

# Amy C. Sedgwick, MD, FACEP

78 Bayberry Drive  
North Yarmouth, ME 04097  
802-233-5221  
amysedgwick73@gmail.com

March 17, 2017

Mr. Paul Ryan, Speaker of the House of Representatives  
H-232 The Capital  
Washington, DC 20515

Dear Speaker Ryan,

As you work with your colleagues to craft health care policy for our nation, I am writing to you as an emergency physician, mother, and concerned citizen. I urge you to consider the implications of the current proposed decrease in federal Medicaid funding to disabled people.

Disabilities in the human population cover a broad range and in this letter, I will specifically speak to cognitive and behavioral issues as I have had the most experience with this population seeking emergency care and also have a young daughter who has severe intellectual disability (mental retardation) and autism. I have seen and experienced how services and lack thereof impact people both professionally and personally and hope that you will take the time to consider what I have to say.

I have worked as a board certified emergency physician for ten years in many of the emergency departments in the state of Maine. I have worked in major tertiary care centers where I have many colleagues and consultants available to help me care for my patients as well as working single coverage in rural hospitals where I am the only medical provider available for many, many miles. In all of these settings, I have cared for many patients and families in crisis. In many circumstances, families bring a loved-one into the emergency department because they have simply run out of options to cope with the oftentimes destructive behavior that their loved ones are exhibiting. Often these families have little support, the patient has often had minimal education, therapy, or counseling to help them employ strategies to control or augment their behavior, and the result is that the caregivers simply cannot care for them any longer in their condition. Thus, they arrive in the emergency department as there is nowhere else to go for help.

A person with a condition that lends them to have behavioral issues - eg, autism, intellectual disability, speech, hearing or cognitive impairment to name a few - can be immensely helped with therapies such as speech, occupational and physical therapy. In addition, in-home support with a behavioral health provider to help these individuals with activities of daily living can be life-changing. Many of these people take a much longer

time and need much more specific instruction to learn skills such as dressing and bathing and using the bathroom than typically developing peers. Without support, these individuals often become frustrated and belligerent, and can develop medical problems associated with lack of basic self care and coping strategies. With support, however, they can make progress with many tasks, eventually achieving partial or complete independence.

Many families cannot access these services without the support of healthcare insurance and Medicaid. Reducing access to healthcare coverage puts these families at high risk for over utilization of expensive, last-resort care such as emergency departments and also fractures the healthy functioning of the family unit by increasing the stress in the home and making it much more difficult for family members to work and run the household smoothly.

I can speak directly to the personal impact that having a person with special needs in the family brings to my own family dynamic. My younger daughter, Gabrielle Sedgwick ("Elle") is one such person. Soon into her toddlerhood, Elle was diagnosed with global developmental delay when we realized she was not meeting typical milestones. She is now 7 years old and has the diagnoses of severe intellectual disability, cognitive and speech delay and autism. Elle cannot tell us what she wants or needs most of the time and is still incontinent of stool and urine and must wear a diaper. She often becomes frustrated when she cannot communicate or help herself and fortunately, we have strategies in place that can help de-escalate these moments - all thanks to the wonderful therapists and home aides we continue to work with. Elle also needs constant 1:1 supervision at home, at school and at any at all extracurricular activities. If she became lost or separated from me or a caregiver, she would be unable to tell someone what her name is, where she lives, who her parents are and what her phone number is. When it became apparent that she had these issues, we made the choice that I would scale back my career goals and work part time in order to provide care and advocate for Elle.

Since the age of 18 months, Elle has been receiving speech, occupational, and physical therapy as well as behavioral support with a behavioral health provider, Nina, who comes into our home several times per week and helps her with everything from eating with utensils to using the bathroom effectively. Nina also takes Elle out into the community where she can interact with her neighbors and friends as other typically developing children would. Last summer, Nina accompanied her to summer camp for 4 hrs per day so she could participate with typically developing peers. After this experience, we saw huge changes in Elle's abilities to play meaningfully with other kids and also noticed an increase in her vocabulary. Some of these peers recognize Elle at the grocery store and come and say hello. She continues to make gains every day and we are so grateful for the support system we have been able to set up using a combination of our own private health insurance as well as the supplemental insurance through Medicaid that Elle is approved for due to her disabilities.

