# Communicating with and about People with Disabilities

National Center for Health in Public Housing

NCHPH
National Center for Health in Public Housing

10/09/2024

# National Center for Health in Public

- The National Center for Health in Public Housing (NCHPH) is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U30CS09734, a National Training and Technical Assistance Partner (NTTAP) for $2,006,400 and is 100% financed by this grant. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.
- The mission of the National Center for Health in Public Housing (NCHPH) is to strengthen the capacity of federally funded Public Housing Primary Care (PHPC) health centers and other health center grantees by providing training and a range of technical assistance.


NCHPH
National Center for Health in Public Housing

# Today's Speakers

**Fide Pineda Sandoval, CHES**
Manager of Training and Technical Assistance

**Jose Leon, MD**
Chief Medical Officer

NCHPH
National Center for Health in Public Housing

# Housekeeping

- All participants muted upon entry
- Engage in chat
- Raise hand if you would like to unmute
- Meeting is being recorded
- Slides and recording link will be sent via email


NCHPH
National Center for Health in Public Housing

# 2024 Training and Technical Assistance Needs Assessment Evaluation


- We invite you to complete the 2024 National Health Center Training and Technical Assistance (T/TA) Needs Assessment by **November 1, 2024.** This assessment, released every three years, is used to identify priority training topics and professional development needs. Don't miss this opportunity to contribute!

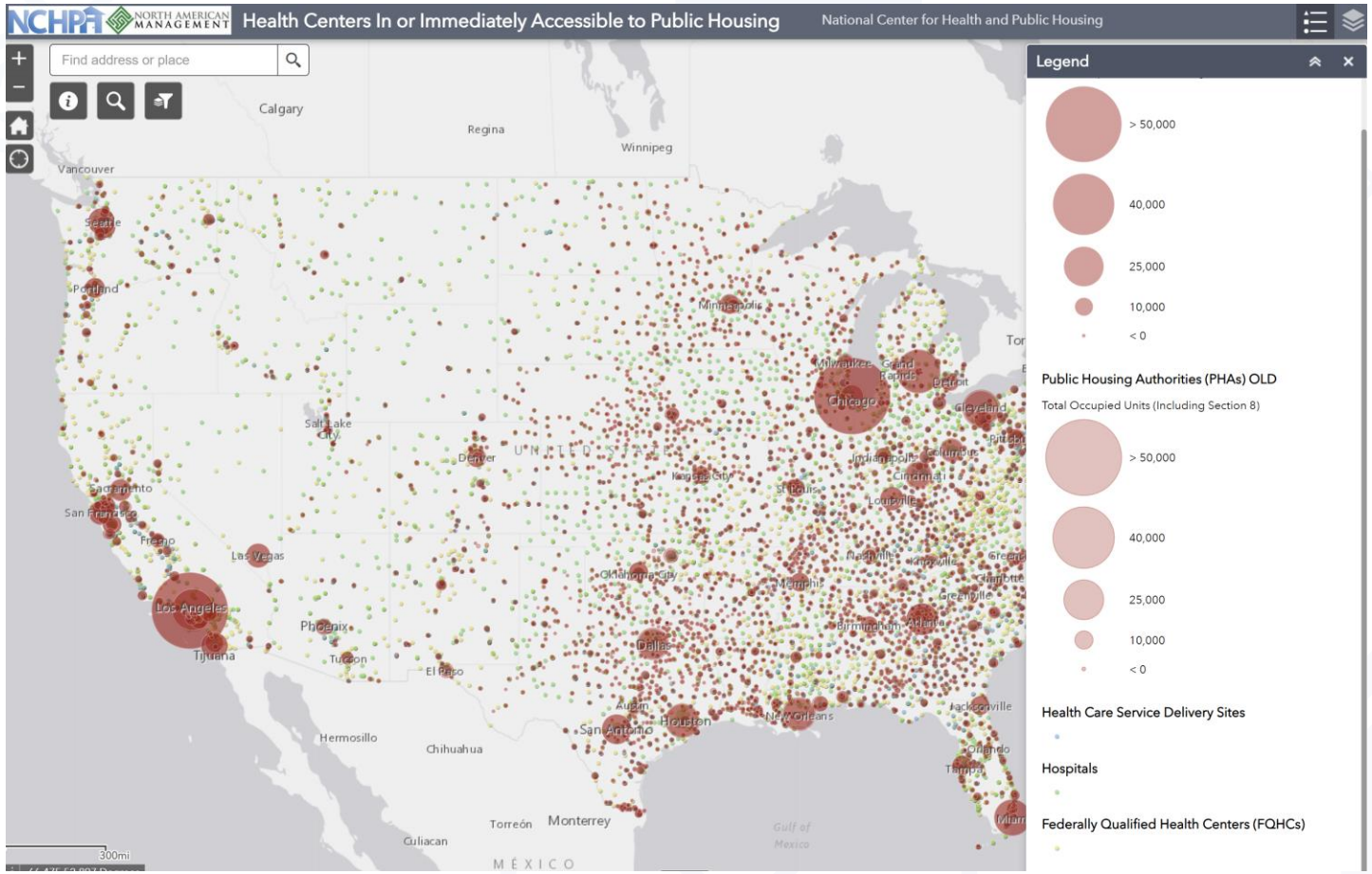
NCHPH
National Center for Health in Public Housing

