



AADMD
ADVOCACY
TOOLKIT



WELCOME

Inside this Toolkit, you will find resources to help you learn about the HEADs UP Act of 2018 (Bill 2417) and educate your Congress members both locally and nationally about why it is important.

We have included information about the Bill (pg 2); how to find your congress members (pg 1); suggestions for talking points for phone, mail, or in person conversations (pg 3-4); with links to further information about the Bill and legislative visits, throughout.

Enjoy!

#HEADsUPCongress

CONTACT YOUR REPRESENTATIVE

<https://www.house.gov/representatives/find-your-representative>

To see an updated list of sponsors, go to GovTrack.us and search for HR 2417



FOCUS ON THE DECIDING COMMITTEE

See if your representative is in the HOUSE COMMITTEE ON ENERGY AND COMMERCE

<https://energycommerce.house.gov/about/>



READ THE ASSOCIATED LAWS

If approved, would be incorporated into the Public Health Service Act, 254ba3 and 330: Medically underserved populations

[http://uscode.house.gov/view.xhtml?req=\(title:42%20section:254b%20edition:prelim\)](http://uscode.house.gov/view.xhtml?req=(title:42%20section:254b%20edition:prelim))



HEADs UP

H. R. Bill 2417

Bill 2417 is a bipartisan Bill re-introduced to the House in 2019 by **Rep. Seth Moulton, D-MA** and now cosponsored by a bipartisan group of Congressional Representatives..

The Bill requests an amendment to the 1944 Public Health Service Act (Title 42, Chapter 6A, Subchapter II, Part D, Subpart I, Section 330(a)(1)) which describes Medically Underserved Populations (MUPs) and how funds can be used to improve access to health services for these populations. MUPs are generally designated by geographic proximity; however, there are exceptions to this designation called “special medically underserved populations” which currently include migratory farm workers, homeless individuals, and residents of public housing. This Bill would add “individuals with a developmental disability” to the list of special MUPs and add specific language to include this group in funding and service provision language in the Act. Overall, this Bill, when approved, would enable increased funding for training, research, health professionals, and health centers specifically targeted towards improving the health of people with Intellectual and Developmental Disabilities.



Read the bill itself and track its progress at:

<https://www.govtrack.us/congress/bills/116/hr2417>

“80% of congressional offices say less than 30 posts will demand attention.”

- AAFP Congress 101 Webinar, Dr. Conrad Flick

Find More Online:

AAFP Resources: “Meet with your Legislator” –

<https://www.aafp.org/advocacy/involved/toolkit.html>

- Last 20min of Congress 101
- Lobbying101 (5min)

AAFP Resources –

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/CPTI/Pages/Advocacy-Training-Modules.aspx>

- Training Module 3: Working with decision makers
- AAP Advocacy Guide (PDF)

Phone Calls, Letter Writing, Social Media

KEY: How does the problem affect you/your patients, and how will this Bill affect direct change

YOUR MESSAGE:

The first thing to do is to make your message, and remember to personalize! Whether you are speaking or writing the message, you want to talk about how this issue affects you personally as a physician, student, parent, and community member. When you are drafting your message, remember that those few extra minutes of adding a personal story have been shown to have a greater impact on legislators.

Remember also that you want the story to support your message, and that you want the message to be clear, concise, memorable, relatable, and repeatable. Whoever you are connecting with, you want them to remember your message and story, know how this Bill will affect the issues you are facing, and be able to share this information easily with others.

Think about when you are online, the most memorable messages are simple, relatable, and easy to share. In every message, don't forget to ask specifically for support!

NOTES ON LETTERS/CALLS:

- Make sure to say that you are a constituent of their area!
- Put it on your own stationary
- Keep it to 1-1.5pg at most (1. why this is important, 2. connect the bill to what you see in your area, 3. thank you)
- If emailing, your subject line should say: “constituent and physician” (if applicable) – physicians have lots of sway (and lots of patients/constituents to influence)
- Give your contact information, ask for a reply
- Be prepared to leave a short message

USING SOCIAL MEDIA

- Use pictures, videos, links
- Like and comment on your Rep's page when you agree
- Disagree in private (be polite and non-threatening)
- Re-tweet your Rep's post
- Add your district hashtag to your posts (IDs you as a constituent)
- Use your Rep's handle (add a “.” before the @)

The Legislative Visit

Once you have made your message (see above), there are a few things to consider specifically for the legislative visit. First, always remember common courtesies like silencing your cell phone and wearing professional clothes. Do consider picking something that is neither too bright nor too dull, and no patterns or flashy jewelry. While it is ideal to talk with the legislator themselves and in their office, it is important to be flexible as you may need to meet in a hallway between congress sessions or in a side office. This is why it is important to practice your pitch, as you may only have a few minutes. Know your bullet points, then go to the meat if you have time.

Flexibility also means you may end up meeting with staff. The staff members are often the individuals doing background work and research on legislation, so be courteous and willing to speak with them about your issue. They are often people who work for a legislator because of common goals, and have sway over the legislator's decision making. If possible, try to do research on your legislator to understand past work and interests. If they are connected to the Bill, than them for their attention to the issue.

At the end of the meeting, get the business cards for the people in attendance, and send a thank you note as soon as possible. See above for comments on notes, but make sure to reiterate your key points, provide any materials you promised, and thank them for their time.

More Talking Points:

- Supported by AMA, ADA, APHA, AAP
- 7-8million Americans suffer some degree of intellectual disability (based on 2004 numbers)
- **On average – people with I/DD need to contact 50 doctors before finding one with training in caring for patients with I/DD**
- **81% of medical students receive no training on how to care for people with I/DD**
- 66% of medical students receive inadequate training in care of people with I/DD
- Medical school deans report that medical school graduates are not competent in the care for people with I/DD
- **28% of people with severe disabilities live in poverty**
- **People with I/DD were significantly more likely to have fair or poor health status**
- People with I/DD are less likely to have early diagnosis of cancer or proper management of chronic disease
- People with I/DD are living longer and people in the fields of adult medicine and geriatrics lack the training to care for this population
- **This designation would give medical schools, residencies, clinics, National Health Service Corps, NIH funding to improve research in caring for this population, create innovative outreach and primary care approaches, and train providers to care for this population better**
- We need research on health disparities, quality of life and we need the impetus to truly evaluate the health of people with I/DD (this is not currently being consistently done)
- We need HRSA support for residencies, loan forgiveness, and training programs for PCPs including NPs and PAs and financial incentives for curriculum development if there is truly going to be a workforce of properly trained providers; This includes continuing medical education
- National recognition would give organizations the opportunity to agree on common terminology, methods of surveillance, and best data collection models to improve research
- With research, we could develop best practice guidelines for a variety of issues including prevention and promotion and treatment of the health care needs
- **It would also push towards reimbursement that reflects the time and skills needed to meet the health needs of the population**
- Of 48 Fellowship programs in the country, only 35 were filled last year

