ILLINOIS

The Arc.

Date: 2017-09-24 10:07:29
To: My Senator
From: Sharon Conrad
State: Illinois
Email: [redacted]

Dear Senator,

I'm writing to you about my son who is 29 years old, he has an Intellectual disability (ID) along with that diagnosis he also has bipolar disorder. Wow that's a lot for a family to take in! We've worked very hard to make sure he's had as much of a normal life that we could give him.

We searched high and low for a placement in the community so that he could have a "normal" life. You know, be able to leave home like his other siblings have, have friends, a workshop to go to to help him learn some skills that may one day help him get a real job. He also has made many friends there. He loves to come home every other weekend and holidays, but he also looks forward to going back to his home. Without a medicaid waiver that we've received none of this would be possible for him. He would be stuck at home with his dad and I and not be able to have any type of independence. When we found this placement my heart found peace that we have him set up somewhere where he could live the rest of his life. I worried about what would happen to him when we pass. He has two loving sisters who will watch after him and make sure his needs are being met, but placing him with one of them would be asking a lot of them and their families. Again, without this medicaid waiver this would not be possible.

We also depend on medicaid to pay for his medications. He is on at least 3 to keep

his bipolar under control. I know what he is like when his medication is a little "off" and I can't imagine if he loses his medicaid and not be able to get his medication what would happen. He has no means of getting other insurance to pay for this. He gets $50.00 from SS a month for his "pleasure" (movie, any activities, McDonald's) which by the way has to pay for his clothing, shoes, etc. That $50.00 wouldn't be a drop in the bucket for the medications he is on or help him buy insurance to cover his medication.

I hope you will take to heart what I am trying to get across in this letter. Believe me there are a lot more parents out there in the same situation. The cuts you are about to make or thinking about making will be devastating to my family and all the families out there with a special needs child.

PLEASE, PLEASE vote NO to the Graham-Cassidy bill!!!

Thank you!

The Arc.

Date: 2017-09-22 08:34:47
To: My Senator
From: Susan Agrawal
State: Illinois
Email: [redacted]

Dear Senators,

I am the parent of a child, Karuna, who passed away in 2014 due to cerebral palsy and severe systemic autoimmune disease. Karuna was fortunate enough to be covered by both private insurance and Medicaid, and these programs allowed her to live at home throughout her lifetime.

Unfortunately, for children like Karuna today, the opportunity to live at home, and even to just remain alive, is severely threatened by the Graham-Cassidy Repeal and Replace Legislation.

I have grave concerns with Graham-Cassidy, particularly its conversion of the Medicaid program to per capita caps or a block grant system. While in theory these changes are intended to introduce flexibility for states, in reality they are simply a cut to Medicaid over the next decade. In my state, the projections suggest that in 2020, we are looking at an 11% cut to Medicaid reimbursements, and by 2030, a 34% cut.

Let me share exactly what these cuts mean to cash-strapped states, because I have already lived through the ramifications of cuts to Medicaid when my state was forced to significantly reduce its budget.

In 2011, my daughter Karuna caught what would normally be a simple infection. In her case, it turned into bacterial pneumonia, sepsis, and acute respiratory distress syndrome. As she lay in her ICU bed hooked up to a ventilator, with 10 chest tubes and on more than 50 IV medications--as she literally lay dying--I received news that our state was short on money and needed to cut her Medicaid waiver program. Because Medicaid is already a financially efficient program, there was little to cut besides optional programs like the Medicaid waiver my daughter participated in.

My state attempted to do exactly what all states will be forced to do when they receive less money for Medicaid as in Graham-Cassidy: cut or ration the optional Medicaid programs for children and adults with disabilities. These programs allow children and adults like Karuna to live at home, go to school, work, and thrive in their communities by providing extra services such as in-home care. They allow kids to be kids, and adults to be independent. Medicaid was the only reason Karuna was allowed to live at home instead of spending her entire life in a hospital ICU. Our private insurance did not cover this type of care.

Let's return to Karuna in her final two years of her life while on hospice. Instead of spending what little time I had left with my dying child, I spent an average of two hours per day, every single day, for the remainder of her life either fighting to save her Medicaid or fighting to save her private insurance.

