
LOUISIANA

Nicole Jorwic

From: Northshore FHF [REDACTED]
Sent: Wednesday, July 19, 2017 3:43 PM
To: Nicole Jorwic
Subject: Louisiana

We are the members of the Northshore Chapter of People First of Louisiana self-advocacy group. Medicaid services are very important to us. We depend upon Medicaid for many daily living, independent living, and lifesaving supports and services. Medicaid is important to us because it provides funding for waivers. This covers the cost of services to live independently in the community.

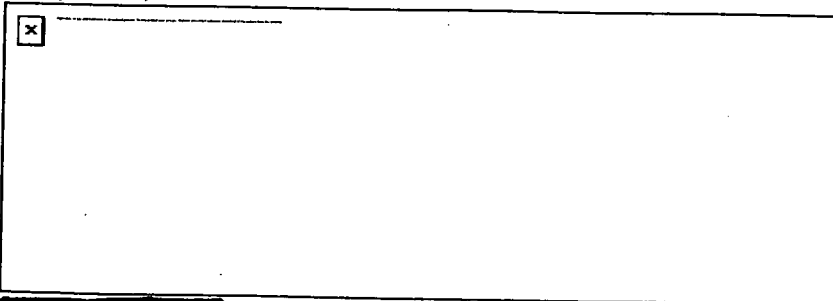
Some of us live in our own apartments or at home with elderly parents and the wavier provides transportation to doctor appointments, shopping for personal items, keeping my apartment clean, grocery shopping, helps me eat, do laundry, use the bathroom, take a bath, teach me how to live on my own, and helps me with banking/budgeting.

Without Medicaid, we would not have lifesaving medical care: pays for doctor visits, covers my sleep apnea machine, covered the cost of my open-heart surgery, makes my medication affordable or free.

Please save Medicaid and the vital services for people with disabilities like us.

Maria Caserta, Scott Smith, Roshanda Barney, Brianne Rideaux, Jeff Arseneaux, Joshua Keller, Megan Ott, Morgan Brownlee, Stephanie Assaf, Josh Yanez, Sean Leehans, and Robert Verrett

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People First of Louisiana Northshore Chapter
Scott Smith, Co-Leader
Perry Evans, Co-Leader



[REDACTED]
Covington, LA [REDACTED]
[REDACTED]

Mission Statement:

People First of Louisiana supports people with disabilities to empower themselves in becoming effective decision makers, to gain more independence, and enjoy life as equal citizens of the United States of America.

Vision:

People with disabilities build personal visions that are reached through respect, equality and many different experiences that lead to choices and life decisions. People with disabilities support one another to control their own lives, understand and speak up for their rights and live up to their responsibilities.

Nicole Jorwic

From: [REDACTED]
Sent: Tuesday, July 18, 2017 4:45 PM
To: Nicole Jorwic
Cc: [REDACTED]
Subject: Senator Cassidy - Why Louisiana Medicaid Matters to Me!

Senator Cassidy,

Re: Why Louisiana Medicaid Matters to Me!

~~I am writing you about Louisiana Medicaid. It matter to me because I am a person with a disability and I have many friends who use Louisiana Medicaid. They use the Louisiana Medicaid Waiver to assist them to be able to live in their own apartment. They also use it to have supports to be able to work and do things in the community.~~

Cuts or caps to Louisiana Medicaid would devastate home and community based services that provide the supports and services that people with disabilities need to be able to live in their own apartment or to be able to work or do things in the community.

Cuts or caps to Louisiana Medicaid could force people into institutions which cost Louisiana much more dollars than the dollars for the Louisiana Medicaid Waivers Home and Community Based services. Cutting Louisiana Medicaid would be taking away supports and services that some people with disabilities need to be able to live. Some people I know use Louisiana Medicaid for equipment and health services to be able to keep them alive. Cuts or caps to the services they use would cause them to die!

Please do not cut or cap Louisiana Medicaid!

