
IOWA

Date: 2017-09-22 08:35:12
To: My Senator
From: Kendra Richards
State: Iowa
Email: [REDACTED]



Hi, my name is Kendra Richards. I am an educated registered nurse in the state of Iowa. But I do not come to you as a professional. I come to you as a single mother of a son who has a rare genetic disorder called Phelan-McDermid Syndrome. There is about 1,400 kids worldwide with this condition. It causes things such as developmental delay, delayed or absent speech, feeding difficulties, seizures, kidney and brain abnormalities. The information known is low because we need more research. But again, I am not here to give you statistics. I am here to give you our story.

We are the Richards from Iowa. I have a daughter who is 9 and my son will be 2 in November. I had a normal pregnancy and birth. At the age of 2 months, I knew something was different with Daxton because he was not holding his head up as he should. This led to testing which resulted in the diagnosis of Phelan-McDermid Syndrome. The next few months seem pretty uneventful despite the continued pneumonias. It wasn't until July of 2016 when Daxton was unable to swallow....anything. Fluids, baby food, medications. He was admitted for the first time to the hospital for placement of a g-tube feeding option, his first of three surgeries so far. I was working as a nurse myself taking care of other children when my own child was in quite need but I didn't have the resources. His father left.

Because I didn't have Medicaid or the resources or knowledge, I had to resign my position as an emergency room and pediatric gastroenterology nurse to stay home with him. I fought LONG AND HARD to get Daxton covered by Medicaid. He was finally placed on Medicaid for kids with disabilities SECONDARY to his primary insurance. You see his primary insurance doesn't cover medical foods or equipment, among other things. They cap therapies needed for Daxton to continue to grow. So once we were finally approved for Medicaid, Daxton started physical therapy, occupational therapy, and speech therapy to give him the opportunities and tools to advance and grow.

Next came his second surgery, he was constantly unhappy and in pain and after a month of two trying to figure out the issue, it was discovered that his g-tube feedings were going straight into his lungs and burning, much like a very bad case of reflux. He was then sent to undergo anesthesia and have a Nissan Fundoplication completed. This worked tremendously and my happy, smiling boy was back immediately.

We continued therapies and I researched ways to get Daxton eating orally again. Not only for the health benefits and pure enjoyment but the cost of g-tube supplies alone each month is quite high. I researched a therapy called VitalStim which is intensive and only covered by Medicaid. We went every day but Sunday for an hour to retrain his muscles to swallow by "shocking" them while he was swallowing. He now eats meals with my daughter and I which would not have been the case if it wasn't for Medicaid services.

He sits up on his own and is on the verge of crawling. Medicaid provided equipment for us such as a stander and walker to get him upright and interacting with his environment which has changed our lives. Medicaid provided a special stroller so I can take him to watch his sister play softball or go grocery shopping. He laughs and smiles and responds. In fact, his testing shows he understands everything you are telling him, he just can't respond. So who covers a communication device? Medicaid.

This program is truly saving his life. By providing therapies to keep him moving and working hard to decrease complications such as pneumonia and muscle atrophy. They are providing nutrition in which he would most likely die from if he didn't have.

People in Congress need to see faces, see people. Not numbers and money. You are truly making life and death situations in some cases if this program worsens. We are still on the medicaid waiver wait list which I was told is 3 and 1/2 years long. This will only worsen if block grants are in place. I am his only provider. I don't receive in home nursing for him. I don't receive respite care. I am his sole provider and I am happy to be that. I CAN be that because of with the resources we have been given thus far.

I wish I could send you pictures of our journey, because his smile and strength would change your world forever. Please oppose the Graham-Cassidy bill as this will truly ruin and end the quality of life of a lot of medically fragile children including Daxton Richards.

