
WEST VIRGINIA

Date: 2017-09-22 17:07:59
To: My Senator
From: Priscilla Spence
State: West Virginia
Email: [REDACTED]



My name is Priscilla Ann Spence and myself and daughter, Micah Holley, who is severely disabled, rely on Medicaid in the State of West Virginia for our Healthcare. I currently receive Medicaid through a program called M-Win, the Medicaid Working Incentive Network. I pay a premium each month for my care based on my income. I have to qualify each year for disability based on my medical conditions, and without this care through Medicaid, I would be dead in a few months. Then who would care for my daughter?

My daughter, Micah, receives a Title XIX Medicaid Waiver that provides her with case management, behavioral support, staffing and nursing services. It also provides monies for Day Hab services that allow me to keep a full time job. She attends a Day Hab every day of the week except weekends and is able to interact with other adults with mental and physical disabilities. These are her friends that she loves very much. She also receives Medicaid and Medicare through the death of her father. Without these supports, she would most likely have to live in a group home or an institution, instead of at home with me, her mother. She would not receive the care she currently enjoys by being home with her mom, whom she loves and relies on greatly. With her condition, she requires twenty-four hour care and assistance with daily living skills such as bathing, meal preparation, medication administration, laundry, household chores, and many other intimate and required services that are provided by myself and staff that are paid through the Waiver Program. She has a seizure disorder that must be monitored on a daily and nightly basis, and without these supports, she would surely lose the current skills she has and regress significantly.

These cuts to Medicaid, that will affect millions in our country, are not necessary. They will hurt the most vulnerable in our great country and only allow the rich to get richer on the backs of the poor, the ill, the disabled, and the elderly. We cannot let this bill pass. It will mean a death sentence to myself, my daughter, and many others that we deeply care about.

Date: 2017-09-21 22:01:19

To: My Senator

From: Becky Folden

State: West Virginia

Email: [REDACTED]



My daughter, Sara, needs Medicaid services desperately every day. She has Traumatic Brain Injury and requires 24 hour care daily to survive. Sara is 34 years old and enjoys going to the theatre to see live plays, calls friends on the phone, goes to church, and loves everyone she meets the same. On the other hand, Sara, sometimes can't remember what she ate for breakfast, is incontinent, needs transfer assistance to move from her bed to her wheelchair, needs help to shower, eat, dress, and take her medications, etc. She receives services from Medicaid I/DD Home and Community Based Waiver. In 2014, DHHR started cutting her services and she now only has one person to help her each week. If that person can't come, she only has her father and I (we are 64 and 62 years old) to rely on for her daily care. She has waited 10 months for a new shower chair and 3 years for a new chair cushion. If more cuts to Medicaid are handed down, we aren't sure what will happen to her. We are just like any other parents who only want what is best for their child. But instead of helping her to survive in her community and be productive, it is becoming more evident that DHHR (Medicaid) and those in Congress want her to be institutionalized and segregated from society. If Medicaid funds are cut more and people with disabilities are segregated more in institutions, the cost of their care will be at least twice what it is now. I am asking for our representatives to hear our cry of desperation and vote no to the Graham-Cassidy Health Care Bill that will cut Medicaid and services for people with disabilities.

