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# Elevating Voices of People with Disabilities in Health Care

## Lunch and Learn Topical Working Series



The Arc of PA Initiative to Address  
COVID-19 Health Disparities  
Among People with Disabilities



December 8, 2023



# Welcome

## **The Arc of PA Initiative to Address COVID-19 Health Disparities Among People with Disabilities**

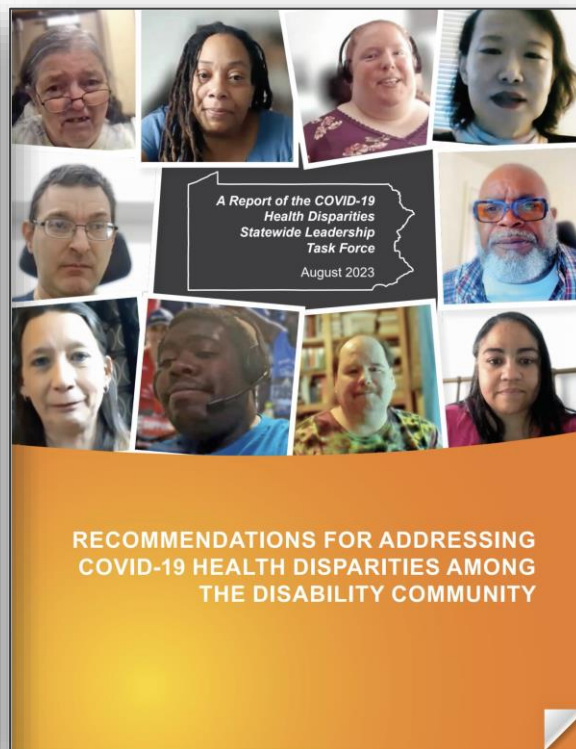
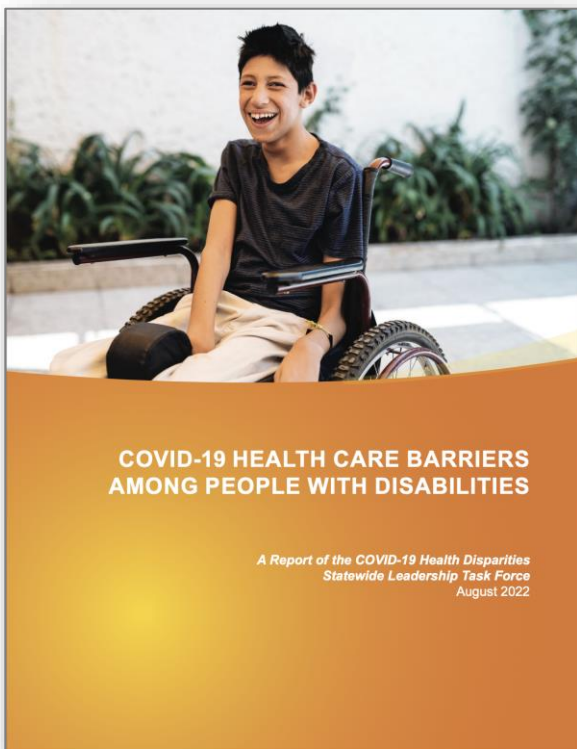
Emma Nolan, Manager of Government Relations and Health Initiatives, The Arc of Pennsylvania





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Pennsylvania

# Calling for disability-inclusive health care



- COVID-19 Health Disparities Task Force
- Regional Community Work Groups
- Over 400 individuals with disabilities, family members, caretakers, health professionals across diverse ethnic, racial, rural populations
- The Arc of PA and local chapters
- Funded by the PA Department of Health



## Today's focus: **Our recommendations to...**

- #1. **Elevate voice:** Involve people with disabilities, their families, and caregivers in policy making and health care decisions.
- #9. **Effectively communicate:** Provide information in ways that everyone can understand, such as in plain language, in braille, and in multiple languages.

