

Welcome!

Disability Squeeze Symposium



September 26, 2025

Organized by the Stony Brook School of Social Welfare
Hosted by New York Law School

Opening Remarks



Cara Yar Khan

International Disability Rights
Advocate & Event Moderator

We want to hear from you today

We'll ask you 4 quick multiple-choice questions to bring your voices into the room using Mentimeter.



Or go to: www.menti.com

Enter the code: 3477 9828

Mentimeter Question #1 now posted:
**Which phrase best describes the
'Disability Squeeze' to you?"**

Your responses will appear live.

And we want to hear your stories



Share your experiences of the disability squeeze at DisabilitySqueeze.org

Stories help us connect data to lived reality.

[Click here to share your story](#)



Welcome Remarks



Anthony W. Crowell, JD

Dean and President

New York Law School

Putting the Disability Squeeze on the American Economic Agenda



Zach Morris, PhD

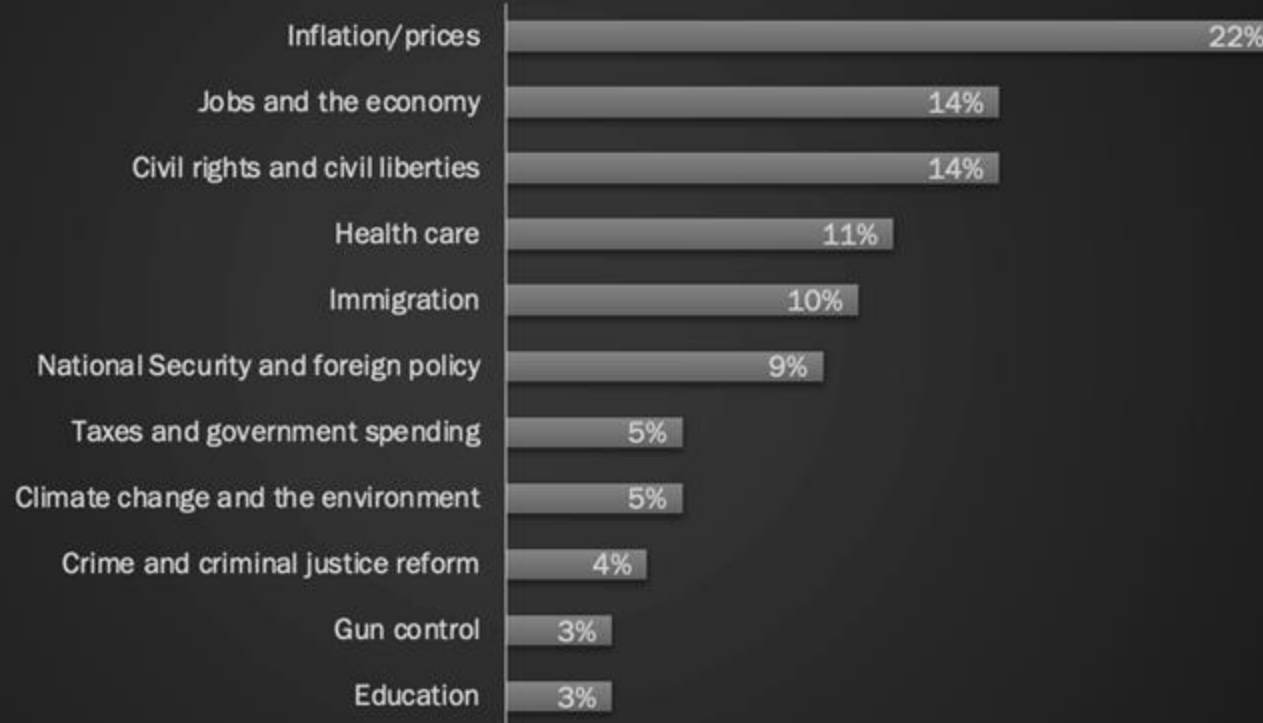
Associate Professor

Stony Brook School of Social Welfare

**It shouldn't cost more
to live with a
disability
but it does.**

Cost of living is the most important issue in the U.S.