# NCHPH Announcements

- Upcoming Activities:
  - 10/16/2024 at 2:00 pm EDT - Health Center Preparedness and Response Forum: Emerging Issues
  - 11/12/2024 at 1:00 pm EDT - Screening for Violence Risk in People Living with Disabilities
  - 11/13/2024 at 2:00 pm EDT – The Intersection of HIV, Aging, and Housing: Considerations for Health Centers

NCHPH
National Center for Health in Public Housing

# Location of PHPC Health Centers and Public Housing Developments




**1,363 Federally Qualified Health Centers (FQHC)=31 million patients**

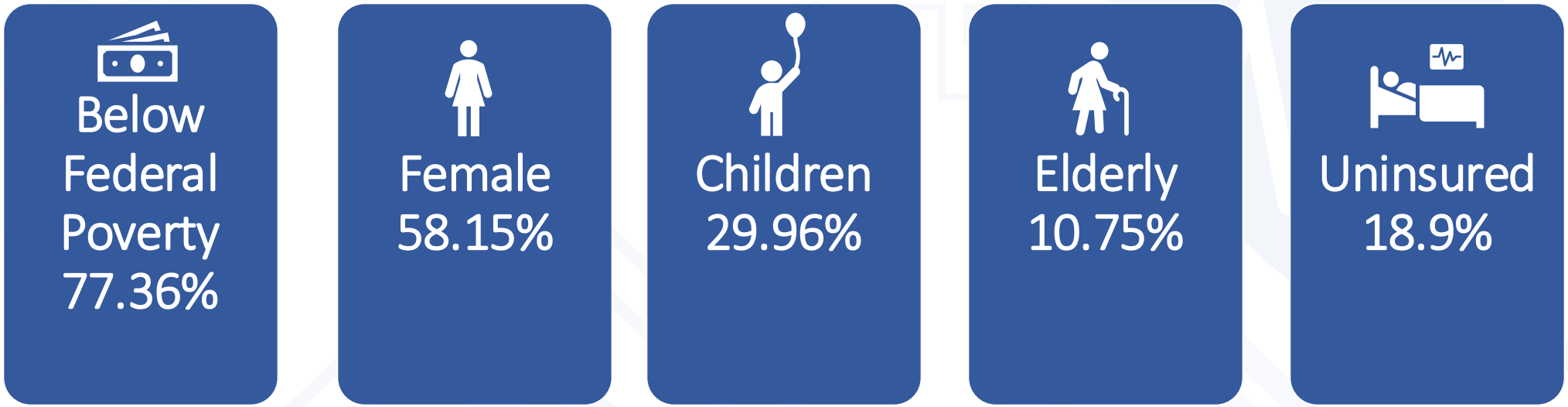
**475 FQHCs near Public Housing= 6.5 million patients**

