

# HCBS Access Act

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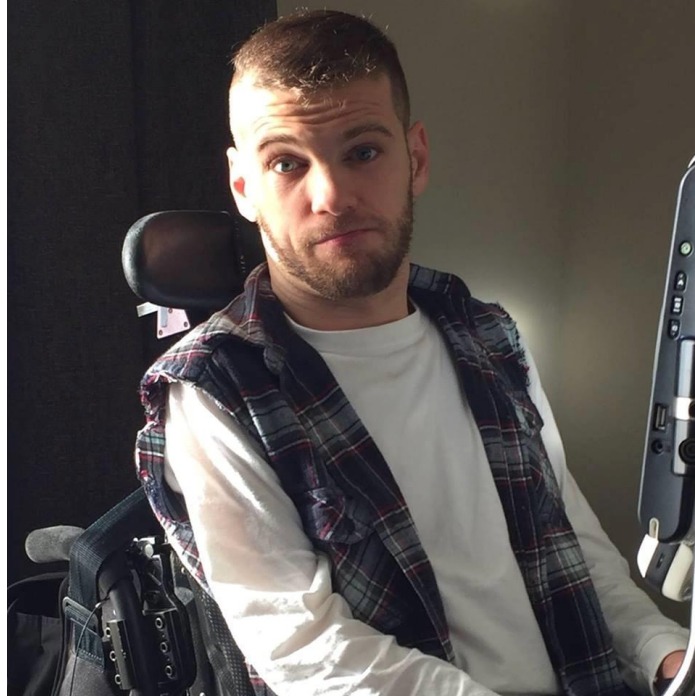
WHY THIS IS HUGE, THE HISTORY, AND THE FUTURE  
AND HOW IT CONNECTS TO CURRENT PROPOSALS

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My Why....

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# Historical Perspective

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- For much of history, people with disabilities have not been seen as deserving or equal
- There were many misconceptions about the capacity of people with disabilities and they did not have the same rights as everyone else
- Beginning in the 1800s, people with disabilities began to receive help, but these misconceptions continued—forcing people with disabilities to be dependent on others and not supporting them to lead independent lives
- Society didn't view people with disabilities as deserving direct participation in society or the political process
- Even those with the best intentions did not treat people with disabilities well
- Care / services and supports were provided by families, then by large institutions
- For aging adults there has also been a historic over reliance on large congregate settings and unpaid family care givers

# A New Vision

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- Lead by families and self-advocates, a new vision for people with disabilities began to emerge
- This vision was for people with disabilities to determine their own lives and focused on self advocacy, independent living, equal rights and access to full citizenship
- Aging adults want to age in place
- We still have a long way to go

# **The Groundwork**

# 2017 Fight to Protect Medicaid and the ACA

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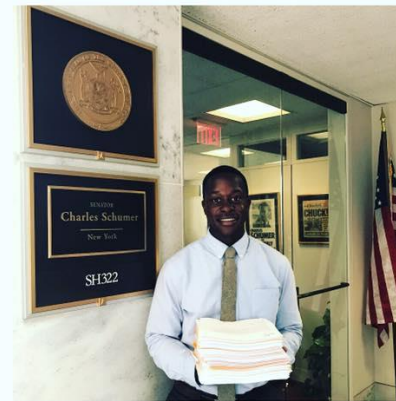
In 2017, The Arc opposed structural changes that would eliminate the Medicaid program we have today and the repeal of the Affordable Care Act

- As we had before when Social Security and Medicaid were threatened, we showed the power of The Arc network and defeated these efforts
- Members of Congress saw the power of the disability community and public awareness of the importance of Medicaid is at an all-time high
- This is not the last threat to Medicaid, we must continue to be vigilant. Unfortunately, the fight is never over.
- But The Arc will always be at the table!