YouGov Weekly Tracker U.S. voters on 9/8/2025: Most important issues facing the US



A telling omission:
Crosstabs by
age,
education,
gender,
race/ethnicity
**but not
disability.**

What we mean by the “Disability Squeeze”



The financial pressures disabled people face affording needed disability-related goods and services.

- Disabled people (~40M voters) already face higher costs of living.
- Additional costs for technology, health care, home modifications, transport deepen the affordability crunch for disability people

Research Gap

A U.S. household containing an adult with a disability must spend an estimated **28% more income** to obtain the same standard of living as a household with no disability.



We had **indirect quantitative evidence** of the extra costs of disability but lacked **direct information from disabled people** about how much they end out-of-pocket **and** how often they go without things they need.

Research Objective

To quantify how much disabled people spend out-of-pocket on disability-related goods and services *and* the prevalence of unmet needs in the United States.

Barriers to Inclusion: Quantifying Disability-Related Out-of-Pocket Costs and Unmet Needs for People with Disabilities with a Focus on Underserved Communities

PROJECT NUMBER
90IFRE0065

AGENCY/FUNDING ORGANIZATION
NIDILRR

FUNDING YEAR
2022

[View Full Project Details](#)

- Developed & validated a survey instrument based in part on the Model Disability Survey (WHO/World Bank)
- Examined disparities in costs and unmet needs across diverse disabled population.

It takes a team.



Stephanie Rennane



Arielle Silverman



Amber Davis



Brooke Ellison



Nanette Goodman



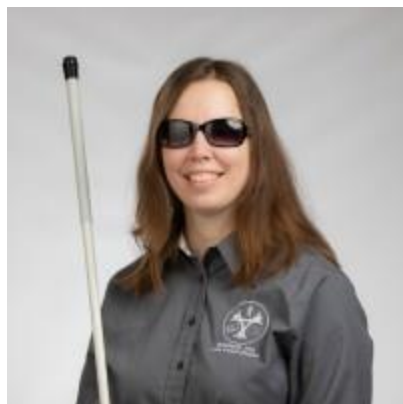
Ghenet Weldeslassie



Sarah Malaier



Daniel Mont



Sarahelizabeth Baguhn



Michelle Ballan



Zach Morris



Stephen McGarity



Phil So

Honoring Dr. Brooke Ellison



Associate Professor, Stony Brook University
Chair, Expert Advisory Panel
Advocate for accessible technology &
disability rights

***We dedicate this research to her
memory and her vision of a
world where disabled people can
thrive without barriers.***

Robust national evidence

Nationally representative survey of disabled adults in 2023:

Survey Results

Annual amount spent on disability related expenses	\$5,341
% income devoted to disability-related expenses	20%
% reported an unmet need for disability-related good/service	67%



Disability and Health Journal

Available online 19 July 2025, 101930

In Press, Corrected Proof  [What's this?](#)



The disability squeeze: Out-of-pocket expenses and unmet needs for disability-related goods and services in the U.S.