**107 Public Housing Primary Care (PHPC) = 992,815 patients**

**Source: [UDS 2023]**

NCHPH
National Center for Health in Public Housing

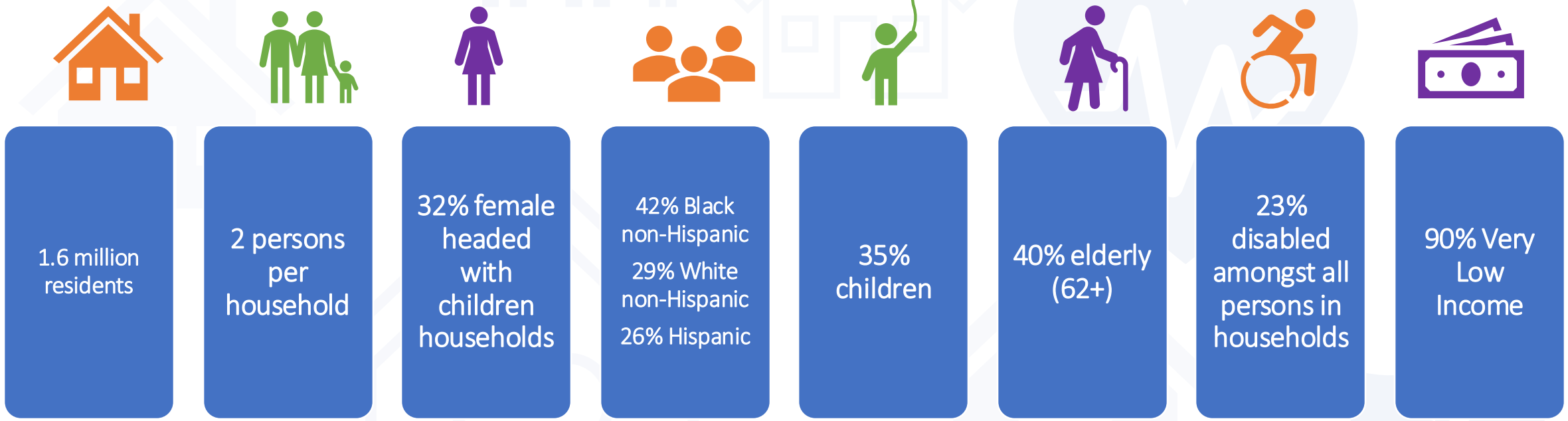
# PHPC Health Center Patient Demographics 2023




Source: UDS 2023

NCHPH
National Center for Health in Public Housing

# Public Housing Resident Demographics 2023




Source: HUD Picture of Subsidized Adults

NCHPH
National Center for Health in Public Housing

# Learning Objectives

01

Enumerate strategies to communicate with patients with disabilities effectively and respectfully

02

Apply inclusive health community models to reach out to patients with disabilities

03

Adapt disability inclusive tools that can be used by health center staff to communicate with patients with disabilities

NCHPH
National Center for Health in Public Housing

# Myth or Fact

- People with disabilities are brave, courageous and inspirational for living with their disability.
- Myth.

- People with disabilities are often portrayed as superhuman or courageous as they triumph over adversity. George Covington, a writer who is blind, has said, “We’re seen as inspirational, and inspiration sells like hotcakes. My disability isn’t a burden: having to be so damned inspirational is.
- Source: **Mayer, S. (2021, July 19). Destigmatizing disability**

# Myth or Fact

- There are many invisible disabilities
- Fact
- Mental health conditions (e.g. depression, anxiety)
- Autism
- Traumatic brain injury
- Learning disabilities

- Source: **University of New Hampshire (n.d.) Misconceptions about disability**

NCHPH
National Center for Health in Public Housing

# Myth or Fact

- People with autism feel love
- Fact
- Believe it or not, one of the most Googled questions about autism is, ‘can someone with autism love?’.
- Of course they can! People with autism can feel the full range of emotions including love and affection. Sometimes they can even be more pronounced than usual.
- However, this myth might come from the fact that some people with autism can find it a bit hard to express these emotions and share what they are feeling.
- Source: ALSO

NCHPH
National Center for Health in Public Housing

# Myth or Fact

- People with down syndrome die young
- Myth
- This one used to be true…. Back in 1910, a child born with Down syndrome often passed away before his or her 10th birthday.
- Fast forward 100 years, and the life expectancy of people with Down syndrome has gone up and up!
- These days, many people live into their 60s, and some even into their 80s.