It is beyond cruel to force parents of medically complex children to spend all of their time negotiating with politicians and insurance corporations simply so their children can stay alive and live in the community like other children. We are literally left to begging politicians to let our children live. To let our kids be kids. To let our families not be bankrupted.

Our current system is by no means perfect and surely needs improvement. But Graham-Cassidy provides absolutely no improvement. Instead it will:

•Cut total Medicaid dollars. These cuts force states to ration or eliminate care, especially for children like Karuna and adults with disabilities in optional programs.

•Eliminate annual and lifetime benefit caps. Like many families of children who are medically complex, Karuna went through her first million-dollar plan in less than a year. As she approached the cap on her second plan, our financial well-being was saved by the ACA's provision eliminating lifetime caps. Without this provision, our family would be bankrupt.

•Eliminate pre-existing condition protections by making essential health benefits optional. Children like my daughter, who happened to be born with a catastrophic medical condition through no fault of her own, would be forever denied insurance due to their conditions.

It's hard to even imagine what life would be like for children like my daughter Karuna under the type of healthcare system proposed by Graham-Cassidy. If she were alive today, most likely she would lose her Medicaid waiver, forcing her to live permanently in a hospital ICU at a much greater cost to taxpayers. More importantly, we would lose the gift of the all too short number of years we had with her.

To those of us with children who are medically complex, healthcare reform is not just political maneuvering or a means to balance the budget. Your decisions as Senators will be the difference between a child living at home or living in a hospital, a family working or being bankrupted, and a child living or dying. Please consider the actual children who will be most affected by Graham-Cassidy and how your decisions will profoundly impact their lives in a destructive manner.

Now that Karuna has passed away, I will never get back all the hours I spent fighting to keep her Medicaid and private insurance. All I can hope is that you will reject Graham-Cassidy and instead help build a robust bipartisan healthcare plan to help children like Karuna today.

Sincerely,

Susan Agrawal

Date: 2017-09-22 10:47:47
To: My Senator
From: Christina Fedor
State: Illinois
Email: [redacted]

My daughter Emma has CP due to HIE at birth. She has a g-tube, a trach, she is non-verbal, non-mobile, takes 5 meds 2 x a day, and requires O2 at night. She is also a very bright, happy 6th grader that loves being with her family and going to school.

The Graham-Cassidy Bill goes after kids like my daughter because it wants to allow things like pre-existing conditions, and caps to benefits. It also wants to cut funding for medicaid (which is our secondary insurance and covers things that Aetna does not, like nursing, so Emma can go to school). Without insurance and medicaid we could not afford the thousands of dollars each month that it costs to have her equipment like feeding pump, suction machine, oxygen. We could not afford the cost of her seizure medicines, and her food. Without insurance and medicaid we could not afford the specialists that we see that help keep her healthy. Her life expectancy would drop significantly and she would be unable to go to school without medicaid because she would lose her nursing.

Date: 2017-09-23 14:57:57
To: My Senator
From: Curtis Harris
State: Illinois
Email: [redacted]

The Arc.