Ours is an example of a highly functioning family with parents who know not only how to navigate the system but also the details of the medical issues that complicate Elle's wellbeing. In my work as an emergency physician, I see children much like my daughter who come to me in crisis when their families who do not have access to services have reached the breaking point. Many times, these kids remain in my ER for an average of 34 hrs while we try and find 'placement' for them at a psychiatric institution where they might stay for a day or two and then head either back to their families to repeat the cycle or to foster homes - truly infective care. To that note, the basic breakdown of ER costs for one psychiatric/mental health visit are as follows: emergency physician fee: \$350, facility fee: \$2,000, lab fee for medical clearance: \$750, contracted psychiatric fee: \$350, addition fees for acute medications: \$100-\$300. One also must consider security and nurse coverage costs to do 1:1 supervision - sometimes these are add-on and sometime they are bundled into the cost of the stay. So for ONE visit (and usually these are ongoing as once the patient goes home, these instances recur without supports and therapy in place) the cheapest estimate is \$3,550 per visit. In my career, I have seen the same patients for the same problems so many times, we start to refer to each other on a first-name basis!

Another important thing to consider as well is that many of these patients who are in behavioral crisis are using beds that we could otherwise be using for critically ill patients. More than once, I have had people in the waiting room with chest pain and I am scrambling to find a way to see them and start working them up with no bed to do so! My point is, most of these crises could be averted with lower-cost care in the home with workers who are objective caregivers and with access to ongoing therapies that develop skills and confidence in the person with the disability. Isn't our hope as a country to make everyone as productive and participatory as possible to Make America Great?

Through access to on going physical, speech and occupational therapy as well as in-home behavioral health support, Elle has much exposure to tools to increase her skill set which facilitates her integration into our community. Other adults and children at school and on the playing field and in the library see her as part of the community. This is the kind of integration that makes productive and successful adulthood possible for kids like my daughter. My husband and I of course do a lot of this work with Elle on our own but we simply cannot do this level of 1:1 care at all times. We are both practicing physicians and are very active in our communities. We also have an older typically developing 9 year old daughter who needs parents who can attend her events without being completely distracted by caring for her sister who otherwise would be disruptive. I am not looking for sympathy points but rather, am trying to paint a picture of how crucial support like behavioral health support and therapy is for families like us.

Maine is a rural and relatively poor state with neither a broad nor deep tax base. Any legislation that decreases funding or shifts costs to states to cover therapeutic and in-home care will only increase the costs to taxpayers in the end as these people are brought to the care of last-resort: the emergency department. As you know, EMTALA laws require us to

evaluate and treat anyone who comes through our doors. Any uninsured patients will be treated of course, but the hospital will incur these losses and will then spread the cost over other covered services. In the end, while it may look good on paper, your constituents will still end up absorbing these costs overall. There are no cost-savings with this approach of less access to healthcare, only cost increases and worse outcomes, lost productivity at work for parents and caregivers and less harmony and health at home and in our communities.

If you really look at what makes a healthy community with lower rates of mental health problems, drug use, obesity and other chronic illnesses, it starts with preventative medicine. Prevention is not sexy or glamorous but is at the heart of what will solve our health care crisis. Prevention for people with behavioral disabilities includes reliable access to ongoing therapy, support in and outside the home, and access to basic healthcare. If we take away benefits to this vulnerable population, the long term costs to society will be large and the consequences grave.

Thank you for your thoughtful consideration. I hope you will work with your colleagues to do the right thing and vote in support of keeping federally funded Medicaid and affordable healthcare accessible for this vulnerable population.

Sincerely yours,

Amy Chekos Sedgwick, MD, FACEP

[amysedgwick73@gmail.com](mailto:amysedgwick73@gmail.com)

(802)-233-5221