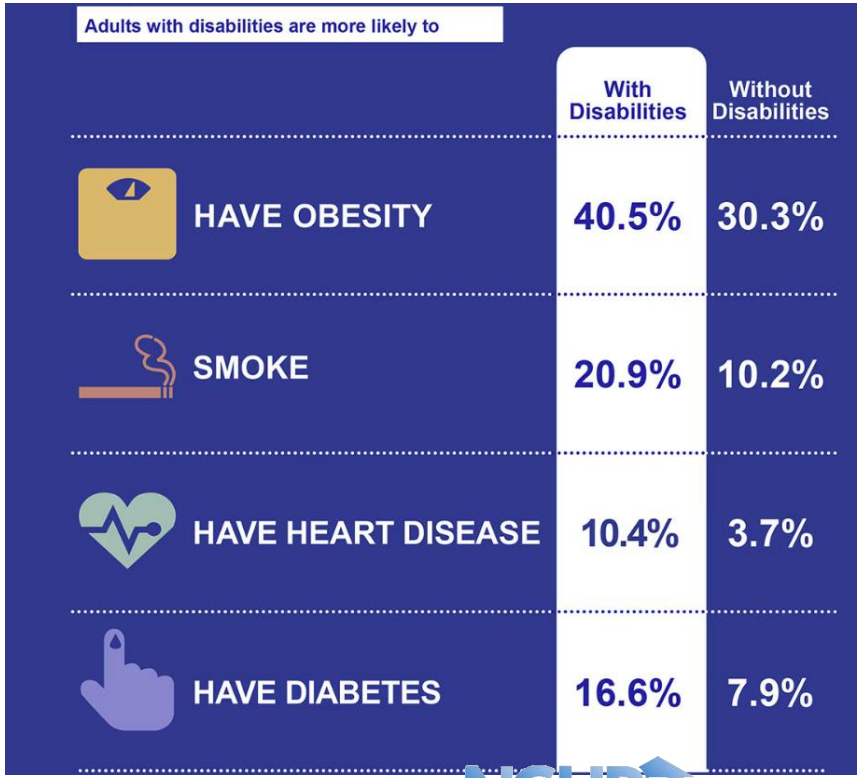
- Source: ALSO

NCHPH
National Center for Health in Public Housing

Percentage of people with disabilities in PH: 23

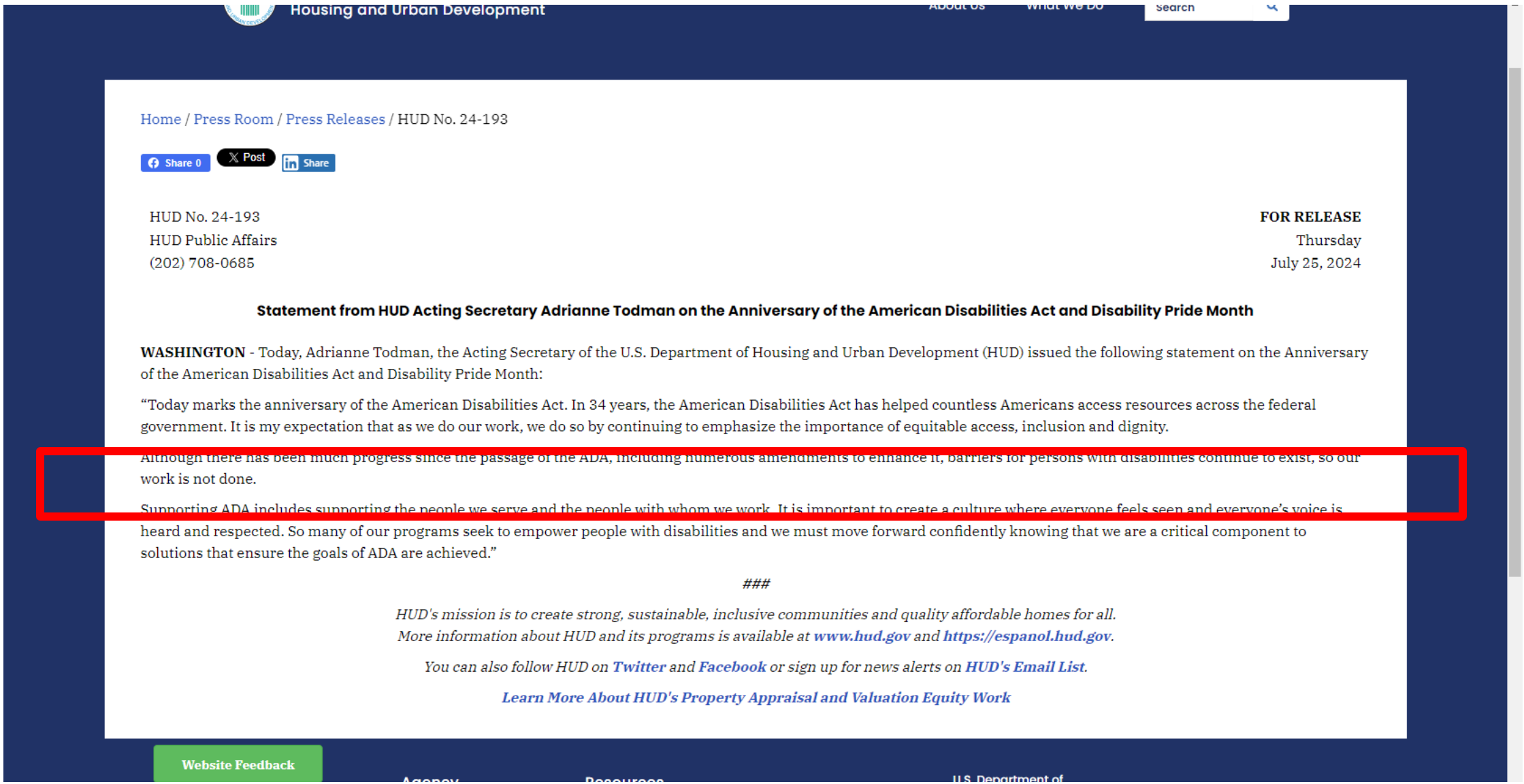
US Percentage of People with Disabilities: 28.7