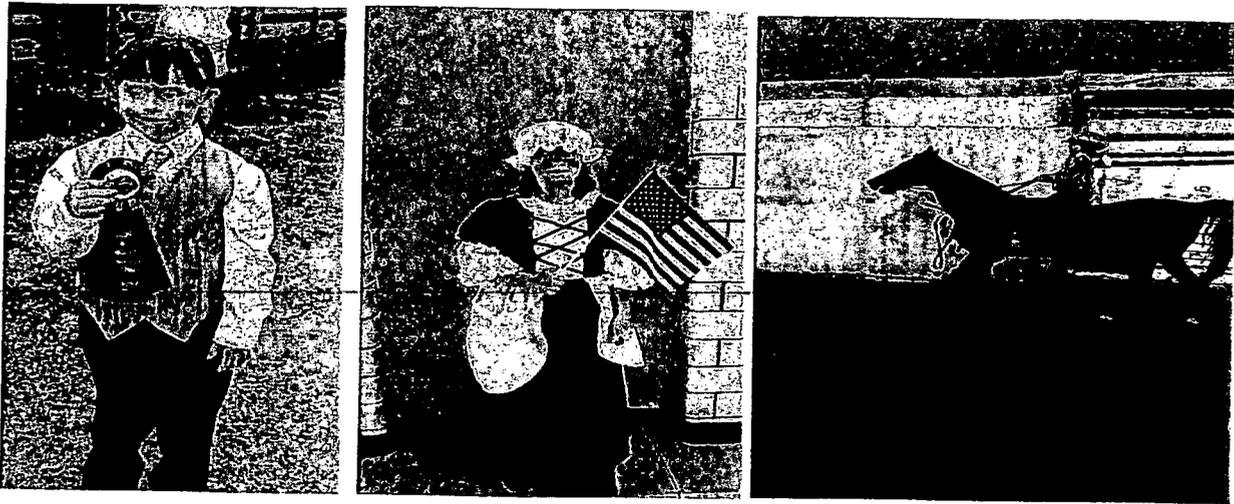
Nicole Jorwic

From: Black, Christy D [REDACTED]
Sent: Wednesday, July 19, 2017 3:57 PM
To: Nicole Jorwic
Subject: West Virginia
Attachments: Medicaid Letter.docx

I have attached my daughter's Medicaid story. You can share my letter. However, you can respond to this email address, but don't share this email address. Use my personal email address which is [REDACTED] or call me at the number below.

Thank you,
Christy Black
[REDACTED]

PLEASE PROTECT MY DAUGHTER'S LIFELINE!



Dear Senator Capito:

Let me tell you about my daughter. Her name is Gracie and she is 13 years old. Gracie also has Down syndrome. Gracie has a lot of interests. She has modeled in a fashion show in Washington D.C. She won first place at a horseshow riding a saddlebred. She was the keynote speaker at the WV Exceptional Children's Conference last year. Gracie also pages every year for the WV House of Delegates. Gracie has lots of friends. She is getting ready to start Middle School which she is very excited about. She is included in general education classes for most of the day. However, she does receive supports in school. Medicaid pays for some of those supports. Gracie also has lots of health issues, and sees seven physicians. As you can imagine, Gracie does have pre-existing conditions. Gracie receives home and community based supports, as well as a secondary insurance through Medicaid. These services are going to first and foremost, keep her alive because with my primary insurance alone I cannot afford her medical care. Secondly, they are going to help her to reach her full potential and to be a contributing member of society. Gracie has dreams of working one day. She can attain those dreams with supports that Medicaid pays for. Gracie receives Medicaid through the WV Title XIX I/DD Waiver program. This is an optional State program. With cuts to Medicaid, this program could be discontinued or cut so drastically that my daughter will basically not receive the supports and services she needs. I don't know what I will do if something happens to this program. A parent shouldn't have to worry how they are going to afford their child's medication, or how I am going to provide work exploration and job supports in a few years because I have to work in order to make sure we have a home to live in and food on our table. Please Senator Capito, protect my daughter's Medicaid and her lifeline.

Sincerely,

Christy Black,
Gracie's mom

Nicole Jorwic

From: Black, Christy D [REDACTED]
Sent: Wednesday, July 19, 2017 3:57 PM
To: Nicole Jorwic
Subject: West Virginia
Attachments: Medicaid Letter.docx

I have attached my daughter's Medicaid story. You can share my letter. However, you can respond to this email address, but don't share this email address. Use my personal email address which is [REDACTED] or call me at the number below.

Thank you,
Christy Black
[REDACTED]

Nicole Jorwic

From: CARI SHEPARD [REDACTED]
Sent: Monday, July 17, 2017 5:08 PM
To: Nicole Jorwic
Subject: Re: Emergency Medicaid Matters to Me Letter Writing Campaign - Deadline Extended to Wednesday! (West Virginia)

Dear Senators Capito & Manchin:

~~I am writing you to urge you to vote against the GOP's attempt at replacing the Affordable Care Act. While that Act is not (and never was) the perfect solution to our health care crisis, I do not believe the plan proposed by the GOP (written in the back room with men only) is the answer.~~

I am writing to you as a concerned parent of a child (now an adult) that just happens to have Down Syndrome, OCD, ADD and Autism. My son relies on his Medicaid card AND Title VIX Waiver (I/DD Waiver) to meet his health care needs as well as allowing him to live and work in his community. As you know, WV has been a leader in the Home & Community-Based Waiver programs providing for their disabled citizens in such a way that not only is the recipient able to stay in their family home (or choose to live semi-independently in their own place) but the families have been able to receive compensation for caring for them. The recipients of these programs require 24/7 ISS (technically institutional care) support and care, many times family members have been forced to resign from employment to ensure care for their loved one (the Person Centered Support received through the I/DD Waiver helps offset this loss of pay).

