senate bill cuts to Medicaid are implemented.

Our severely disabled adult (33 years old) daughter has lived with us all of her life. My husband is 71 and still is working fulltime. I am 68. I have degenerative disc disease and suffer from atrial fibrillation. Our daughter is one of the lucky individuals in Virginia who has a Medicaid waiver. This waiver allows us to pay for personal attendants to help care for her and to keep her out of an institution. If the Senate health care bill passes and the states are in a financial crunch, I am very concerned that this Medicaid optional program will be drastically reduced or eliminated, resulting in the loss of community living for individuals like my daughter. We will not be able to care for her ourselves or afford to pay for the extensive care she needs. Right now, she has a high quality of life. This will end quickly if she needs to be institutionalized.

I hope that enough Republican senators will join you and the other caring Democrats to prevent this terrible situation, as well as even more drastic losses of healthcare for other people with disabilities. What I cannot understand is why so many Republican senators support this bill when is has the support of less than 20% of the population, including their constituents and when it is, as our president notes, "mean".

Thanks you for all that you do for the citizens of Virginia and of the US.

Sincerely,

Sharon Schoeller

From: Cathy Gagnon [redacted]
Sent: Saturday, July 15, 2017 2:50 PM
To: Nicole Jorwic
Subject: Fwd: Virginia medicaid support

---------- Forwarded message ----------
From: **Cathy Gagnon** [redacted]
Date: Sat, Jul 15, 2017 at 2:45 PM
Subject: Virginia medicaid support
To: cathy gagnon [redacted]

Matthew 25 "whatever you did for one of these least brothers of mine, you did for me."

We are the parents of a daughter with autism. For the past 17 years Megan has worked at an electronic assembly company. While this is not the most glamorous job, Megan takes pride in her work. We, like most parents of any young adult, are happy she is a productive member of society and not just sitting at home watching TV!

My husband and I are hard working people. He spent his career as a Foreign Service Officer and I was a teacher in a Catholic school. We sacrificed to purchase a condo for Megan so that she would have a safe, familiar place to live at such time Jim and I are unable to care for her. Because Megan doesn't have the ability to live alone she has a "companion" who is there to help her cope with the challenges of daily living. Her living arrangements and her employment are possible because Megan receives a Medicaid subsidy.

If the ACA is repealed or is revised in such a way that it cuts and caps Federal Medicaid funding, it is very likely Megan and the disabled colleagues with whom she works will lose their jobs. Megan also will be unable to live in the condo because the life support she requires also will be unavailable. This is particularly worrisome because over the longer-term Jim and I will no longer be able to provide that support.

Please reconsider the changes being proposed for the ACA - in particular the changes to Medicaid. This is not a partisan political issue, rather it involves providing protection for our most vulnerable citizens. The changes to ACA that are being contemplated may not affect you but the proposed Medicaid revisions will have a very adverse effect on many disabled people who cannot speak for themselves.

"A Nation should not be judged by how it treats its highest citizens, but rather its lowest ones."

~Nelson Mandela

Thank you.

Catherine Gagnon

--

Cathy Gagnon
[redacted]

--

Cathy Gagnon
[redacted]

From: Nancy Evinger [redacted]
Sent: Saturday, July 15, 2017 1:04 PM
To: Nicole Jorwic
Subject: Virginia - Medicaid Matters

Medicaid is THE element in our son's life that is the <u>most important factor</u> in assuring that he will continue to have the health care and other services he needs in order to maintain his very existence (life itself). Medicaid is his secondary health insurance.

Our son has Down Syndrome and offers much to our family and the larger community in love and example. However, he needs support services that cannot be found anywhere other than Medicaid waiver programs, even if he, or we, could pay for them . We have been **waiting for 20+ years** to access such services for which he has been eligible all of this time, but for which the Medicaid budget has not allowed (wait list grows, services impossible to find). Not funding these services is no doubt actually shortening many lives that could be very productive and add much to our communities (including the family members who serve as care providers)!