Wallace Johnson
Westlake, Louisiana
[REDACTED]

Nicole Jorwic

From: [REDACTED]
Sent: Tuesday, July 18, 2017 4:41 PM
To: Nicole Jorwic
Cc: [REDACTED]
Subject: Senator Kennedy - Why Louisiana Medicaid Matters to Me!

Senator Kennedy,

Re: Why Louisiana Medicaid Matters to Me!

I am writing you about Louisiana Medicaid. It matter to me because I am a person with a disability and I have many friends who use Louisiana Medicaid. They use the Louisiana Medicaid Waiver to assist them to be able to live in their own apartment. They also use it to have supports to be able to work and do things in the community.

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Please do not cut or cap Louisiana Medicaid!

Wallace Johnson
Westlake, Louisiana
[REDACTED]

Nicole Jorwic

From: Elizabeth Fussell [REDACTED]
Sent: Tuesday, July 18, 2017 10:54 AM
To: Nicole Jorwic
Subject: Update on Action Around Healthcare

Healthcare Reform

To develop a healthcare plan that works for everyone, the planning committee would need to include a great deal of input from people that USE healthcare. Currently I am hearing a lot of comments from congressmen and insurance administrators about how healthcare works. Have you asked the recipients what works for them? What do they need in order to live a quality life? What do they need for preventive care?

If you cannot answer these questions with comments from healthcare users, then we need to start over!

Insurance administrators are in this for the money. They do not need to tell anyone what will and will not work. Insurance companies need to support the plan that is developed to serve the needs of the users. Insurance administrators should not be at the planning table. If you are including insurance administrators, STOP.

Capping Medicaid is not the answer! Medicaid covers a vast amount of services that are vital to the lives of Americans. The term Medicaid cannot be used a simple term.

Medicaid is an insurance that people use for preventative care.
Medicaid is an insurance that people use for medical services.
Medicaid is a waiver that people use to live quality lives in the community.

By capping Medicaid you are saying people's lives do not matter. We need to look at the specific uses of Medicaid. This is where REFORM needs to start. REFORM needs to identify what is NOT WORKING.

Who abuses the system? How is the system abused?

re·form

verb

1. make changes in (something, typically a social, political, or economic institution or practice) **in order to improve it.**

noun

2. the action or process of **reforming an institution or practice.**

(Source: <https://www.google.com/#q=reform>)

In order to reform it is necessary to look at what needs to be changed. What practices are you changing? How will you change it? People depend on Medicaid to live productive lives in the community. Don't CAP Medicaid. Identify the specific services/areas that are not successful.

Thank you!

Elizabeth Fussell, Ed.D., CRC
The Arc Iberville

[REDACTED]
[REDACTED]
Plaquemine, LA 70764
[REDACTED]

From: Nicole Jorwic [REDACTED]
Sent: Sunday, July 16, 2017 7:13 PM
To: nce-local-executives@groups.thearc.org
Subject: [nce-local-executives] Update on Action Around Healthcare

Good Evening:

As you have most likely seen, due to Senator John McCain's surgery, the vote planned for this week has been delayed by Leader McConnell: <http://thehill.com/business-a-lobbying/342206-mcconnell-delays-healthcare-vote-after-mccain-surgery>

Because of this delay we have extended the timeline for the Emergency Medicaid Matters to Me Letter Writing Campaign, I will be collecting letters until THIS Wednesday at midnight. The response has been great, thank you for getting the word out, please keep spreading the call to action.

Here is an updated blog on the campaign: <https://blog.thearc.org/2017/07/14/emergency-weekend-medicaid-matters-letter-writing-campaign/>

We will be sending out updated materials tomorrow, thank you for your continued advocacy!

Nicole

Nicole Jorwic, J.D. | jorwic@thearc.org

Director of Rights Policy, **The Arc**

sent from my iPhone
[REDACTED]

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You received this message because you are subscribed to the Google Groups "NCE Local Executives & Senior Management" group.