My concern is with the proposed cap/block grant process for Medicaid. This population is not a static population as those of us on waiver and those waiting to get on it know. At this time WV has over 1,000 individuals on the wait list to receive the waiver, their only hope is for someone to die or move or miraculously be healed. Without these programs (straight Medicaid and I/DD Waiver) I'm afraid my son's health and well-being will be greatly diminished as we are a single income family due to one of us having to be home to care for my son.

Please, vote against this proposed plan. I do have an alternative suggestion, as a former federal employee, I remember the Federal Health Benefit's Plans fondly. My suggestion is to open those plans to all US citizens (allow employers to purchase in for their share if they are large enough), have the employees share payroll deducted, for citizens whose employer will not pay for the employer share let their tax dollars be their portion. This solves several problems:

- insurance is for all citizens (what everyone says they want)
- the largest employer in the nation with the biggest negotiating power can negotiate the best rates from a variety of insurers (free market)
- citizens have a large group of policies to choose from and at various price points.
- Everyone from the President down to the newborn can be covered (private plans can still be offered by insurance companies for those that demand more or better).

Just an idea.

Cari Shepard

Marion County WV

Wife of Jeff, Mom to Nick, Mitchell & Zack

Nicole Jorwic

From: Disaree Rush [REDACTED]
Sent: Sunday, July 16, 2017 8:36 AM
To: Nicole Jorwic
Subject: West Virginia

My daughter is beautiful, loving, joyful and smart. She fights everyday to have a good day.

My child is unable to eat, talk, walk, sit or stand without assistance. she's in a wheel chair as I provide all her needs.

My daughter sees numerous doctors to keep her healthy, and medication to further her care.

Without Medicaid my child would suffer.

Nicole Jorwic

From: [REDACTED]
Sent: Saturday, July 15, 2017 3:42 PM
To: Nicole Jorwic
Subject: West Virginia

I am a service coordinator for individuals who get their services through Medicaid Waiver. All of these individuals depend on Medicaid for not only their medical needs but for the supports that allow them to have as normal a life as possible. Many do not have any support from family and would be devastated by the loss of this program. Not only that but without Medicaid many people would not have a job either.

Nicole Jorwic

From: Christy Judd [REDACTED]
Sent: Saturday, July 15, 2017 1:04 PM
To: Nicole Jorwic
Subject: West Virginia

I made a statement in a previous email but here are two additional items



Ethan then and

Horses with Hearts has Ethan. In just the first year of his fear of animals and over three weeks we could see improvement in his trust. This time he became less down and backwards. He is 1 year old today; before that he was afraid of failing. Now when he talks about Penny

- Christy J

I had the wonderful opportunity with Ethan as a student rotation in an outpatient center. Ethan shared his HwH and "Penny the horse" sessions, which inspired

Ethan, age 8

ABOUT ETHAN: Piano, horseback riding, church spending time with family and friends

ETHAN'S DIAGNOSES: Congenital Myasthenic Syndrome- Slow channel

CURRENT MEDICAL NEEDS: G-tube, tracheotomy, night time mechanical ventilation, walker, stroller, pulse ox

WHAT DOES ACCESS TO AFFORDABLE QUALITY HEALTHCARE MEAN TO YOU? Ethan will have access to treatment like OT and PT and maintain access to the CDCSP Waiver which serves as a gap coverage with his private insurance.

HOW HAS THE ACA AND/OR MEDICAID HELPED YOU? Ethan received Medicaid as a result of a waiver program which covers his home nursing which enables him to attend public school. He also receives therapies which have improved his quality of life by increasing accessibility as a child with a genetic condition he will never be denied lifesaving medical coverage.