Our biggest concern at this point is that we are now elderly and need supports ourselves and are finding it very difficult to give our son the care and supports he is due. Even more of a concern is what will happen to him when we are no longer here. This concern is a major burden weighing on us and affects our health and well-being as well as our son's.

Our legislators need to be concerned about PEOPLE and not themselves, their political parties, and winning! They need to understand the art of compromise and making things better, not destroying lives!!

Nicole Jorwic

From:	Leann Lindsey [redacted]
Sent:	Saturday, July 15, 2017 12:33 PM
To:	Nicole Jorwic
Subject:	Please Vote No on BCRA, from Virginia

My daughter is an adult with autism and learning disability. Her life, and ours will be further complicated and made far less bearable with the proposed cuts to medicaid. The limited funds she receives from medicaid make all the difference between a life of sitting in her room watching television, and having employment and some independence services.

I cannot imagine what the people in D.C. who are supposed to be representing the rest of us are thinking. I can only assume that the majority of them are either fortunate enough to have never experienced serious, lifelong disability within their circle of family and friends, or are independently wealthy enough to provide themselves and their loved ones with the seminal services necessary for a life of basic decency.

For the rest of us--the poor, working, and middle classes—the proposed "replacement" for the ACA will be an unmitigated disaster that will have consequences for us far beyond any election cycle.

It is my understanding that the members of Congress have a separate heath care plan provided by my tax dollars. Lucky for them. I have to wonder how they might legislate differently on this subject if they were limited to the same health care they propose for their constituents.

They now have my full attention. My family and I are more engaged politically than we have ever been. We are watching what congress does. And we will not forget.

Leann Lindsey
Herndon VA

Nicole Jorwic

From:	CHARLES PARFITT [redacted]
Sent:	Saturday, July 15, 2017 8:57 AM
To:	Nicole Jorwic
Subject:	Medicaid Matters-virginia
Attachments:	July 15.docx

MVLE has sent out a memo to MVLE Program Participants and their families requesting that we write a breif message about how Medicaid impacts our life.

~~I am attaching the breif statement~~

July 15, 2017

My daughter, Katherine Parfitt, is developmentally/intellectual challenged. She has been with MVLE since transitioning from the Davis Center (post high school education/work training. She has worked at Chic-Fila through MVLE's enclave program for several years. Because of falling while working there, posing liability issues, and the recession, she was brought back to the day center. Being there has kept her in touch with the community and helped with her skills while participating in their production dept. I am also hoping that MVLE will again be able to place her in a group working situation.

She has balance issues and occasional falling issues due to having Coffin-Lowry Syndrome. With the passing of her father, we are now a one parent family. My concerns are for the future when I am gone. She may need a group home, transportation, employment and other services. I am concerned that cutting the Medicaid program will impact her life, and not for the better.

PLEASE VOTE NO on the latest version of the Better Care Reconciliation Act.

Respectfully,

Donna Parfitt

Fairfax, Virginia

Nicole Jorwic

From: David Elchert [redacted]
Sent: Saturday, July 15, 2017 8:14 AM
To: Nicole Jorwic
Subject: I am from Virginia and I am NOT in favor of Medicaid cuts

I am from Virginina and the proposed cuts in Medicaid under the Better Care Reconciliation Act will be disastrous for my daughter who is handicapped and depends on Medicaid to live.

David and Patricia Elchert

Nicole Jorwic

From: Christine Jawish [redacted]
Sent: Friday, July 14, 2017 6:59 PM
To: Nicole Jorwic
Cc: [redacted]
Subject: Medicaid Impact - VIRGINIA

To U.S. Senators:

VOTE AGAINST the Better Care Reconciliation Act. ***Medicaid Matters to me and my family.*** The bill makes devastating cuts to the Medicaid program that over 10 million people with disabilities rely on to live and work in their communities.

My son was repeatedly mis-diagnosed in his childhood. Finally, when he was 15, my son was diagnosed with autism and multiple learning disabilities. We were told to get on the wait list for the Medicaid Developmental Disability (DD) waiver.

