



WE NEED YOU IN THE GAME... EVERYONE IN THE DOWN SYNDROME COMMUNITY NEEDS TO SPEAK OUT...

The federal legislation to repeal ACA and make changes to health care benefits is now in the hands of the US Senate. A committee of 13 Republican Senators has taken on the task to draft the Senate's version of the legislation, that if passed will be reconciled with the House bill that was passed. Pennsylvania's US Senator Pat Toomey is one of the members of this committee and needs to hear from his constituents (the people he is in Washington to represent) their concerns about the proposed changes on individuals with disabilities.

LET'S GET AT LEAST **321** INDIVIDUALS FROM THE PENNSYLVANIA DOWN SYNDROME COMMUNITY TO CONTACT SENATOR TOOMEY REGARDING REPEAL OF ACA AND CHANGES TO HEALTHCARE COVERAGE...

Post on Facebook that you sent your message and include @PDSACemail in your post.

To Contact Pennsylvania US Senators:

[Toomey, Patrick J.](#) - (R - PA)

248 Russell Senate Office Building Washington DC 20510
(202) 224-4254

Contact: www.toomey.senate.gov/?p=contact

[Casey, Robert P., Jr.](#) - (D - PA)

393 Russell Senate Office Building Washington DC 20510
(202) 224-6324

Contact: www.casey.senate.gov/contact/

Consider the overall needs of individuals when making policy decision

Points to reiterate (It is important for you to tell your own story.):

Maintain existing ACA policies on the following:

- *Maintain dependent coverage (coverage for dependents until 26 yo)*
- *Guarantee availability and renewal (prohibit exclusion for pre-existing conditions)*
- *Ensure affordable access to habilitative and preventative services*
- *Maintain the Community First Choice State Plan Option (expands Medicaid opportunities for the provision of home and community-based long-term services and supports and facilitates community integration)*
- *Prohibit annual and lifetime caps in private insurance policies*

Additional Reforms Needed:

- *Enact the Advancing Care for Exceptional (ACE) Kids Act (creates a mechanism for states to participate in a national framework for children with medical complexities to receive cost-effective and coordinated healthcare and support, and have access to out-of-state specialists)*
- *Incentivize productivity and work (remove Medicaid penalties for individuals to obtain integrated employment and not be in subminimum wages and segregated environments)*
- *Address lifespan needs (wellness and prevention services, health and health disparities research, patient-centered models and increased professional training for health professionals)*

Block granting Medicaid Funding and Per Capita Payment Caps Could Negatively Impact Individuals with Down Syndrome.

- *Medicaid allows people with Down syndrome to live and work in their communities, develop assets that reduce dependence on public benefits, and avoid costly and segregated nursing homes or institutions.*
- *Medicaid provides therapy services and support that allows individuals with Down syndrome to progress within the education system*
- ***Medicaid's reach is beyond the scope of healthcare.***
- ***Avoid setting arbitrary limits or caps (block grants or per capita payments) that do not adequately address the overall needs of individuals with Down syndrome. Fully address the healthcare needs, access to care and vast scope of services that programs like Medicaid offer to all individuals with Down syndrome. Tight state budgets could reduce levels of services available to individuals with Down syndrome.***

Also, consider contacting your Pennsylvania State Legislator to ask them to communicate concerns with our US Senators.

Contact your Pennsylvania State Legislator:

Yes, we recognize the ACA repeal is a federal level decision, but it will have major impact at the state level and will land at the feet of state government officials. Our Congress members need to hear the concerns from our state legislators on behalf of their constituents.

To find out who your state legislators are:

<http://www.legis.state.pa.us/cfdocs/legis/home/findyourlegislator/>

What to ask of your state legislator?

- Why am I contacting you? –
 - I recognize the repeal of ACA is a federal issue, but if passed, will impact health care decisions, coverage and delivery at the state level.
 - Pennsylvania's state budget is already challenged and any reductions in financial resources from the federal government will force the state to consider significant

reduction and potential elimination of health and development services to PA citizens – especially at risk and disabled individuals. Block grants, per capita payments, no or higher premium caps, changes to essential benefits, etc. impact state budget share and individual out of pocket costs.

- As the parent/caregiver/family member of an individual with Down syndrome I am concerned what this will mean to my child/family member/friend, who depends upon the services supported through Medicaid and other state programs. **Tell your story!**
- This issue is not about politics but about individuals – there are faces of thousands of individuals in PA that will be impacted and our US Senators (and US Representatives) need to hear from you how the changes that might come out of Washington would impact decisions that will need to be made at the state level and ultimately impact the lives of individual Pennsylvania citizens.
- Ask of state legislators
 - Contact Senator Toomey and Senator Casey (and your Congressional District Representative) to inform them of the potential impact of the proposed legislation on your constituents.
 - Express concern for individuals with special needs and the need to maintain current service levels and benefits that make a difference to the health and well-being of thousands in Pennsylvania – your constituents!