Thank you for your time,

Kendra Richards

Date: 2017-09-22 11:47:40
To: My Senator
From: Craig Barnum
State: Iowa
Email: [REDACTED]



Koan, my youngest son, has global developmental delays. He is ten years old and doesn't walk, talk, or feed himself. No doctor or specialist has been able to tell us why these delays happened. We named him for the answerless riddles or parables that Zen monks meditate upon to reach enlightenment. We gave him this name before he was born and long before we knew he would face these types of challenges. It is, of course, a very fitting name. While it's been a wild, wonderful adventure raising Koan, I do have some anxiety when I think about what his life will be like if the Cassidy-Graham Act would pass.

The supports Koan and our family have received from Medicaid have made life manageable and ensure that Koan is safe and healthy. In short, these systems have worked really well. But, I'm deeply troubled by the almost certain disruptions to these essential services in both the immediate future and in subsequent years if Cassidy-Graham is passed. Here are just a few of the services we rely upon that come from Medicaid and would be in jeopardy:

Medical care: Koan has a seizure disorder and Medicaid provides access to neurological specialists, treatments, and prescription medication. Also, because Koan is not mobile and non-verbal, he's dually incontinent. We can't run out to the store and buy diapers for a 10-year-old. This product does not exist in the consumer market. We need medical grade briefs to maintain a sanitary environment.

Community-based supports: We rely heavily upon local organizations, like the Arc, to provide respite services and other quality of life experiences for Koan. These experiences add richness and value to his life -- they make it meaningful and a life worth living. It's been my experience that this is every parent's most profound wish for their child -- to live a happy, healthy, independent life. Organizations like the Arc make this possible for people like Koan. The respite services also make it feasible for my spouse and I work outside our home and maintain full-time employment. I understand why someone without a disabled person in their life might view community-based services as "nice to have" but not a "need to have" service. However, after living with a disabled person for ten years, I can emphatically attest that these supports are absolutely essential.

Mobility supports: Koan does not walk now. But, he might someday. We have a Convaid wheelchair we use to move him about. We also have a walker to practice guided walking. He needs AFOs (custom, form-fitting plastic leg braces) to help him support his weight when he stands. The AFOs need to be adjusted every few months and replaced annually because he's a growing boy. All of these were appliances were funded by Medicaid dollars.

Therapy: As I said earlier, we want Koan to be happy, healthy, and as independent as possible. A person with his disabilities will need a lot of intensive, guided instruction and practice to make this happen. So, we have him enrolled in physical therapy (to support mobility), occupational therapy (to assist with feeding and other manual tasks), and speech therapy (to enhance communication). He receives all of these services at school and privately. Cassidy-Graham would slash funding that schools for Medicaid and the severe reduction in overall Medicaid funding would endanger access to these crucial private therapy services as well.

Deep, overall cuts to Medicaid spending, block grants to states that provide less money and inadequate growth of monies over time, and per capita lifetime spending caps will put all of the essential services I listed above in immediate and long-term jeopardy. Plain and simple: this is a bad piece of legislation. To quote Gandhi, "A nation's greatness is measured by how it treats its weakest members." Please do not support this bill.

Nicole Jorwic

From: Amy Belice [REDACTED]
Sent: Monday, July 17, 2017 5:57 PM
To: Nicole Jorwic
Subject: IOWA

I am the parent and legal guardian of a special needs young man. He was born with a rare birth defect, a variant of spina bifida. Instead of a hole in his spine he has a hole in his skull.

He is moderately mentally handicapped, has hydrocephalous, has seizures, a swallowing disorder, is about 50% physically impaired with serious fine motor problems, a sensory integration disorder and can be considered pdd/nos. Caring for him is a huge relentless job.

He was born this way and it's what he knows, he never complains. We rely on Medicaid for his medical expenses and for his services. He is still living at home with supports. It is very difficult to locate a group home that can accommodate a person with such a difficult medical itinerary.

Medicaid gives Jared Day Habilitation services, which give him somewhere to go each day so I can work. He loves it—his Dayhab does volunteer work and community integration. IN order to exist the DayHab program needs the funding. I am concerned that should these funds be cut that businesses that perform such services will no longer be able to make ends meet. We are already seeing that in Iowa with our switch from State medicaid to Managed care.