To unsubscribe from this group and stop receiving emails from it, send an email to nce-local-executives+unsubscribe@groups.thearc.org.

To post to this group, send email to nce-local-executives@groups.thearc.org.

Nicole Jorwic

From: becka huff [REDACTED]
Sent: Tuesday, July 18, 2017 10:08 AM
To: Nicole Jorwic
Subject: LOUISIANA Medicaid

Good morning!

I just want to take a moment to express how important Medicaid funding is to our family. In 2015, my husband and I adopted our daughter through the Louisiana State foster care system. At the time of adoption she was unilaterally implanted with a Cochlear Implant and wore a hearing aid. Thanks to Medicaid she was able to be bilaterally implanted as of July 2016. The growth we have seen in our daughter has been tremendous. She went from only vocalizing 30 words at the age of 3 to an astounding vocabulary now at the age of 6.

Through Medicaid funding she receives all her equipment for her Cochlear Implants as well as services provided through her audiologist. During school she receives speech sessions two times a week from the school speech pathologist as well as speech once a week through a private speech pathologist. Without funding this may not be possible for her to continue to grow and learn. Her world has opened up so much since her Cochlear Implants and we can not wait to see where life will take her.

Thank you for your time!

Rebecca Huff

Nicole Jorwic

From: Elizabeth Brusseau [REDACTED]
Sent: Tuesday, July 18, 2017 12:24 AM
To: Nicole Jorwic
Subject: Louisiana-Save Medicaid Letter

Please find my personal Medicaid story below.
Thank you for your advocacy!

To whom it may concern:

I am 26 years old and on Medicaid. I take two maintenance medications. The ACA allowed me to stay on my parent's insurance until I was 25, and then, because I was in graduate school and only working part time, I went on Medicaid. Without this insurance, I would have lost access to the medications that not only keep me healthy, but also a functional member of society. Medicaid has saved my life. I obtained my Master's degree this past May, all because of Medicaid. You see, I need healthcare. My maintenance meds total over \$400/month out of pocket, which I certainly cannot afford now, and certainly not when my student loans come due. Without Medicaid, I would have had to forgo obtaining an advanced degree in order to work for insurance.

There is a pervasive myth that people on Medicaid are lazy, don't want to work, and just want to live off the government. This could not be further from the truth. I am an active member of my community. I was in school to make a better life for myself. I am currently actively looking for work to continue to be a productive member of society. I went on Medicaid because I could not afford out-of-pocket coverage, and could only work part time while in school. The ACA has allowed me to have the luxury of obtaining a master's degree: without the ability to stay on my parent's insurance until 25 and then get Medicaid, I would not have been able to go to school, I would have had to work somewhere for insurance.

Underfunding, or worse, scrapping Medicaid entirely, would devastate so many real lives. There is not one type of person on Medicaid: we are young and old, able-bodied and disabled, and more. But more than that, we are Americans. Americans deserving the most basic right: to live. Without Medicaid, that right would disappear for many. Please, keep this life-saving program.

Thank you for your time.

Best,
Elizabeth Brusseau
New Orleans, LA [REDACTED]

Nicole Jorwic

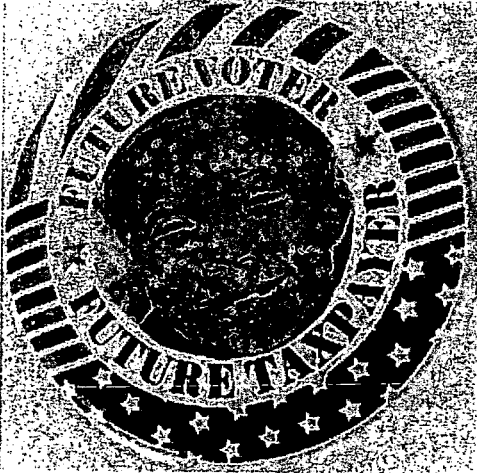
From: Hilary Bordelon [REDACTED]
Sent: Monday, July 17, 2017 10:35 PM
To: Nicole Jorwic
Subject: LOUISIANA