Percentage of patients with disabilities reported by HCs: 0




Sources: CDC.gov & HUD.gov

NCHPH
National Center for Health in Public Housing



Housing and Urban Development

About Us What We Do Search

Home / Press Room / Press Releases / HUD No. 24-193

Share 0 Post Share

HUD No. 24-193
HUD Public Affairs
(202) 708-0685

**FOR RELEASE**
Thursday
July 25, 2024

**Statement from HUD Acting Secretary Adrianne Todman on the Anniversary of the American Disabilities Act and Disability Pride Month**

**WASHINGTON** - Today, Adrianne Todman, the Acting Secretary of the U.S. Department of Housing and Urban Development (HUD) issued the following statement on the Anniversary of the American Disabilities Act and Disability Pride Month:

"Today marks the anniversary of the American Disabilities Act. In 34 years, the American Disabilities Act has helped countless Americans access resources across the federal government. It is my expectation that as we do our work, we do so by continuing to emphasize the importance of equitable access, inclusion and dignity.

Although there has been much progress since the passage of the ADA, including numerous amendments to enhance it, barriers for persons with disabilities continue to exist, so our work is not done.

Supporting ADA includes supporting the people we serve and the people with whom we work. It is important to create a culture where everyone feels seen and everyone's voice is heard and respected. So many of our programs seek to empower people with disabilities and we must move forward confidently knowing that we are a critical component to solutions that ensure the goals of ADA are achieved."

###

*HUD's mission is to create strong, sustainable, inclusive communities and quality affordable homes for all.*
*More information about HUD and its programs is available at **www.hud.gov** and **https://espanol.hud.gov**.*

*You can also follow HUD on **Twitter** and **Facebook** or sign up for news alerts on **HUD's Email List**.*

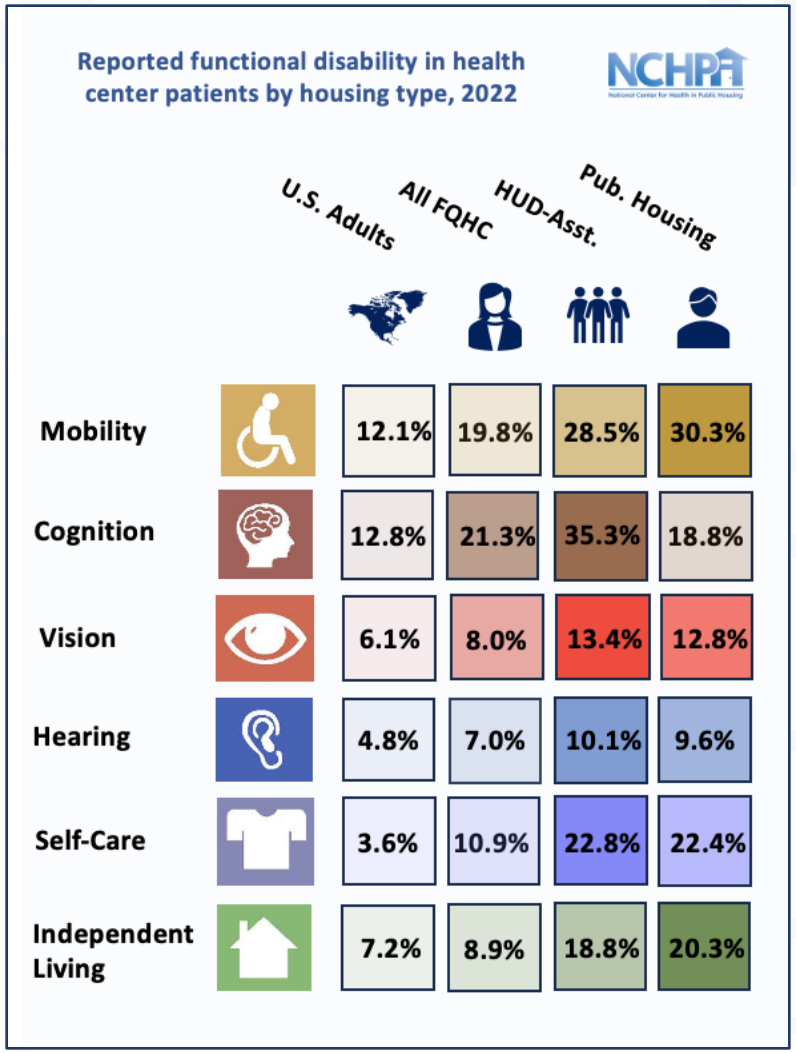
***Learn More About HUD's Property Appraisal and Valuation Equity Work***