HOW WOULD THE PROPOSED AHCA AFFECT ETHAN?

Possible change may mean that he is uninsurable. If he lost the Medicaid waiver which covers nursing I will have to stop working as a teacher and we would no longer be able to pay for our home. Leaving is dependent upon other government programs.

Ethan is a sweet and smart little boy. With the current programs in place he has the ability to grow into a fully functioning member of his community. College and the workforce are in his future. If he loses access to public school due to the loss of a nurse his potential would be limited.



Submitted by Christy Judd, Ethan's mother (Inwood, WV 25428)

[REDACTED]

Nicole Jorwic

From: Christy Judd [REDACTED]
Sent: Saturday, July 15, 2017 12:31 PM
To: Nicole Jorwic
Subject: West Virginia

Mediciade means my son who also has private insurance is able to attend school and access his community, live the life of an 8 year old. It means he gets to live with his family in a house we are buying. We don't live extravagantly, my husband is driving a 2004 Honda Civic, but we are together. Without Medicaid we could not afford all his care needs which exceed the gross income of most Americans. He deserves to be a little boy, but right now he is a lobbyist, helping me fight for his life.

Christy judd
[REDACTED]

Sent from my iPhone

Nicole Jorwic

From: Trudi Shockey [REDACTED]
Sent: Saturday, July 15, 2017 10:50 AM
To: Nicole Jorwic
Subject: West Virginia Medicaid IDD Waiver

Medicaid matters to my family!! I am the younger sister of an IDD Waiver participant and without the program I just don't know how our family would provide the care that is necessary for my sisters quality of life. Please, we can't handle anymore cuts.

Trudi Shockey
[REDACTED]

Vienna, WV 26105

Nicole Jorwic

From: Janet Johnson [REDACTED]
Sent: Saturday, July 15, 2017 7:57 AM
To: Nicole Jorwic
Subject: West Virginia Medicaid

I have a 23 year old daughter with severe profound nonverbal autism on the ID/D Waiver Program in West Virginia. We are aging parents and without the program and services it provides we cannot keep our daughter at home and community were she belongs. We must consider the unthinkable. How is a institutional setting cost effective for the state of West Virginia and on a federal level? She would have to be placed out of State. West Virginia does not have the facility to accommodate her needs.

Medicaid is her life line.

Janet Johnson

Nicole Jorwic

From: Stephanie Holland [REDACTED]
Sent: Friday, July 14, 2017 6:09 PM
To: Nicole Jorwic
Subject: West Virginia Medicaid Matters
Attachments: 20170419_171100.jpg; 20170515_112535.jpg

Dear Senator,

My name is Stephanie Holland and I live in Martinsburg, WV. I'm a single mom caring for my adult son (Joshua, 30) who has Down syndrome. We depend on Medicaid for many reasons.

Recently, for example, my son suffered from a seizure. I have never been more frightened in my life. As I held him for the few moments that he was unconscious, I truly thought I might lose him. Once he regained consciousness, I was able to concentrate on getting him the care he needed without worrying about the costs involved because I knew he had Medicaid coverage.

Since then, he has received excellent care from local physicians who are determined to identify the cause of his seizure and help me prevent future problems.

We also hope to someday access the home and community based services covered by Medicaid. Unfortunately we have been told that there is currently a seven year wait list for the waiver he needs to access them. These services will allow him to participate more fully in the community. Until then, we both stay home with very little options available to us.

Which brings me to another reason why Medicaid is so important to us. The Medicaid expansion coverage in our state provides me with health coverage for my chronic conditions including diabetes, hypothyroidism, and anxiety/depression disorders.

I truly hope that you will help us and other West Virginia families who are caring for loved ones with disabilities, issues with aging in place, and chronic illness by voting NO on the current version of healthcare revisions. The cuts proposed will limit access to physicians in already underserved areas, create even longer wait lists for home and community based services, and eliminate lifesaving healthcare for family caregivers with low incomes.

Sincerely,
Stephanie Holland

Founder of
The Road We've Shared
[REDACTED]

*Pic. 1= Joshua at the Berkeley Medical Center ER following his seizure

Pic. 2= Joshua getting his EEG via Panhandle Neurology