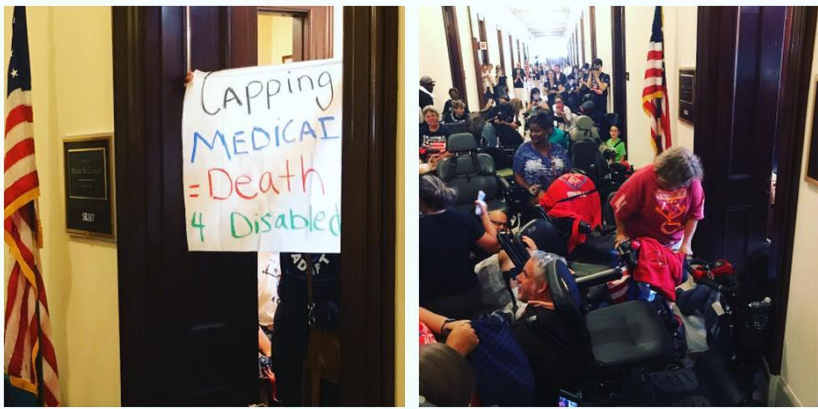
# Medicaid (and HCBS!) Matters

What we did in 2017:

- Led Coalition Efforts
- Led Grassroots Advocacy
- Raised the profile of Medicaid
- Specifically the importance of HCBS
- Educated our Constituency (our network, Members of Congress, and the public)
- National Media Attention and Education







The Arc was there.



# Universal Healthcare

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Using momentum from 2017 fight to protect Medicaid, our advocacy took on a new focus:

- We had to be in the room where it happens (health care reform remix)
- Medicare for All (Senate and House) and Medicare for America ALL NOW INCLUDE LTSS



# **What Exactly is Medicaid?**

# Medicaid 101- It's Complicated

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# Why Medicaid Matters Nationally

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- One in five people rely on Medicaid for health care (74.6 million people in June 2020!)
- Over **11 million people with disabilities** rely on it for health care services and to live independently.
- It is MUCH more than a health care program, Medicaid is the main funder for LONG-TERM SERVICES AND SUPPORTS (LTSS) including HOME AND COMMUNITY BASED SERVICES (HCBS).
- People with disabilities and senior citizens account for about 48% of the total Medicaid budget and about 21% of the beneficiaries because of their use of those LTSS.

# WHAT ARE HCBS?

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## IN THE HOME

- Help cooking
- Help with medications
- Assistance with self care
- Budgeting
- Socializing