Website Feedback

Agency Resources U.S. Department of

NCHPH
National Center for Health in Public Housing

# Research Publication: Disability in Public Housing

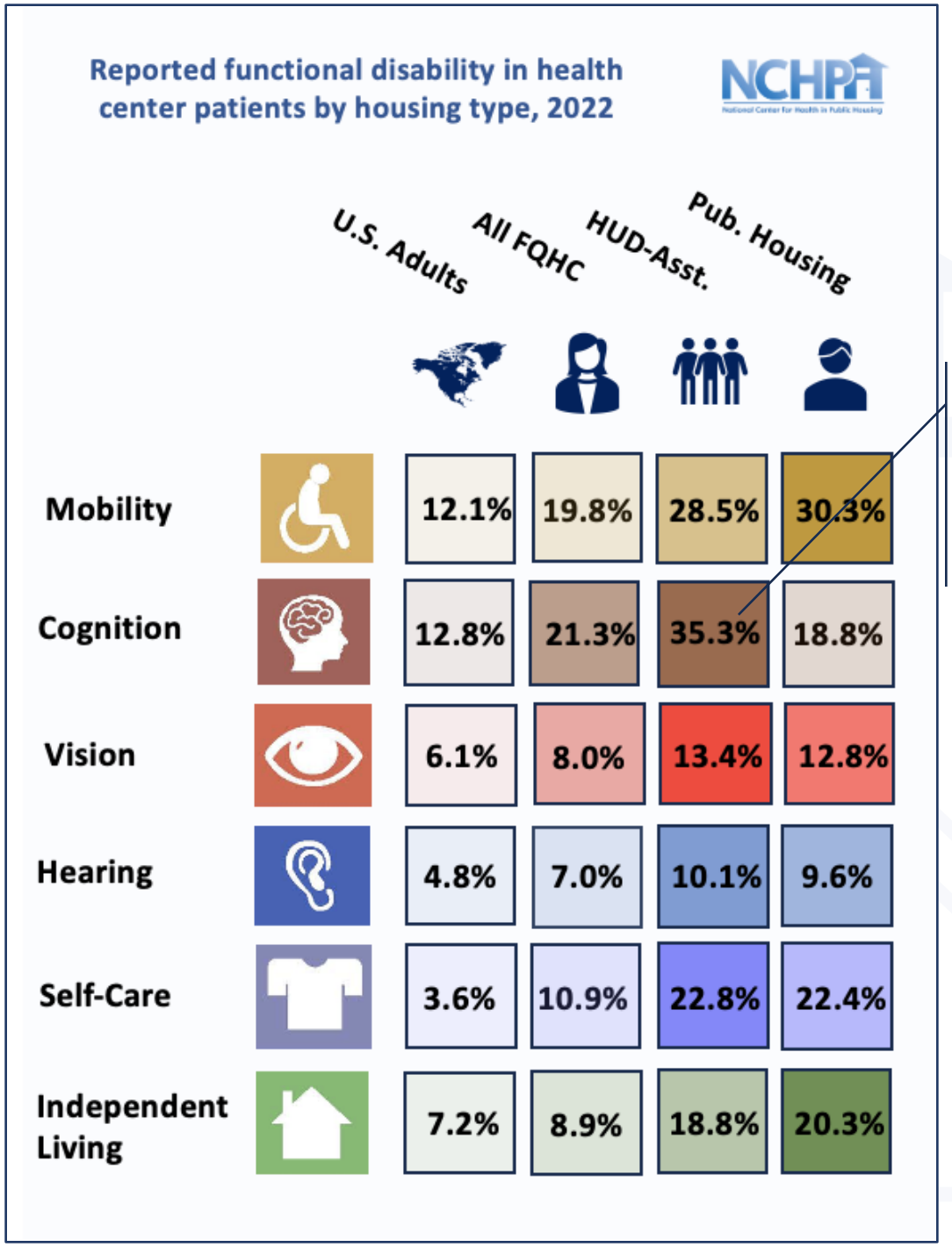



## New Findings Review:

- Six classes of disabilities were investigated utilizing HRSA and CDC databases.
- Residents of public housing and the HUD-assisted are disproportionately impacted by all types of disability.
- These groups were most impacted by cognitive, mobility and independent living disabilities.