We have been on the wait list for two years. My son will finish high school in a few years and will need assistance from Medicaid as he transitions from school to adulthood. My hope is that Medicaid funding could assist him with job coaching and other services so that he can become independent over time and live in the community.

The passage of this bill almost certainly means there will not be Medicaid funding available to help young adults with autism, like my son, make the transition from high school to adulthood and life in the community.

PLEASE VOTE AGAINST THIS BILL. Medicaid funding is crucial to people with disabilities. Please do not turn your back on the disabled constituents in your state and across the nation that rely on this funding.

Christine Jawish

From: Steve [redacted]
Sent: Friday, July 14, 2017 6:43 PM
To: Nicole Jorwic
Subject: Virginia

Dear Senator Kaine and Senator Warner,

For the past five years I've been living in the community and three of those years I have been in my own apartment with assistance from caregivers. Before that I lived in a nursing home for nine years. I am afraid that if Medicaid gets cut I will have to go back to the nursing home which goes against my ADA rights to stay in the community. I encourage you to say no to Medicaid budget cuts so that people like me can remain in the community. Thanks for your support!

Sincerely,
Steve Grammer- Member of the Community Integration Advisory Commission, Graduate of Partners in Policymaking 2013, Advocate for people with disabilities.

Nicole Jorwic

From: Ivy Kennedy [redacted]
Sent: Friday, July 14, 2017 4:34 PM
To: Nicole Jorwic
Subject: my save medicaid story

Save Medicaid. Medicaid is an investment in the well-being of this country. Medicaid pays my Personal Care Attendant. Without her I could not contribute to the community by volunteering and going to my job every day. The Olmstead Decision says I have a right to live in the community. I could not do that without Medicaid. Medicaid allows me to live at home. If I lived in an institution it would cost the government three times more than if i lived at home. Protect Medicaid. Protect my dignity and civil rights as an American citizen.

Ivy Kennedy
Virginia Beach, Va.

From: Dan Raessler [redacted]
Sent: Friday, July 14, 2017 1:41 PM
To: Nicole Jorwic
Subject: Virginia

As the parent of a 36-year-old daughter with Down syndrome, I am keenly interested in Medicaid funding. Medicaid is a critical component in financial planning for most, if not all, families who are responsible for a member with an intellectual or developmental disability. While a disability may, by definition, inhibit one's ability, it does not diminish one's desire to integrate with or participate fully in his/her cultural milieu. Most of us want a life that offers opportunities for meaningful experiences and engagement with others; surely we want no less for individuals whose disadvantages put them at risk of being denied participation in mainstream life. Medicaid funding helps individuals experience greater inclusion and offers at least a degree of peace of mind for parents who try to plan for futures whose only certainty is that the time will come when they no longer will be present to help their child experience life as fully as possible. If we embrace the moral imperative that we should want for others no less than what we want for ourselves, then Medicaid should be expanded, not curtailed.

Thank you.

Dan Raessler
Lynchburg, VA

From: mary tartaglione [redacted]
Sent: Friday, July 14, 2017 1:17 PM
To: Nicole Jorwic
Subject: Virginia Needs Medicaid

To Whom It May Concern:

We are the parents of a 15-year-old son who is intellectually disabled as well as post-kidney transplant.

He fought against the 95 percent odds against him at birth to survive, and he has continued to battle over the years to succeed.

How can the subject of medicaid be an issue for him with all of the other hurdles he has faced? It's surreal.

Please fight to keep medicaid for him and all of the Americans, young and old, who have earned it.

Yours sincerely,
Mary Tartaglione

From:	Sharon Mullen [redacted]
Sent:	Friday, July 14, 2017 12:25 PM
To:	Nicole Jorwic
Subject:	Dont cut Medicaid in Virginia

I am a 49 year old single Parent in Virginia with 2 special needs kids. Medicaid pays for so many of their services its hard to name them all.

They both have Doctors, Specialists, Counselors & Therapists and they all bill to Medicaid. We need all of the funding available. Please vote no to Medicaid cuts.

Sharon Mullen
Autism Mom since 2001
[redacted]