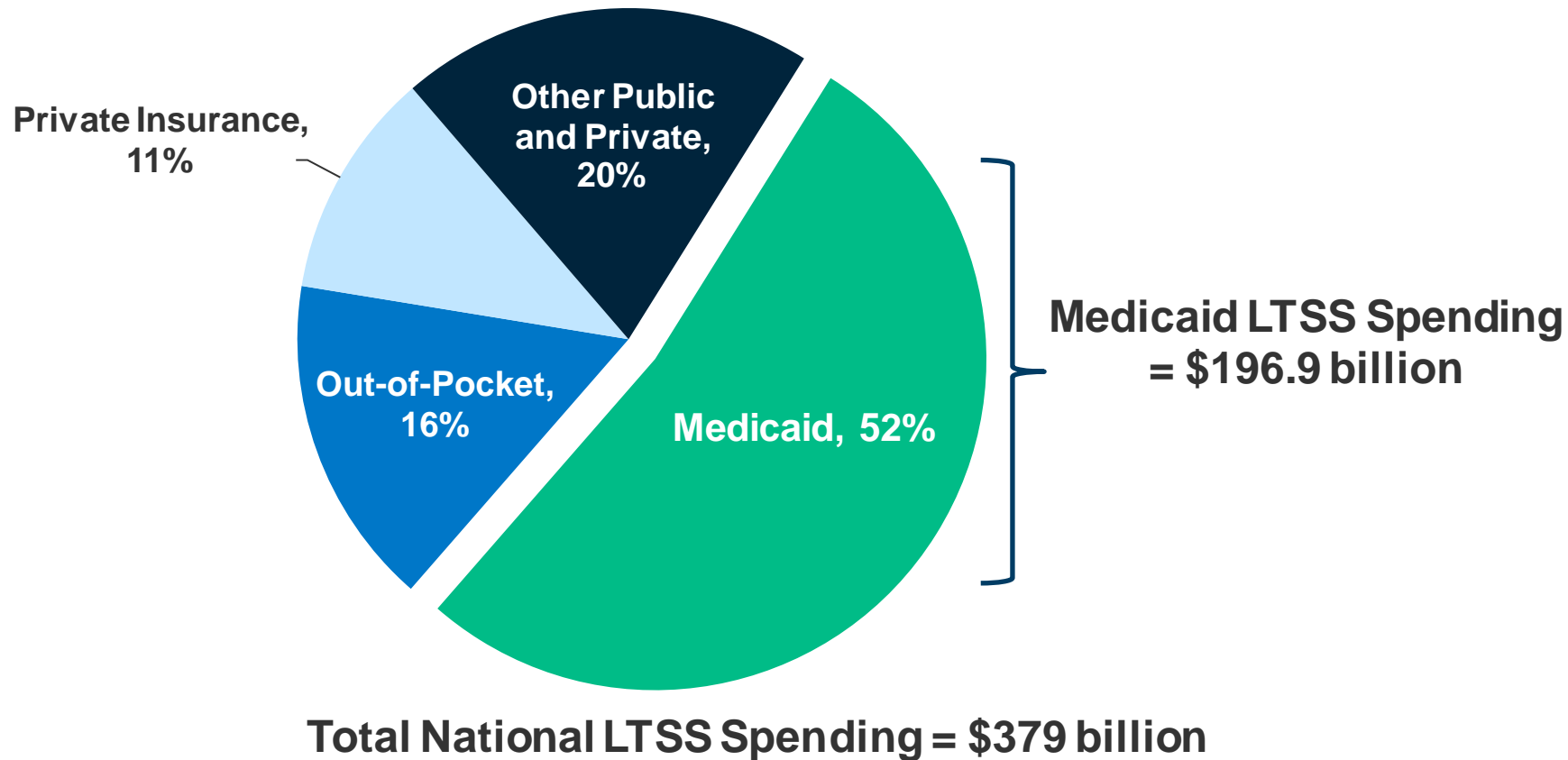
## ON THE JOB AND IN THE COMMUNITY

- Job coaching
- Community volunteering
- Day programs



Figure 14

# Medicaid continues to finance the majority of long-term services and supports (LTSS), 2018.



NOTE: Total LTSS expenditures include spending on residential care facilities, nursing homes, home health services, and home and community-based waiver services. Expenditures also include spending on ambulance providers and some post-acute care. This chart does not include Medicare spending on post-acute care (\$83.3 billion in 2018). All home and community-based waiver services are attributed to Medicaid.

SOURCE: KFF estimates based on 2018 National Health Expenditure Accounts data from CMS, Office of the Actuary.

# Medicaid's Current Structure

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Federal Government and states share actual costs of coverage

Agree in each state on who is eligible and what services and supports are provided

Feds pay on average 63%

Different matching rates by state (50-75%)

# State and Federal Partnership

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Because Medicaid is a Federal-State Partnership, the Federal Government makes a basic set of rules and states can decide what else they want to cover as part of Medicaid. This creates some Mandatory services (required by the Feds) and some Optional services (the state has chosen to cover these):

## Mandatory Services

- Most “traditional” health care services
- Prescription drugs
- Nursing Home Services and other Institutional Services\*
- Match guaranteed to states (thanks to advocacy in 2017)

## Optional Services

- **HOME AND COMMUNITY BASED SERVICES**

# **Medicaid Challenges**

# Current Medicaid Challenges

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- Waiting Lists: due to lack of investment in HCBS
- Workforce Crises: staffing shortages and low wages for Direct Support Professionals (DSPs) who are the workers providing HCBS
- COVID-19: The pandemic resulted in a recession which means that state budgets are stressed and there will likely be cuts to Medicaid