Source: HRSA.gov

NCHPH
National Center for Health in Public Housing




**Cognitive Disabilities:** Includes Intellectual disability, Autism spectrum, severe persistent mental illness

**35.4%** of HUD-Asst. Health Center patients reported a cognitive disability in 2022

Source: HRSA.gov

NCHPH
National Center for Health in Public Housing

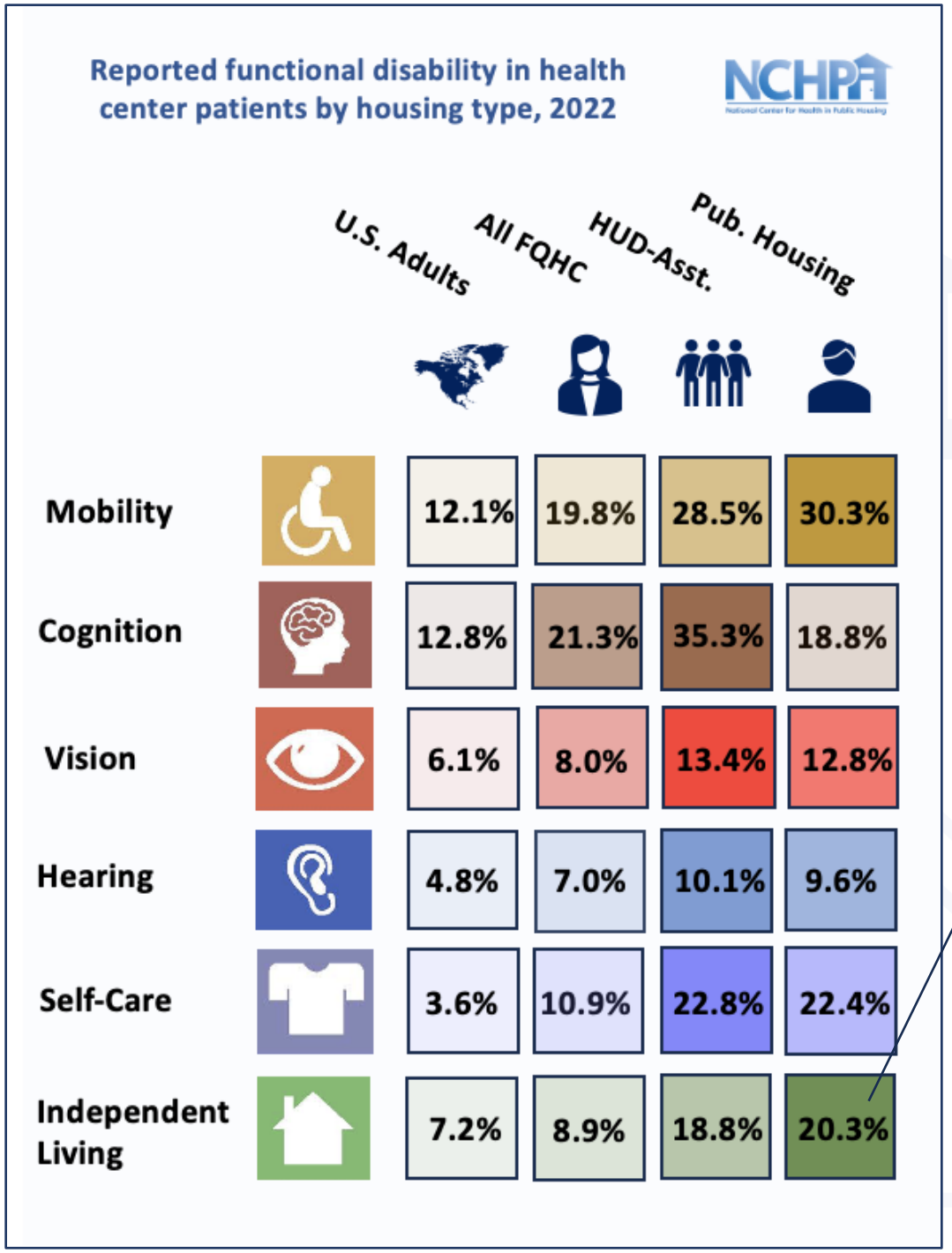
## Reported functional disability in health center patients by housing type, 2022

| | U.S. Adults | All FQHC | HUD-Asst. | Pub. Housing |
|---|---|---|---|---|
| Mobility | 12.1% | 19.8% | 28.5% | 30.3% |
| Cognition | 12.8% | 21.3% | 35.3% | 18.8% |
| Vision | 6.1% | 8.0% | 13.4% | 12.8% |
| Hearing | 4.8% | 7.0% | 10.1% | 9.6% |
| Self-Care | 3.6% | 10.9% | 22.8% | 22.4% |
| Independent Living | 7.2% | 8.9% | 18.8% | 20.3% |