My name is Curtis Harris

The Cassidy-Graham bill affects people like me, people with autism and developmental disabilities. If the bill passes I will be at risk of not getting Medicaid services, services that will help me live independently in my own home instead of an institution. In Illinois, there is a waiting list for people with developmental disabilities to receive services. The list is called the Priority of Urgency Needed Services which we shorted it to PUNS. Like tens of thousands of others in Illinois, I've been a part of that waiting list for a long time. I hope to secure services soon, but if the Senate passes the Cassidy-Graham bill, states could lose hundreds of millions of dollars in Medicaid supports. The fate of healthcare leaves a big question mark for people with disabilities like me. I hope to receive the supports I need to be healthy and independent in my own home instead of a hospital or institution. The Cassidy-Graham bill poses an even greater threat to individuals with mental illness and addiction disorders and the providers that serve them. Patients with mental health and addiction disorders will be especially hurt as they disproportionately rely on traditional Medicaid and Medicaid expansion. The cuts in mental health and substance addiction in Cassidy-Graham will be close to $4oo million forcing states to cut funding to community mental health centers where people reclaim their lives of going to therapeutic structured groups, Supportive Affordable Housing and Supportive Employment Specialist and live better lives. Community Mental Health Centers are less expensive than Emergency Room, Hospital, Incarceration and nursing homes and institutions. Illinois spends more money on incarceration like Cook County Jail for mental health treatment than community mental health centers. Cook County Jail is the No. 1 mental health center treatment in Illinois No 2 in the nation behind Los Angeles County Jail. The cuts of mental health treatment in Cassidy-Graham bill will make Cook County Jail overcrowded more overcrowded. Cuts to Developmental Disability/Intellectual Disability will amount to $72.4billion in the Cassidy-Graham bill, leaving many to lose their freedom and Independence to live in the Community as opposed to more expensive institutions. The Trump Administration is planning to cut $610 million in cuts to Medicaid $72.4 billion in cuts to Social Security's disability programs; and hundreds of billions more in cuts to other effective federal programs that are vital to people with I/DD Intellectual Disability and Developmental Disability including in the Cassidy-Graham bill.

I have benefited from Medicaid from going to Community Mental Health Center like Thresholds Dincin Center For Recovery in Ravenswood for 10 years of going to therapeutic structured groups, Supportive Employment and being on the waiting list for affordable housing and to get and keep a job through Supportive Employment and potentially live in my own home. All of this is uncertain. Medicaid has taken the reminding care for my primary care doctor, dietitian, social worker/therapist, psychiatrist and if need in non-life-threaten Crisis Center like the Turning Point Living Room in Skokie and Swedish Covenant Warming Center. Let's not go back to the days when people with developmental disability and mental illness are put away in institutions. Thank You and God Bless You

Date: 2017-09-23 14:28:09
To: My Senator
From: Curtis Harris
State: Illinois
Email: [redacted]

My name is Curtis Harris

The Cassidy-Graham bill affects people like me, people with autism and developmental disabilities. If the bill passes I will be at risk of not getting Medicaid services, services that will help me live independently in my own home instead of an institution. In Illinois, there is a waiting list for people with developmental disabilities to receive services. The list is called the Priority of Urgency Needed Services which we shorted it to PUNS. Like tens of thousands of others in Illinois, I've been a part of that waiting list for a long time. I hope to secure services soon, but if the Senate passes the American Health Care Act, states could lose hundreds of millions of dollars in Medicaid supports. The fate of healthcare leaves a big question mark for people with disabilities like me. I hope to receive the supports I need to be healthy and independent in my own home instead of a hospital or institution. The Cassidy-Graham bill poses an even greater threat to individuals with mental illness and addiction disorders and the providers that serve them. Patients with mental health and addiction disorders will be especially hurt as they disproportionately rely on traditional Medicaid and Medicaid expansion. The cuts in mental health and substance addiction in AHCA will be close to $4oo million forcing states to cut funding to community mental health centers where people reclaim their lives of going to therapeutic structured groups, Supportive Affordable Housing and Supportive Employment Specialist and live better lives. Community Mental Health Centers are less expensive than Emergency Room, Hospital, Incarceration and nursing homes and institutions. Illinois spends more money on incarceration like Cook County Jail for mental health treatment than community mental health centers. Cook County Jail is the No. 1 mental health center treatment in Illinois and No 2 in the nation behind Los Angeles County Jail. The cuts of mental health treatment in AHCA will make Cook County Jail overcrowded more overcrowded. Cuts to Developmental Disability/Intellectual Disability will amount to $72.4billion in the AHCA bill, leaving many to lose their freedom and Independence to live in the Community as opposed to more expensive institutions. The Trump Administration is planning to cut $610 million in cuts to Medicaid $72.4 billion in cuts to Social Security's disability programs; and hundreds of billions more in cuts to other effective federal programs that are vital to people with I/DD Intellectual Disability and Developmental Disability including in the Cassidy-Graham bill.

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Date: 2017-09-21 18:28:44
To: My Senator
From: Louise Ores
State: Illinois
Email: [redacted]

The Arc.

