

USING A LEGISLATIVE TOOLKIT TO ACTIVATE A STUDENT NETWORK

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AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY (AADMD)

- National interdisciplinary professional organization (Physicians, Dentists, Nurses, Optometrists, Others)
- Goal: Reduce health disparities and inequities for people with IDD by
 - Fostering improved care
 - Advocacy
 - Education
- Active student chapter groups in over 40 schools nationwide
- ~300 student members
- National Training
 - Monthly Virtual Grand Rounds
 - Annual Meeting
- Local Activities
 - Educational meetings
 - Special Olympics Healthy Athletes
 - Spread the Word/Move to Include

GOAL: TRAIN ENGAGED STUDENTS IN ADVOCACY SKILLS

- Relatively few doctors participate in advocacy
 - Busy, so needs to be quick and easy
 - Careful about controversy
 - Only respond to things they care about
 - Their patients (early in career 😊)
 - Their pocketbooks (later in career 😞)

HEADS UP!! A BILL TO RALLY 'ROUND

HEALTHCARE EXTENSION AND ACCESSIBILITY FOR DEVELOPMENTALLY DISABLED AND UNDERSERVED POPULATION

- Medically Underserved Population Bill
- HR 2417
- House Sponsor: [Seth Moulton \(MA\)](#)
- Co-Sponsors
 - [Brian Fitzpatrick \(PA\)](#)
 - [Sean Maloney \(NY\)](#)
 - [Jose Serrano \(NY\)](#)
 - [Joe Morelle \(NY\)](#)
 - [Sheila Jackson Lee \(TX\)](#)
 - [Josh Harder \(CA\)](#)
 - [Peter Visclosky \(IN\)](#)
 - [Paul Tonko \(NY\)](#)
 - [Jamie Raskin \(MD\)](#)
 - [John Katko \(NY\)](#)
- To amend the Public Health Service Act to expand and improve health care service by health center and the National Health Service Corps for individuals with a developmental disability, and for other purposes.
- Adds people with IDD to federal list of populations that are designated Medically Underserved everywhere, without geographic delimiter (along with Homeless, Migrant Workers, and People Living in Public Housing)

WHAT THE BILL DOES

- Provides FQHC status to clinics serving people with IDD
- Encourages all FQHCs to better serve people with IDD
- Offers loan forgiveness for practitioners focusing on IDD health care
- Offers visa advantages to providers focusing on IDD health care
- Encourages research related to IDD health care at NIH level

ENGAGING STUDENT ADVOCATES

- AADMD Virtual Grand Rounds
- Legislative Toolkit development and dissemination
- Encourage/facilitate student outreach to legislators at local office level
- Bring data and stories

HEADs UP

H. R. Bill 6611

Bill 6611 is a bipartisan Bill introduced to the House on July 26, 2018 by Rep. Seth Moulton, D-MA with cosponsors Rep. Gregg Harper, R-MS; Rep. Sean Maloney, D-NY; Rep. Brian Fitzpatrick, R-PA; Rep. Andre Carson, D-IN; and Rep. Jose Serrano, D-NY.

The Bill requests an amendment to the 1944 Public Health Service Act (Title 42, Chapter 6A, Subchapter II, Part D, Subpart 1, 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:

- <https://www.congress.gov/bills/115/house/6611>

Follow the Bill's Progress: (currently requires approval by the House Committee on Energy and Commerce; see prior page for list of members)

- AAFP Bill Tracker
<https://www.aafp.org/advocacy/tracker/bill-tracker.html>

Read more about the reasons to support the Bill:

- https://www.fhscadvocacy.org/wp-content/uploads/2014/04/MUP_ASAN_PolicyBrief_20140522.pdf

"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/roolbill.html>

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

AAFP Resources -

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

- Training Module 3: Working with decision makers
- AAFP 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, reliable, 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, thank 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, AHA, AAP
- 7-8 million Americans suffer some degree of intellectual disability (based on 2004 numbers)
- On average - people with IDD need to contact 50 doctors before finding one with training in caring for patients with IDD
- 81% of medical students receive no training on how to care for people with IDD
- 66% of medical students receive inadequate training in care of people with IDD
- Medical school deans report that medical school graduates are not competent in the care for people with IDD
- 28% of people with severe disabilities live in poverty
- People with IDD were significantly more likely to have fair or poor health status
- People with IDD are less likely to have early diagnosis of cancer or proper management of chronic disease
- People with IDD are living longer and people in the fields of adult medicine and genetics 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 IDD (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 our future 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 36 were filled last year



As a _____ I strongly support House Bill 6611 because:

As your constituent, I have seen first hand the impact of diminished healthcare resources for individuals with Intellectual/Developmental Disabilities and their families. **[add a sentence or two about your practice or your personal experiences]**

Adding people with Intellectual/Developmental Disabilities as a Medically Underserved Population under the Public Health Services Act will enable dedicated education and funding to significantly improve the health disparities, health status, and barriers to health care experienced by these individuals and their families. It is long since time to address their needs and develop innovative practices to care for this diverse and underserved population. I hope you will remember my experiences and **Vote Yes on Bill 6611.**

Sincerely,

Healthcare professionals for: Healthcare Extension and Accessibility for Developmentally disabled and Underserved Population Act of 2018



H. R. Bill 6611: HEADs UP Act
House Committee on Energy and Commerce

OUTCOMES SO FAR

- Toolkit disseminated via AADMD website:
<http://aadmd.org/heads-up-act>
- Bill re-introduced 4/30/19, 5 co-sponsors signed on, from 5 states since June
- Used in LEND advocacy sessions
- New crop of student chapter members each year, visiting local offices, plus Disability Policy Seminar, plus this week...