## Today's Agenda:

- The Health Disparity and Recommendation
- Practice Panel



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# The Health Disparity and Our Recommendation



[ARC of PA Barriers Report 8-9-22.pdf](#)



## COVID-19 HEALTH CARE BARRIERS AMONG PEOPLE WITH DISABILITIES

*A Report by the COVID-19 Health Disparities  
Statewide Leadership Task Force*

June 2022

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# 2021-2022 Listening Tour: COVID-19 Health Care Strengths and Barriers



## Diversity by role

- Mostly persons with lived experience of disability, caretakers and family members
- Also, professionals in the fields of disability and health care

**Diversity by disability** – intentional outreach across physical, intellectual developmental, behavioral, or emotional, sensory impairment, and complex medical disabilities

**Diversity by race** – intentional outreach to Black Indigenous People of Color (BIPOC)

**Diversity by location** – rural, urban, suburban; intentional outreach to rural settings



# Social Determinants of Health

## Education Access and Quality

- Systemic educational barriers
- Technology barriers

## Economic Stability

- Financial security barriers
- Social supports



## Health Care Access and Quality

- Systemic health care barriers
- Mental and physical health issues
- Vaccination and testing barriers
- Staffing barriers
- Technology barriers

## Neighborhood and Built Environment

- Local conditions
- Transportation barriers
- Accessibility

## Social and Community Context

- Information barriers
- Cultural, linguistic barriers
- Communication





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**THEO BRADDY**

“You do not have lived experience, you leave stuff out, and in leaving stuff out you put people with disabilities’ lives in danger, to the point where we can die.”

- Theo Braddy, a person living well with a disability in Dauphin County







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“People with disabilities were struggling but they had options and people with disabilities didn’t have those same options and access to accurate information.

We didn’t get it.”





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“That health information is so critical, any kind of inaccuracy or discrepancy in information could lead to something significant.”

- Jenny, Parent and advocate for a child with autism, Montgomery county



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**Recommendation:** Involve people with disabilities, their families, and caregivers in policy making and health care decisions.



**Examples:**

- Individual and systemic health care decisions
- Equitable employment of people with disabilities in leadership positions
- Listening sessions, panel discussions, participant forums
- Boards and advisory groups



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**Recommendation:** Provide information in ways that everyone can understand.



- **Timely information in various formats** – such as braille, large print, American Sign Language, closed captioning, qualified accurate language interpreters
- **Timely information in plain language** – clear, concise, accessible literacy levels, meaningful graphs and images, alternate text descriptions of images, embedded definitions
- **Communication supports** – such as social stories, bilingual consultants in healthcare settings



# Resources and Practices

Rhonda Beach Tyree, Facilitator





## Human Development and Disability

# Become a Disability A.L.L.Y. in Your Community and Promote Inclusion for All

[Print](#)



**A** **Acknowledge** and respect individual experiences and abilities.

**L** **Learn** about different disability types.

**L** **Leverage** your influence to promote accessibility and inclusion.

**Y** **Yield** the floor to people with disabilities to help identify and eliminate barriers.



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National Association of County and City Health Officials

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Public Health®  
Prevent. Promote. Protect.



HEALTH & DISABILITY

## Organizational Support to Amplify the Voices of People With Disabilities

Apr 21, 2022 | Guest Author



## PLAIN LANGUAGE

Plain Language

Training

Resources

Contacts

Language Access

### Plain Language: Getting Started or Brushing Up

This website consists of five sections and a checklist you can print. In each section, you will find a number of cards you can flip through to learn about using plain language in your work. When you are done with the final section, you can print a certificate of completion.

Where would you like to go? If you are new to plain language, begin with [Before You Start Writing](#).



Before You Start Writing



Connecting with Your Readers



Presenting Your Information



Formatting and Visual Clarity



Testing and Revising



## National Center on Disability and Journalism



About

Disability Language Style Guide

## Disability Language Style Guide



Explore Temple University

Institute on Disabilities

Search

## Self-Study Module 1: Disability Language and Etiquette







Philadelphia Coordinated Health Care  
A Core Program of PMHCC, Inc.

Empowerment through  
education, **support** and advocacy



### FAQs for Technical Assistance

#### What can the Outreach Department assist with when contacted?

- Durable Medical Equipment (DME) needs
- Denials and appeals with insurance companies
- Dental care issues
- Alternative therapies (art therapy, music therapy, etc.)
- Community resources
- Aging resources
- Mental health resources
- Letter of medical necessity guidelines

#### What information should I prepare to receive health related technical assistance from PCHC?

When contacting PCIC for health related technical assistance, please be sure to have the following when you call or email:

- Name and age of the person
- All insurance information (i.e. Medicare, Medicaid, MCOs, HMOs, Behavioral Health MCOs)
- Specific issue you need addressed
- Any updates or information related to the person on the issue

#### Who can the Outreach Department help and assist ?

We provide assistance to anyone in Southeastern PA, who is seeking information for themselves, family or friends with an intellectual disability (ID) diagnosis and /or autism.