Dear Senator:

My son Morgan receives Medicaid as a secondary insurance through Louisiana's Children's Choice Waiver program. Due to his functional communication delays and the physical abuse he experienced at school, Morgan's behavior was out of control. Thanks to Medicaid, he was able to get ABA therapy (research-based behavioral therapy), which includes parent training and therapy for Morgan. Our private insurance does not cover ABA. His Children's Choice Waiver provides him 20 hours a week of support from a direct service provider. This allows Morgan to participate in home and community routines with support from a trusted adult. Without Medicaid, Morgan would not have access to the help he needs.

Hilary Case Bordelon, M.Ed.
Slidell, LA

[REDACTED]



Nicole Jorwic

From: TILLNICE NEWSOME [REDACTED]
Sent: Monday, July 17, 2017 10:11 PM
To: Nicole Jorwic
Subject: Louisiana

To whom it may concern:

Medicaid is important to a lot of people because with these a lot of people young or old wouldn't be getting the care they need. Without Medicaid a lot of individuals would not be able to go to the doctor when they need care for their lives. ~~Another reason Medicaid is important so it helps a lot of individuals stay in their own homes instead of going into a nursing home which would be more costly.~~

Secondly we are a organization that Medicaid pays to take care of these individuals that are on the home and community base services. These people need the help because a lot of them don't have family to take care of them and receiving these services provide them with help with their ADL's and IDAL's. Taking this away would be distraught to these people.

Louisiana does not have many jobs but providing these services to the home and community based services are also providing jobs to otherwise people who maybe left behind. Our organization cares about the people we served and do the best that they would have productive lives. Please by all means reconsider in cutting Medicaid in Louisiana. We need the help and so do the elderly and the mental challenge. Do not take away their ability to maintain their independences and way of living to take are or be taken care.

It is very important that Medicaid be a ongoing services for all that need it.

Thanking you in advance for taking the time to read my brief note.

Sincerely

Arthur & Tillnice Newson

Nicole Jorwic

From: Tarver, Mary [REDACTED]
Sent: Monday, July 17, 2017 5:02 PM
To: Nicole Jorwic
Subject: LOUISIANA Medicaid



• **My son is 5 years old and has Down syndrome. We are on a waiting list to receive services through our Louisiana system. My husband and I both work and pay taxes. As the healthcare legislation stands shifting costs to states – in Louisiana we already have to fight for the dollars to cover bare minimums.**

- The AHCA would shift costs onto states - states will be forced to either restrict services that help people with disabilities live, work and receive
- Changes to Medicaid should *not* be considered in conjunction with
- Congress should work in a bipartisan fashion to improve comprehensive affordable health care and long term services and supports.
- The lack of transparency in this process is unprecedented and Congress should allow people with disabilities, school personnel, parents, and other stakeholders to review any bills being considered by Congress that affect their lives before the debate and passage.
- The block grant option would still result in states having to make decisions on eligibility, services offered, waitlists, and which elements of the program are community-based versus institutional services, or a reduction in 'outcomes' (all of which are critical to facilitating community inclusion).
- A carve-out would cover less than 30 percent, leaving the majority insufficient amount of money to cover their needs.
- The new temporary proposal – 1915 (l) offers only \$8 billion to replace the permanent –\$19 billion 1915(k) Community First Choice (CFC) program under the Affordable Care Act.

Mary Tarver, Parent
Alexandria, LA

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Nicole Jorwic

From: edie swiney [REDACTED]
Sent: Monday, July 17, 2017 4:13 PM
To: Nicole Jorwic
Subject: LOUISIANA

My Daughter Jayla is on the waiver now program. She is 31 years old she is total care due to her Cerebral palsey she can only control her head and mouth. My husband servered 22 years in the CoastGuard. When Jayla was 2 she was put in school in MI , then in mainstreamed classrooms

when we were transferred to FL. She was using computers before most people had them in their homes.