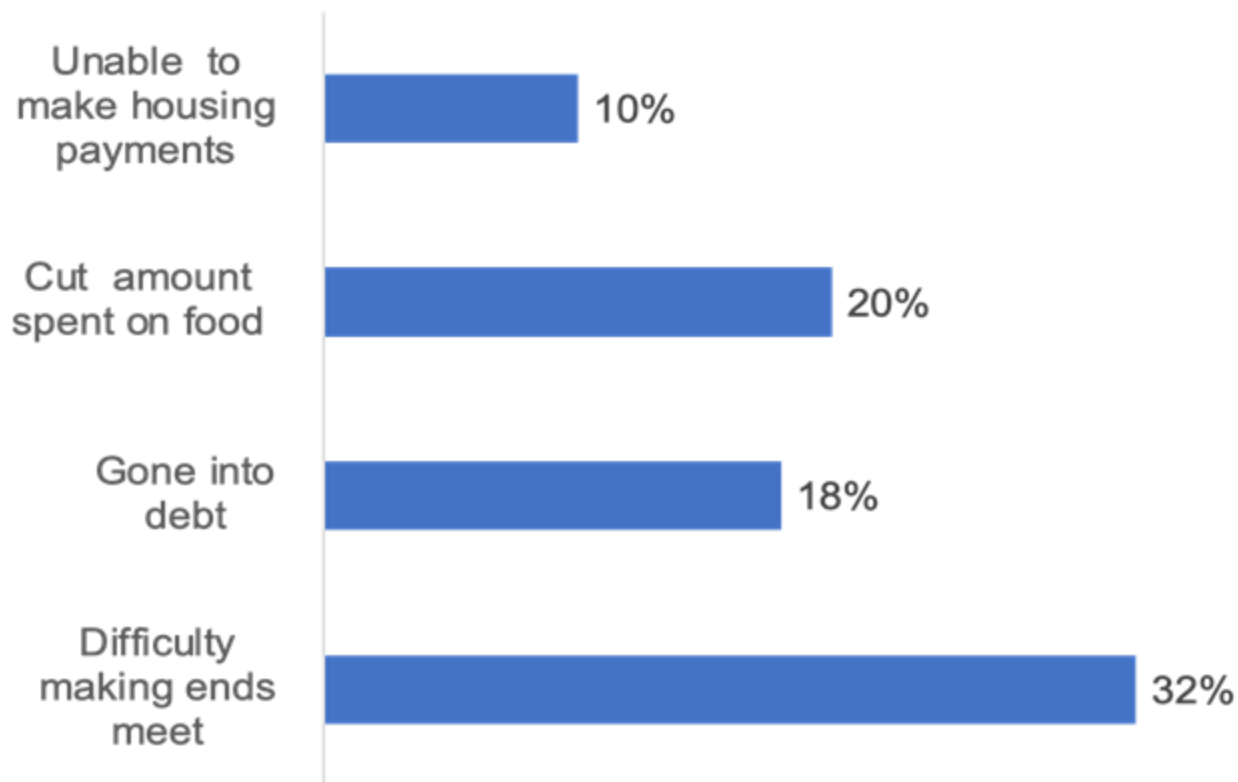
Zachary A. Morris ^a  , Stephanie Rennane ^b, Nanette Goodman ^c, Daniel Mont ^d, Michelle Ballan ^a, Amber Davis ^e, Stephen McGarity ^f, Brooke Ellison ^a, Ghenet Weldeslassie ^a

[Read more here.](#)



Profound impact of disability-related expenses

Because of disability related expenses:

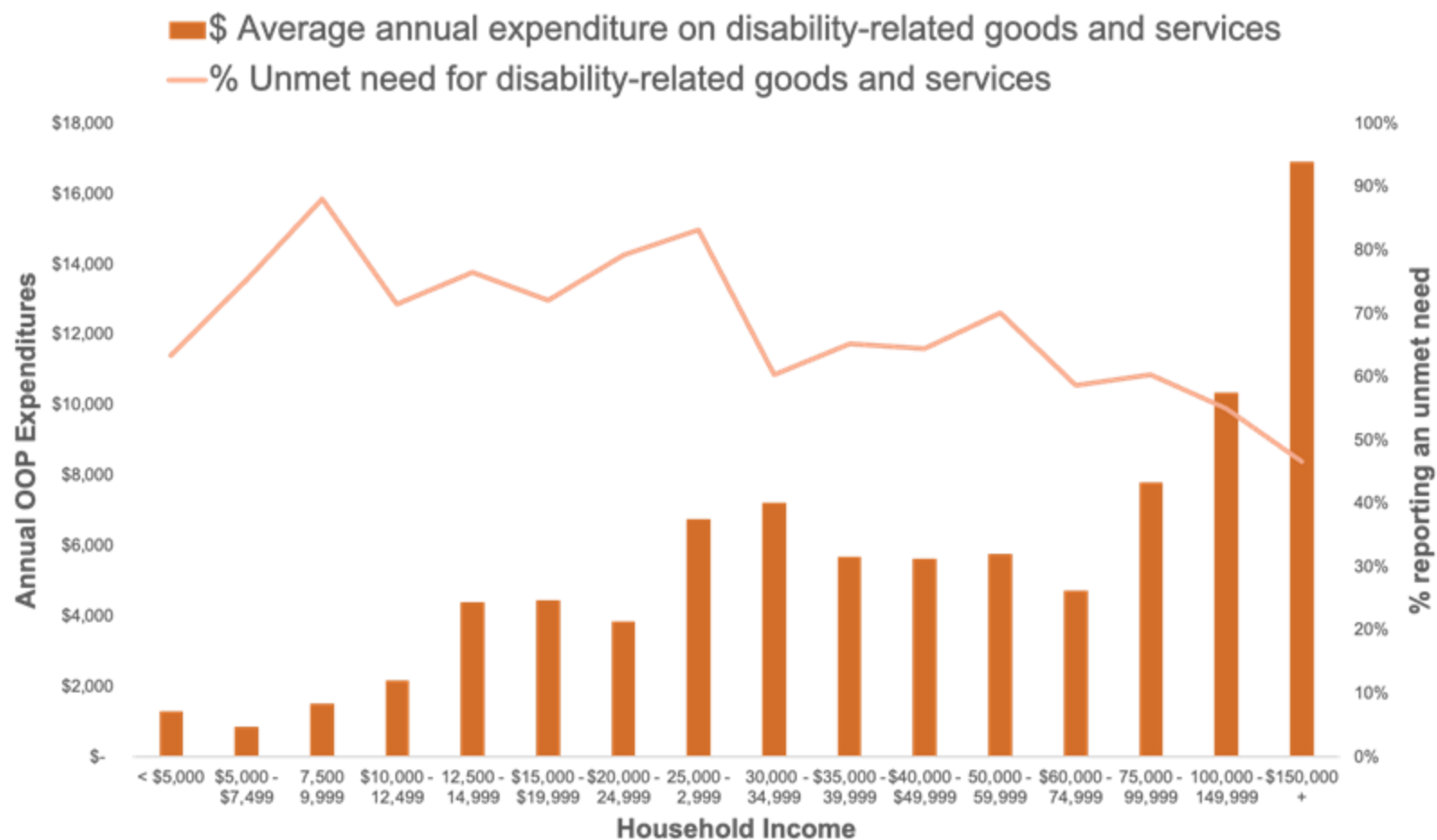


“I was in desperate need of a motorized scooter and insurance would not cover it...I decided to do a GoFundMe campaign...Of course insurance doesn't pay for car lifts either. As someone in a fixed income, these costs are just some of the added extra financial burdens of having a disability.”

– Kelly, 55, Georgia (shared with consent)

Note: Results from the Survey of Disability-Related Goods and Services fielded to the Understanding America Study panel in June 2023. Proportions calculated using survey weights.

Low out-of-pocket expenses not always a positive indicator



Note: Results from the Survey of Disability-Related Goods and Services fielded to the Understanding America Study panel in June 2023. Proportions calculated using survey weights.

The disability squeeze *and* the poverty trap



Benefit and insurance programs provide critical supports but often require poverty.

Catch 22: Working risks losing access to the programs/benefits that help people work.

Video can be accessed here:

<https://www.youtube.com/shorts/09q98ee05Jo>

What this research doesn't capture

We likely understate the true extent of the disability squeeze.

1. We measure financial costs, but **not time costs** (like administrative burdens).
2. The survey relies on **self-reported spending**, which may underestimate costs.
3. Our data shows associations but does not prove **cause and effect**.
4. Some disabled people, especially those not online or with unrecognized needs, may **not be fully represented**.