**HCBS are in danger because they are OPTIONAL services**

**and can be cut!**



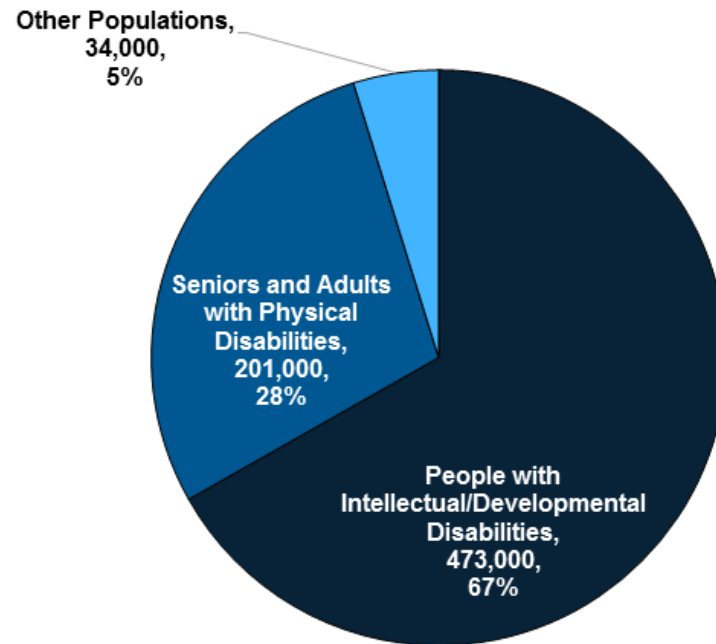
# By the numbers....

BUT THIS CAPTURES ONLY 25% OF THE NEED

(BECAUSE NOT EVERYONE KNOWS THERE ARE WAITING LISTS TO BE ON)

Figure 2

Medicaid HCBS waiver waiting list enrollment, by target population, 2017.



**Total waiting list enrollees = 707,000**

NOTES: Numbers may not sum to totals due to rounding. Data include Section 1915 (c) and Section 1115 HCBS waiver waiting lists except that CA and NY did not report Section 1115 waiting list enrollment, and AL reports its Section 1915(c) IDD waiting list as "unknown." Other Populations include children who are medically fragile or technology dependent, people with HIV/AIDS, people with mental health needs, and people with traumatic brain or spinal cord injuries. SOURCE: Kaiser Family Foundation Medicaid FY 2017 HCBS program survey conducted in 2018.

# Current Medicaid Challenges

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## CORONAVIRUS

### **Illinois National Guard to deploy at developmental disabilities center rocked by COVID-19**

The center is in the middle of a battle. 83 residents and 28 employees have tested positive for the virus.

Two residents and one employee have died.

“But it’s not just at the Ludeman Center,” Mayor Vanderbilt said.

“There are outbreaks at all of the state-owned facilities in Illinois.”

### **People With Developmental Disabilities More Likely To Die From COVID-19**

by Shaun Heasley | June 8, 2020

It’s not entirely clear from the data why individuals with developmental disabilities experience a higher risk of death from the virus, though the findings indicate that this group did have more co-occurring conditions including hypertension, heart disease, respiratory disease and diabetes. The researchers also noted that people with developmental disabilities are more likely to live in congregate settings where it’s harder to limit the spread of COVID-19.

# Where We Are

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The American Rescue Plan (passed March 11, 2021)

- 10% FMAP Bump for Medicaid HCBS
- \$12.7 billion to strengthen and expand access to Medicaid HCBS

# Where We Are

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March 31, 2021: President Biden announces the American Jobs Plan

- \$400 billion investment in HCBS
- Meant to Address Access to HCBS- waiting lists
- Address direct care worker wages
- Create more direct care jobs jobs

# Medicaid and HCBS

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- Momentum and Focus on HCBS
- Part of the American Jobs Plan
- Public Interest and Focus
- Polling

WHY THIS MATTERS?