My husband has worked on Towboats since his retirement to support us get our girls through college the youngest even law school. Jayla lives at home she learned to type with a stick in her mouth and got a college degree. At this point


I will never be able to take care of her on my own again. I have degenerative joint and disc disease. I have had one joint replacement and neck fusion I will need at least 3 other joints replaced most likely in the near future. I have moderate to severe arthritis in practically every joint. I also have herniated disc in my back.

My husband is 59 years old and working on the boats is

taking its toll on him I see it more and more each time he comes in. He is at a point he can't take care of her a lone daily himself.

PLEASE. KEEP MEDICAD COMING FOR US AND FOR OTHERS LIKE US WHO WILL BE IN dire straights.

**Thank You,
Edith Swiney**



Nicole Jorwic

From: Robin Stephanie [REDACTED]
Sent: Sunday, July 16, 2017 7:56 PM
To: Nicole Jorwic
Subject: Keep Medicaid

Please need to keep Medicaid for my youngest son Tyler has cystic fibrosis treatable not curable disease live in Metairie Louisiana thank u

Nicole Jorwic

From: Kathyne Hart [REDACTED]
Sent: Sunday, July 16, 2017 6:51 PM
To: Nicole Jorwic
Subject: Louisiana
Attachments: Carter Hart Medicaid.docx

Please deliver the attached letter to Senator Bill Cassidy. Carter Hart receives Early Intervention Services through The Arc.

--
Sincerely,
Kathyne Hart

Kathryne Hart

[REDACTED]
Baton Rouge, LA [REDACTED]

Senator Bill Cassidy
520 Hart Senate Office Building
Washington, D.C. 20510

Senator Cassidy:

I am writing to ask you to vote NO on the Better Care Reconciliation Act. While my 17 month old son, Carter, is privately insured, our family is on a 13 year and growing waiting list for a Medicaid Waiver in Louisiana. The Medicaid caps proposed in this bill will mean the end to this optional Waiver program in Louisiana as well as Early Intervention services. ~~The option for states to waive yearly and life-time caps or bring back the pre-existing condition clause would make my son~~ uninsurable.

Carter was born full time after an uncomplicated pregnancy and delivery. He was presumed healthy. At 3 months old we began noticing "spasms" and brought him to the pediatrician on a Saturday suspecting seizure activity. After an EEG Carter was diagnosed with Infantile Spasms, a rare and catastrophic form of epilepsy that has caused lifetime disabilities. In the last year Carter has needed almost a dozen medications costing over \$200,000. He has been hospitalized 3 times for paroxysmal sympathetic hyperactivity as well as feeding tube surgery. One year of care is between \$500,000 to \$1,000,000 which would quickly meet the life time cap of most employers and greatly exceeds the \$25,000 per prescription limit, \$100,000 per year total limit, and \$675,000 lifetime limit of Louisiana's high risk pool.

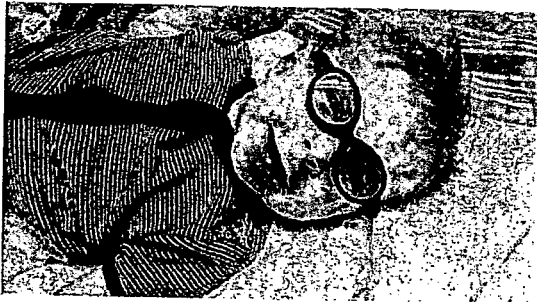
My husband and I both work full time and our income is between 400%-500% of the poverty level. Because of this we do not qualify to buy into Medicaid. Private insurance does not cover private duty nursing or medical daycare. It is for this reason that we are on a 13 year and growing waiting list for a Medicaid Waiver. Carter has dysphagia which resulted in a feeding tube, and he is on continuous feeds due to delayed gastric emptying. His pediatrician told us that we needed a nurse overnight to prevent aspiration, but this is only covered by Medicaid. We go to sleep every night not knowing if Carter will be alive in the morning.