As a widow with two sons with disabilities, we rely on Medicaid for CILA funding. My sons live in the community and work. It would be devastating to them for this funding to be eliminated. Where and what would they do? Please consider what cutting Medicaid would mean to us as well as the problems we

In Illinois would face with block grants. Our State is in serious difficulty now and any reduction in funding will impact our State and jeopardize people's lives.

Date: 2017-09-21 17:19:47
To: My Senator
From: Karen Smith
State: Illinois
Email: [redacted]

My daughter is 22 years old and has Down syndrome. She is on my husbands medical insurance if you take out the "pre-existing" clause she would not have coverage for anything that she has had done in the past. She had open heart surgery when she was 6 months old, has had 2 spinal surgeries. These may not seem like big things to you but for the family that's raising a child with special needs it's the world. Also through Medicaid the Hone Based Waiver is run through. That would help me and my husband out by having someone stay with her.....she would not be able to stay home alone. So with you you stopping this too you're saying it's okay for her to be left alone....NO it's not! Please talk to families of a special needs child. We are not asking for much just please do your research on the programs you want to get rid of. It's more than just food stamps. Thank you for your time!

Date: 2017-09-21 18:08:21
To: My Senator
From: Genevieve Sevilla
State: Illinois
Email: [redacted]

I have been on a waitlist for 15 years in Illinois to receive services and supports that will allow me to live a full and independent life in my community as a person with intellectual disabilities. My name has finally been pulled from the waitlist and I have just received my award letter to start having a personal support care worker through Home Based Services, a medicaid waiver in the State of Illinois. I also received Medicaid because of my disability and the challenges I have in being employed. As a person with a severe intellectual disability Medicaid is a lifeline for me. Please don't move toward block grants. Please don't vote for this horrible healthcare bill. Please don't take away my independence in my community with the supports I need to function and be safe. Please don't cut my healthcare. Please don't make the reimbursements so small that doctors will not take me as a patient. Instead of passing this horrible bill which will hurt me and my mother with breast cancer, please work with all of congress to keep ACA intact and fix the parts that need fixing. Don't hurt us. Don't take away our healthcare or ability to have healthcare. MEDICAID MATTERS TO ME.

Thank you.

The Arc.

Date: 2017-09-22 11:31:35
To: My Senator
From: Erin Saylor
State: Illinois
Email: [redacted]

Good afternoon:

I am a partner in a law firm and we handle Medicaid for providers all over the country. The proposed health care plan would gut vital benefits that millions of elderly adults and disabled persons of all ages depend on to meet their most basic day-to-day needs and keep them safe. Please vote NO Graham-Cassidy bill. Do not take away health care for millions of Americans.

Regards,

Erin Saylor

The Arc.

Date: 2017-09-22 10:19:23
To: My Senator
From: LINDA SHELTON
State: Illinois
Email: [redacted]

I have an adult daugher who is 21 years old and currently lives with her Father and I. Currently, she is enrolled in a transition school who will hopefully help her to get a job of some sort when she leaves the school system next April of 2018. My daughter has an intellectual disability, bipolar disorder, and ADHD. She struggles with daily living skills, social interactions, and just being safe. I don't know if she will ever hold down a full-time job and will most likely be dependent on her Father and I for the rest of her life or until we pass away. She depends on the small SSI income every month to help to pay for doctor bills, medication, food and clothing. She will also need this income to help support her if and when she moves into a CILA or residential placement with supports. PLEASE do not take this away from her and others like her.

The Arc.

Date: 2017-09-21 23:35:59
To: My Senator
From: Kathleen Andersen
State: Illinois
Email: [redacted]

We gave a son Nathan that has a diease called Tuberous Sclerosis. He has calcified tubers (like tumor's) in his brain, kidneys, eyes,liver,and face. He us mentally impaired and has seizures. He also has only 40 percent kidney function. We really count on Medicaid for alot if the medical expenses for Nathan and to send him to a day program. Nate requires alot off medical care and we are keeping him at home and taking care of him ourselves. Nate would not be able to carry on withiur the help he gets from Medicaid. If he was in a home it would be do much more than us keeping him home. Please don't make cuts to people who can't help themselves and count so much on their families to help them get the care they deserve. Thank you!!!