If I cannot keep him engaged and happy and doing something, if we as a family do not have these services, I will not be able to work.

Iowa is a state with a large population of elderly people. This bill cuts Medicaid for the elderly. This bill would greatly and disproportionately harm the State of Iowa.

I do not support the Senate's bill Better Care Reconciliation Act, as it does not provide for the disabled, like my son, it does not provide for the elderly, and it is bad policy.

Amy Belice

Amy Belice Graphic Design | [REDACTED] | [REDACTED]

Good Design is Good Business!

Nicole Jorwic

From: Laura Yindra [REDACTED]
Sent: Sunday, July 16, 2017 8:03 PM
To: Nicole Jorwic
Subject: Medicaid Iowa

Last summer my son, Miles, finally received a diagnosis from the genetics testing done to identify the cause of his seizures.

Miles has received help from early access, AEA, since he was 12 months old because he was unable to crawl or walk or ~~butt scoot. He started having seizures near his second birthday.~~

In preschool last year, he learned a bunch of new words from the speech therapist. He was able to give up his walker and walk independently thanks to his physical therapist and class room aid. He even learned to write his name thanks to help from his occupational therapist and his teacher. This is what Medicaid means to me. It means that there is help for me and my son to learn and grow past the expectations delivered by his diagnosis.

My son's diagnosis does not expect him to ever hold more than a very simple job because it does not expect him to have an IQ greater than 60.

For now, Medicaid means that I am able to hold a job, and my son is able to grow stronger and smarter.

Thank you,
Laura Yindra
From Marion Iowa

Nicole Jorwic

From: Kay [REDACTED]
Sent: Sunday, July 16, 2017 5:39 PM
To: Nicole Jorwic
Subject: Iowa

Senator Ernst,

I am writing to again urge you to vote NO on the Senate health care bill. The latest version still contains provisions to deconstruct, cap, and cut Medicaid.

I have read your responses to my earlier emails seeking to reassure me that these changes will not impact my adult son who relies on Medicaid services provided through Iowa's home and community-based waiver program. Joel's services enable him to live and work in his community. Joel receives services that support him to be employed at Fitness World in West Des Moines and to be involved in various community activities. If you support the Medicaid provisions in the Senate bill these services that Joel relies on for greater independence and freedom will be in jeopardy.

Implementation of a per capita system will result in a substantial reduction in federal funding to the state Medicaid programs. Although you and others in Congress say states will have greater flexibility to operate their Medicaid program and that people like my son and his services will not be impacted, the fact remains that with less federal funding Iowa, like other states, will be forced to either make up the loss of funds with their own funds or cut their programs by reducing the number of people served and the health benefits they cover.

Additionally, eliminating the FMAP increase eliminates the incentive for states to provide home and community-based services. The reduction in funds will force states to reduce or eliminate optional Medicaid services like the home and community-based waiver program that provide greater independence and integration for people with disabilities to live in their own homes instead of an institution and to be employed in the community.

There are numerous other concerns with the Senate bill, including: 1) allowing for waivers to disregard the prohibition to discriminate against pre-existing conditions; and 2) a new section creating two risk pools – one that will segregate high health care need individuals from those with lower needs—and increase premium costs.

I urge you to VOTE NO on the Senate bill and instead pursue bipartisan solutions and reforms that expand options and opportunities for people with disabilities that protect services for people with disabilities instead of jeopardizing those services.

Sincerely,

Kay Marcel

[REDACTED]
Urbandale, IA [REDACTED]
[REDACTED]

Nicole Jorwic

From: Kay [REDACTED]
Sent: Sunday, July 16, 2017 5:38 PM
To: Nicole Jorwic
Subject: Iowa

Senator Grassley,

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I urge you to VOTE NO on the Senate bill and instead pursue bipartisan solutions and reforms that expand options and opportunities for people with disabilities that protect services for people with disabilities instead of jeopardizing those services.

Sincerely,

Kay Marcel
[REDACTED]

Urbandale, IA [REDACTED]
[REDACTED]