What it means to bring the “disability squeeze” onto the disability economic agenda?

Adjust poverty measures to reflect disability costs.

Build stronger data and evidence.

Raise awareness to drive policy change.

Our findings show the disability squeeze is **quantifiable**. Making this research actionable will require additional research and public awareness.

Launch of Survey of Disability-Related Goods and Services



Stephanie Rennane, PhD

Senior Economist

RAND



Survey of Disability-Related Goods and Services (SDGS)

Fielded in the Understanding America Study (UAS) in June 2023

- **UAS is a nationally representative online panel with 13,000 members**
 - Available in English and Spanish
 - Enhanced accessibility features in compliance with ADA standards for design
- **SDGS had two main parts:**
 - Disability screener
 - Questions on disability-related goods and services

SDGS Disability Screener

We included multiple questions to screen for disability:

1. Washington Group – Short Set (WG-SS)
 - Difficulty walking, seeing, hearing, communicating, self-care, remembering/concentrating
 2. Washington Group questions about depression and anxiety
 - Experiencing anxiety/depression daily, “a lot”
 3. Self identification
 - “Do you consider yourself to be a person with a disability?”
 4. Receipt of Social Security Disability benefits
- 2,220/9,088 (24%) of respondents were screened as having a disability

Disability-Related Goods and Services

75 questions across **10 functional domains**:

- Mobility, assistive tech, vision, hearing, personal assistive, interior home modifications, exterior home modifications, health services, health goods, general goods
- Research team developed lists of items within these domains
- Six-person advisory panel provided feedback and rated items
- Research team revised based on feedback
- Content validity increased from 60% to 92% after revisions

SDGS is free to use, available online!

- Can be accessed at <https://uasdata.usc.edu/>
- Survey is UAS 547
- Please reach out to Zach or the research team with further questions!

Keynote Address



Mia Ives-Rublee, MSW

Senior Director

Disability Justice Initiative

Center for American Progress



Conversation: Affordability and Access



Victor Calise

Disability Advocate &

Former Commissioner, NYC Mayor's
Office for People with Disabilities



Lunch Break

In-Person Attendees

- Boxed lunch provided
- Please return by
12:55 PM ET

Zoom Attendees

- We're on a lunch break until
12:55 PM ET
- Stay logged in, the webinar will resume automatically.

Don't forget: Add your input at:
www.menti.com **code:** 3477 9828.

We will share the results after the break!