Without a Medicaid Waiver my husband and I rely on grandparents to watch Carter while we work. Daycare cannot take him and medical daycare only accepts Medicaid. If Carter's grandparents become unhealthy one or both of us will be forced to quit working, something we need to do to pay off our graduate student loans in business and law.

Carter is also enrolled in Louisiana's Early Steps program where he receives physical, occupational, feeding, speech, and vision therapy. The proposed caps to Medicaid would decimate this program. While Carter currently receives private physical, occupational, feeding, and speech therapy, the only suppliers of certified teachers for the visually impaired (TVIs) in Louisiana are Early Steps and the public school system. Currently 6 TVIs serve 30 out of Louisiana's 64 parishes. Many visually impaired children are already not receiving services through the Individuals with Disabilities Education Act.

Please stand with Carter and vote NO on the Better Care Reconciliation Act.

Sincerely,
Kathryne Hart



Nicole Jorwic

From: Victoria Bryant [REDACTED]
Sent: Saturday, July 15, 2017 11:19 AM
To: Nicole Jorwic
Subject: Don't slash Medicaid

To Senators,

It is unbelievable that families have to beg you people for adequate and quality care in this USA. Constant Letters, calls, emails begging & pleading & validating one's worth with a group of aliens but no 'we voted for you' --you are human beings not aliens. You have resided among 'the land' all of your life.

You said you would represent us. You said-all citizens are important.

Why would you rid of a need that supports 'millions' of your constituents.

Medicaid to some is like 'blood to the heart' - like oxygen to the brain-food to the body-well, you get it or do you!!!!

You all know the need for Medicaid but your political party & proof needed to show you crushed 'Obamacare means more than the welfare of 'citizens' in this great country --we blame all parties for not coming together to get this .. SURE.....

Make 'America great again' by letting the elderly die slow,(they've lived their lives -right), people with disabilities will simply not have supports needed to have a meaningful life 🙄 😞 but you have something to prove by any means necessary-right! ---no need for Medicaid services for them right.

My Lord, minorities can simply go into exile (who cares????-anybody!!!! The rich get richer.....let's drink champagne & beer for we signed a great -make America great again healthcare bill for it reduced the future budget deficit, reduced services and care for the fragile, the poor, the weak & the non-paying tax excuses ---their not our responsibility!!!

Somebody help,
Victoria

Sent from my iPhone

Nicole Jorwic

From: Teri Hawthorne [REDACTED]
Sent: Friday, July 14, 2017 10:06 PM
To: Nicole Jorwic
Subject: Senator Cassidy Staffer

Hello Nicole!

I am an ED here in Beaumont, TX closely following this bill. This may be a long shot but at this point I'm sure we are willing to see if anything would make a difference! I travel to Washington every year and have made friends with several staff. One of those staff, Mary Moody, is from my hometown and we have become friends over the years, she was over healthcare at Babins office. Well she just moved to healthcare over at Cassidy's office. Would it be of any benefit at all if I messaged her to see if y'all could get a meeting or FaceTime with the senator or even her? I know you all have prob done this a million times over, but I hated not to ask. If you even have any verbiage or personal stories I can send from folks in LA directly to her, I don't mind doing that.

Whatever else you can think we can do we are here! We are having a call party Tuesday with advocates...calling Cruz and Cornyn. Thanks for all you do for the local chapters, we feel the love and dedication here in Texas!

Thank you,

Teri Hawthorne

Executive Director
The Arc of Greater Beaumont

"Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence." Helen Keller

Visit www.arcofbmt.org to learn more information about:

- * Monthly Adult Social Club Events
- * Dances & Fun and Fitness Activities
- * Summer Day Camps
- * Beaumont Buddy Walk
- * Stars of The Arc Celebrity Style Show and Dinner

The Arc of Greater Beaumont
[REDACTED]