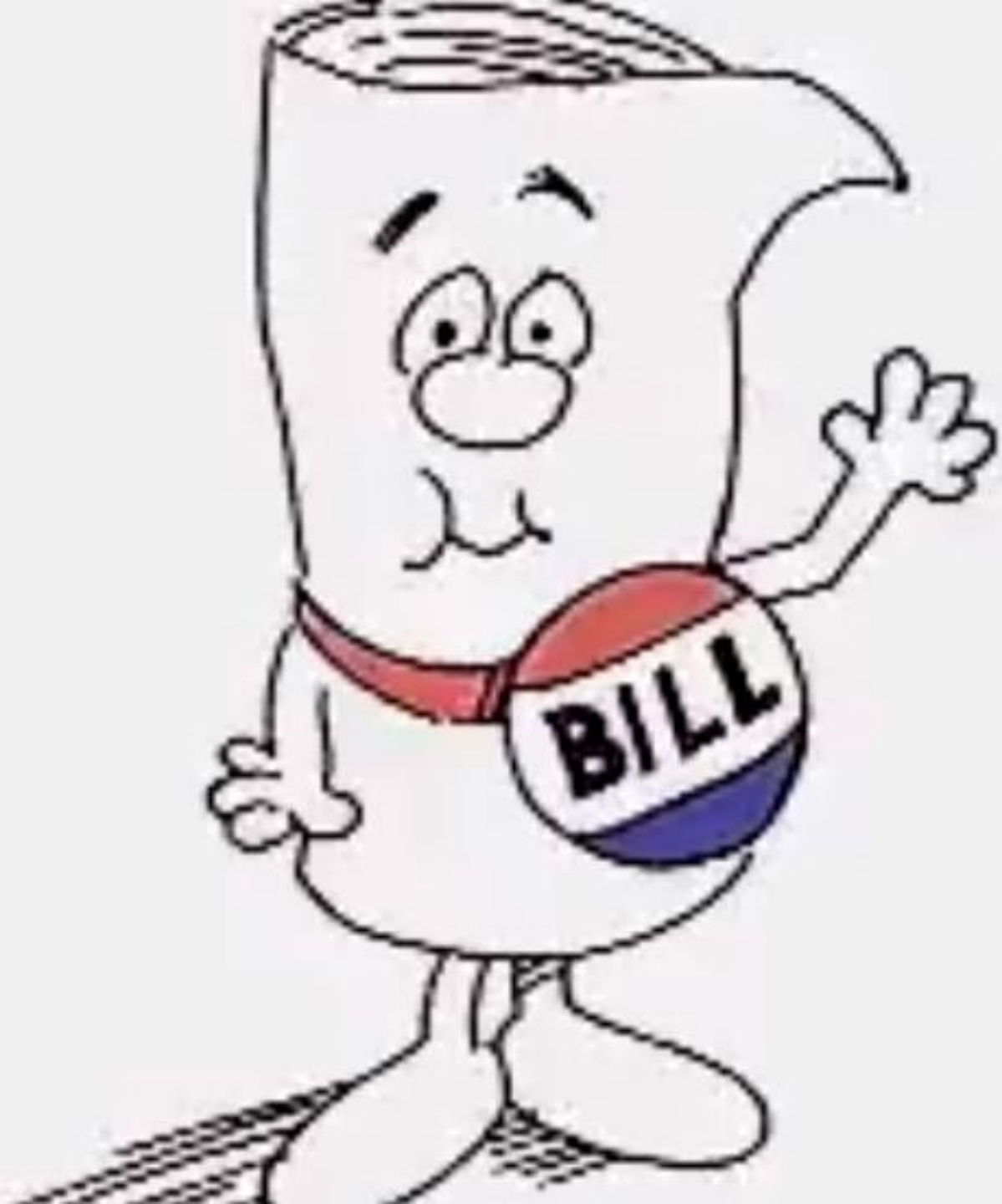


**TIME TO  
ADVOCATE!**

# HCBS Access Act is HERE

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The HCBS Access Act (HAA) would address the long-standing issue of limited access to HCBS, staffing shortages, low wages for DSPs, waiting lists, and the issues that have been highlighted in COVID.



# HAA is the next step in the history of LTSS

The HCBS Access Act (HAA) would:

- Make HCBS services MANDATORY Medicaid services
- Provide funding to build capacity and ELIMINATE waiting lists
- Increase funding for DSP wages
- Make Medicaid portable across state lines

It would also fulfill one of the ORIGINAL PURPOSES of our organization and ensure that people with disabilities can have lives in the community!

# What We Need.....

We have been at the forefront of this from a policy perspective, we need to keep that momentum going:

- We want to be sure the history of this issue is understood.
- Great time to get attention the needs of people with disabilities, aging adults and their caregivers.
- Resources for grassroots to ensure that they have what they need to get “credit” on the issue and to tie Federal and State issues together.
- STORIES