Results from Mentimeter and Comparison with SDGS



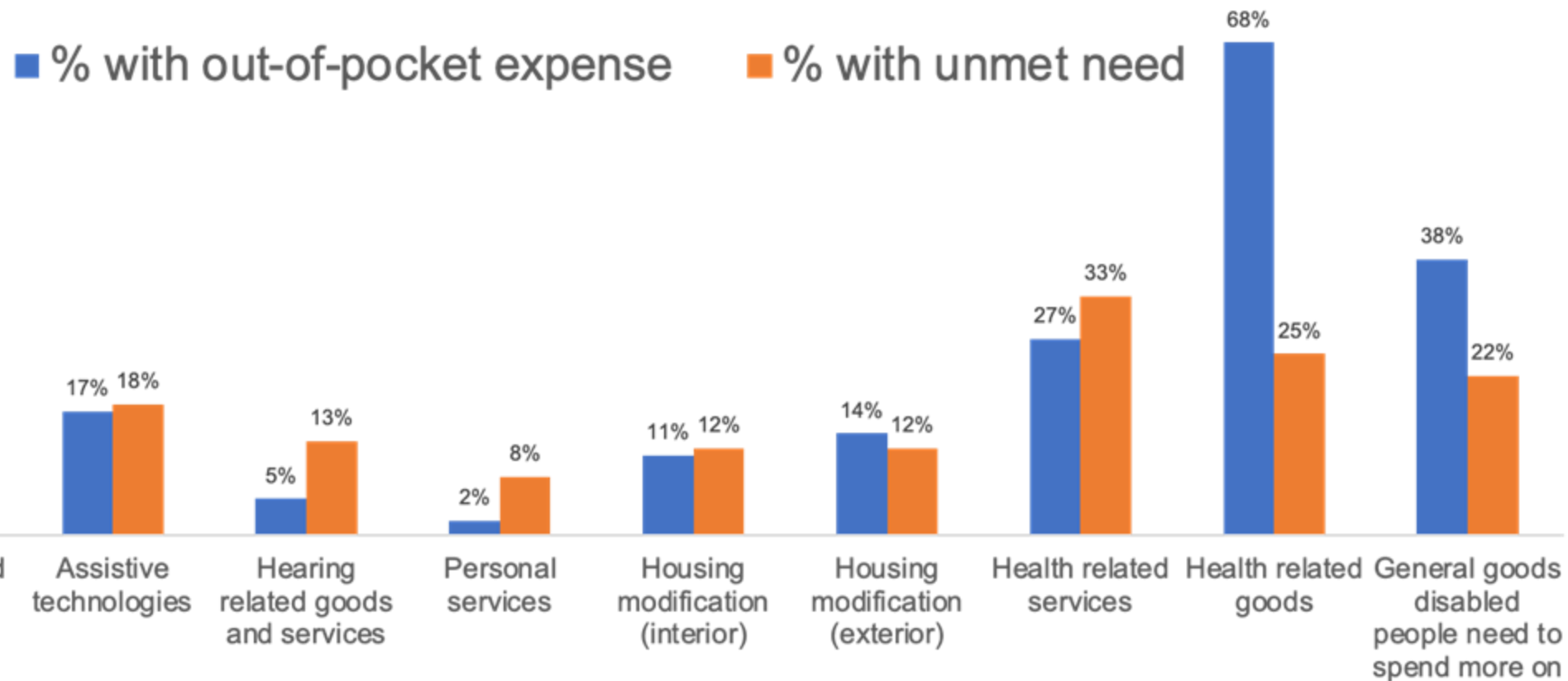
Amber Davis, PhD

Research Associate

Johns Hopkins University
School of Nursing



Out-of-pocket expenses & unmet needs



Community Spotlight: Efforts to Meet Unmet Needs

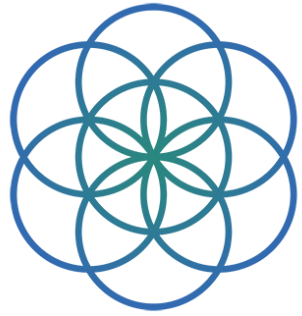


William DeVoe

Director of Communications and
Advocacy

Cerebral Palsy Association of New
York State





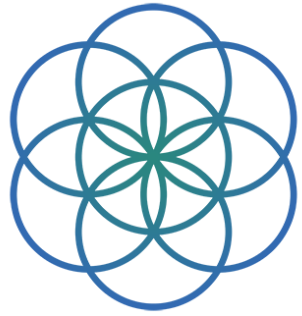
CP State



Mother Cabrini
HEALTH FOUNDATION

CHOP

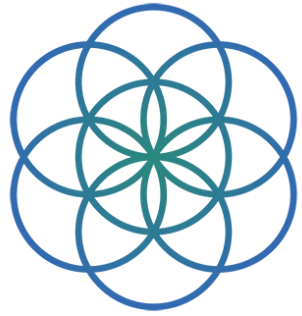
The Community Health Outreach Project



CP State

What is CHOP?