Date: 2017-09-21 18:12:39
To: My Senator
From: Kimbell Gabor
State: Illinois
Email: [redacted]

The Arc®

Hearing: Graham-Cassidy Bill Hearing

Date of Hearing: September 25, 2017

My name: Cynthia Kimbell Gabor

My address: 157 Hawkins Circle, Wheaton, IL 60189

When my daughter was 6, we moved from Illinois to Maryland. In 3rd grade, she was selected for the state's Autism Waiver Program, a newly formed Medicaid waiver program. The supports that the program offered my daughter were tremendous. She was provided with in-home, after-school support by trained staff who were overseen by skilled professionals experienced with crafting meaningful home and community activities tailored to my daughter's needs, aptitudes and goals. And as a parent, I suddenly did not feel alone in the disability world. We always had good school programs for Laura, but we struggled to fill the rest of Laura's life with meaningful, non-therapy related experiences and companionship. And we struggled to give her twin brother a normal, neuro-typical life. My husband worked long hours. Laura has always needed too much care for me to hold down a job. We could not afford to pay ourselves for this sort of support, and it was always difficult to find and figure out how to train people to work with a very autistic, non-verbal, sensory and coordination challenged young girl.

Until Laura was 6, we lived in Illinois. Illinois did not have a 0-3 program. So we paid for therapists out-of-pocket when private insurance would not cover it, which was quite often! We set up a home program for her and found a few teenagers to work with Laura, still hoping she might talk, might be able to learn to write or sign, might take more of an interest in things that interested her peers. I had very little guidance or confidence that I was doing what Laura needed.

Laura's selection into Maryland's Autism Waiver Program added more meaning and helped her to grow in ways that I was struggling with on my own. It also saved me from burnout and gave me much more time with her twin brother than I would have otherwise had. Every time there was a new hurdle, whether it was extended school absences from medication reactions or the onset of intractable seizures, our service provider found just the staff we needed to support Laura and help ease her life.

When Laura was 18, we moved back to Illinois, a state not known for its services, but well-known for its kind people. Laura qualified for the DORS Home Services Program. This has allowed for a qualified companion to take her out in the community several times a week, someone who is not her mom. Laura has health challenges in addition to her severe autism. After aging out of school she attended an adult I/DD program for a year until her health forced her to drop out. The Medicaid funds also helped pay for this program. She now spends her days predominantly at home. Without a Medicaid Waiver provided companion, I would not be able to leave the house to do even basic things like grocery shop, as this sort of thing is too hard for her.

Laura has received Medical Assistance with both waivers. While we are fortunate to have good primary insurance, Laura has had some pretty big hospital bills and other medical needs. Medicaid has served as a backup and we are grateful that it has been there for her. As my husband approaches retirement (he is 67, I am 60), Laura's continued Medicaid coverage will be vital to her well-being. Laura will never work and will never be able to live independently. She requires 24-hour care. And if she outlives me, she will need to live in a Medicaid funded group home. I certainly cannot fund that on my own.

Block grants and the proposed cuts to Medicaid will doom her to a life of neglect due to scarce resources and scarce medical care. Already, there is a long wait list for adult services for those with I/DD. The proposed cuts will only make things worse for a population that is easily overlooked.

As you can tell, Laura also has pre-existing conditions. I do, too, and I'm in good health. This Graham-Cassidy Bill would not only reduce available Medicaid medical and Waiver funds for my daughter. It would make private insurance impossibly expensive for both of us.

So, for families that have disabled people in their family units, you who vote for the Graham-Cassidy Bill are requiring us to pay much more for we can afford, not only for health care, but for the day programs and group homes and the therapies and community living. The image of kicking a person when they are already down comes to mind.

As a parent, I have gladly given up a lot over the years to care for Laura. But we do need the help we get. Do you know how callous this bill is?

Do you realize the message you are sending to us? I hear you quite clearly in Wheaton, Illinois. You are saying: “Mrs. Gabor, your daughter is never going to amount to anything that matters to us. She can’t pay taxes. She’s a burden to us and we don’t like that. She’s not our version of America. And while we don’t exactly wish her dead, we don’t really wish her life either.”