#### How can we get in touch with the Outreach Department?

There are two ways to contact the Outreach Department. We can be reached by phone and email:

**Julio Nieves**—Individual, Family & Community Outreach Specialist  
Email: [JNieves@pmhcc.org](mailto:JNieves@pmhcc.org)—Phone: 267-785-5693

**Nicole Williams**—Outreach Projects Coordinator  
Email: [NWilliams@pmhcc.org](mailto:NWilliams@pmhcc.org)—Phone: 267-785-5280



“Contact Us” at <https://www.pchc.org/about-us/contact-us> .

#### Does the Outreach Department participate in community events?

Yes, we do come out to community events per request. We can provide training, share resources and highlight the services PCHC provides. If you are interested in having us come out to your event, please reach out to Bonnie DiRidolfo at [bdiridolfo@pmhcc.org](mailto:bdiridolfo@pmhcc.org) or call 215-546-0300 and ask for the Outreach Department.

#### What request can the Outreach Department NOT address?

- We do not suggest or recommend specific HMOs or DME suppliers
- We do not give doctor or provider recommendations and/or referrals
- We cannot write a letter of medical necessity on your behalf
- We do not assist with finding residential placement
- We do not provide employment services, but can provide resources



Learn more at [www.pchc.org](http://www.pchc.org)



## GETTING THE CARE YOU NEED

Guide for People with Disabilities





# Join Our Weekly Online Technology Training Series

Being included in the Internet is more important than ever for people with disabilities.

Don't be left behind.

Starting now

[Learn more](#)[Sign up](#)

# Today's Practice Panel



## **Thomas Jefferson University For Adults and Beyond (FAB) Center for Complex Care**

*Karin Roseman, LCSW, Family and Community Medicine Co-Director, Jefferson FAB Center  
Brandon Townsend, Recipient of FAB Center Services*

*Sabra Townsend, Parent and Director of Operations, Jefferson Center for Autism and Neurodiversity*

## **Allegheny Valley Hospital**

*Elaine Brenneman, OTR/L, CBIS, Lead OT for the Brain Injury Rehabilitation Unit*

*Susan Little, PT, Certified Brain Injury Specialist CBIS*



# Question and Answer





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**LUNCH  
AND LEARN**

December 12, 2023  
12:00-1:30PM

Accessible and  
Alternative Health  
Care Delivery

**LUNCH  
AND LEARN**

December 19, 2023  
12:00-1:30PM

Disability-Inclusive  
Healthcare Systems





2024

**Disability Health  
Action Summit**

**Sheraton Hotel  
Harrisburg, PA**

**March 6, 2024**



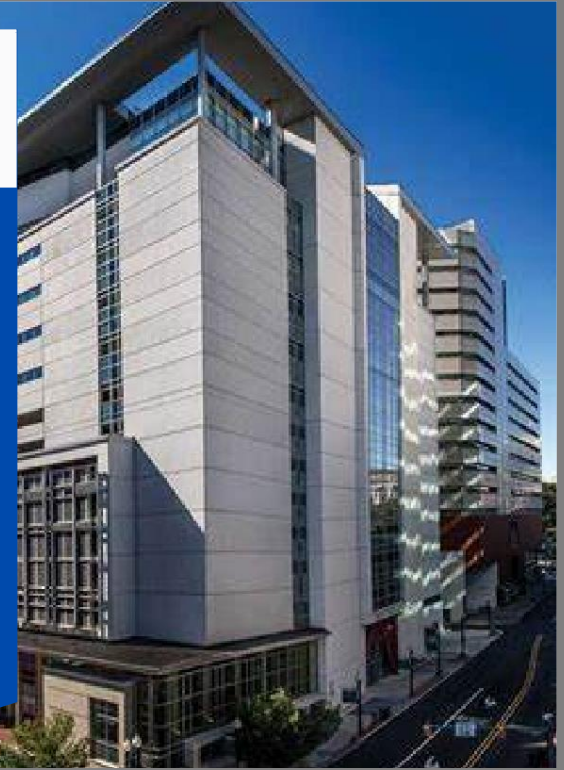
**SAVE THE DATE**

**2024  
Health Equity  
Summit**

Harrisburg University

**Harrisburg, PA**

**April 4 & 5, 2024**





# Thank you!