- **Statewide grant program launched in January 2022**
- **Funded by the Mother Cabrini Health Foundation**
- **Provides financial assistance when Medicaid/Medicare won't**



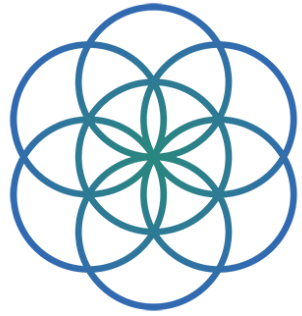
CP State



Mother Cabrini
HEALTH FOUNDATION

Partnership with Cabrini

- **Cabrini's support extended through 2025**
- **Shared commitment to whole-person health**
- **Addressing social determinants of health**



CP State

How it Works

- **Application process for individuals and service providers**
- **Careful review to ensure funds address unmet needs**
- **Bridges the gap between need and coverage**



CP State

What CHOP covers

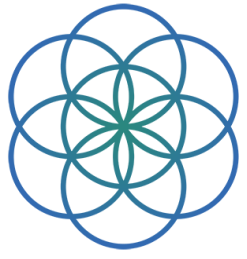
- **Equipment & Accessibility**
- **Medical and dental care**
- **Medical supplies**
- **Other supports essential to health and well-being**



CP State

The Impact

- **7,200+ individuals served since 2022**
- **Families at or below 200% of federal poverty level**
- **Significant improvements in mobility, mental health, and overall health**



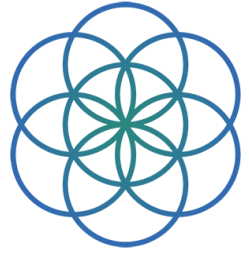
CP State

A Voice for Kaliope

Example: Kaliope, age 10

- **Non-verbal, developmental disability**
- **CHOP funding provided a communication device**
- **Transformed her ability to express herself and connect with others**

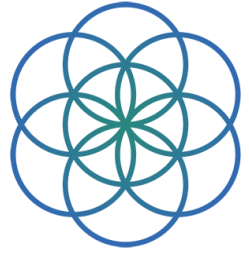




CP State

The Bigger Picture

- **Strengthens families and communities**
- **Prevents crises and costly interventions**
- **Advances health equity for people with disabilities**



CP State

Thank You!

**Together, we're making health and
independence possible for thousands of New
Yorkers.**

The Cost of Moving Around: Disability, Transportation, & Access

Moderator:

Professor Britney Wilson, New York Law School

Panelists:

Dr. Arielle Silverman, American Foundation for the Blind

Edward Mitchell, Statewide Independent Living Council of Tennessee
(virtual)

Elissa Ellis, Association of Programs for Rural Independent Living
(virtual)

Poll time!



- **Question 3:**
- What is the most effective way to account for disability-related costs

www.menti.com

code: 3477 9828

Policy Spotlight



Theo W. Braddy, MSW

Executive Director
National Council on
Independent Living



Policy Spotlight



Tony Wooden Jr.

ASL Direct Program Supervisor
New York City Mayor's Office for
People with Disabilities



Poll time!



Question 4:

When addressing disability related costs we should...

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From DC to the States: Policy Pathways to Reduce the Disability Squeeze

Moderator:

Nanette Goodman, Burton Blatt Institute

Panelists:

Dr. Anjali Forber-Pratt, Former Director of NIDILRR (virtual)

Kim Hill, Chief Disability Officer, NYS Executive Chamber (virtual)

Ly Xīnzhèn M. Zhǎngsūn Brown, National Disability Institute (virtual)

Policy Spotlight



Keely Cat-Wells

Founder & CEO

Making Space for Disabled
Talent



Research & Policy Next Steps



Dr. Daniel Mont

CEO

Center for Inclusive Policy



"Opening Doors" Accessibility Innovation Challenge

Open Call for Ideas to Improve Building Access, Inclusion, and Vertical Accessibility in NYC's Built Environment



Submissions can incorporate ideas that include:

- Retrofitting older buildings
- Improving multifamily and storefront access
- Designing for neurodiversity and sensory inclusion
- Modernizing design standards
- Rethinking ramps, lifts, and elevators
- Integrating new technologies

Challenge closes Oct. 20, 2025

👉 Learn more: <https://lnkd.in/ehhXv4bM>

Closing Remarks

For more information
DisabilitySqueeze.org