**Mobility Disabilities:** Includes physical and mental disabilities which restrict movement in and outside of the home.

**30.3%** of Public Housing Health Center patients reported a mobility disability in 2022

Source: HRSA.gov




**Independent Living Disabilities:** Includes intellectual disabilities that impact independent control of finances

**20.3%** of Public Housing Health Center patients reported an independent living disability in 2022

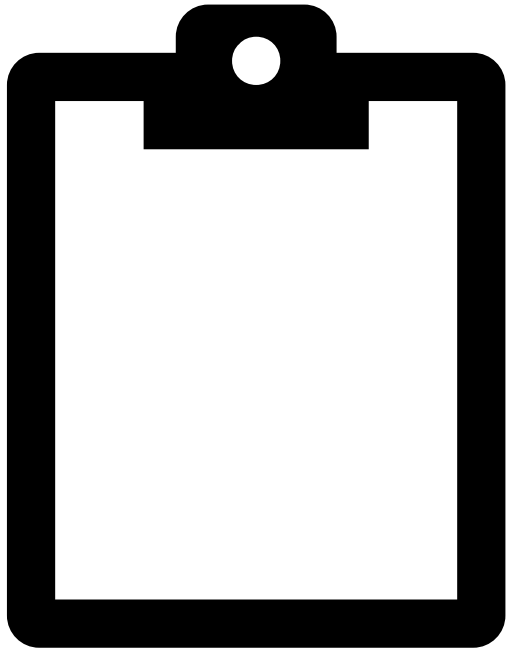
Source: HRSA.gov

NCHPH
National Center for Health in Public Housing

# Poll Question 1

How comfortable would you feel approaching a patient with a disability in the health center setting or the community?

- ❑ quite uncomfortable
- ❑ somewhat uncomfortable
- ❑ neutral
- ❑ somewhat comfortable
- ❑ quite comfortable

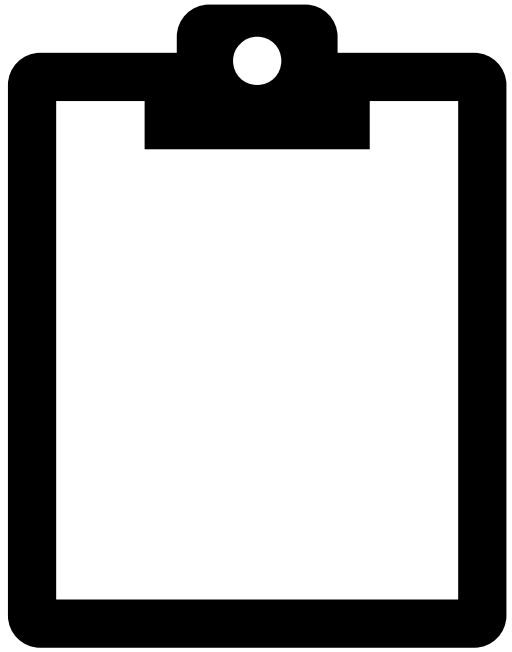


NCHPH
National Center for Health in Public Housing

# Poll Question 2

Does your health center or organization have a strategy to provide preventive services for people with disabilities?

- ❑ Yes
- ❑ No



NCHPH
National Center for Health in Public Housing

# ‘I Am Not The Doctor For You’: Physicians’ Attitudes About Caring For People With Disabilities

Attitudes toward people with disabilities

We’ve gotten to a point in society where a lot of people are wanting some form of accommodation, and a lot are illegitimate. They want their pet peacock on the airplanes and whatnot, and it makes it very difficult.

Structural barriers

Seeing patients at a 15-minute clip is absolutely ridiculous. To have someone say, well we’re still going to see those patients with mild to moderate disability in those timeframes—it’s just unreasonable and it’s unacceptable to me. But training [to address problems common for people with mild to moderate disability] would help.

Communication accommodations

I use paper and pen. And most of my patients have hearing aids that are not working… It’s just better to use paper and pen, sometimes it’s just better, because with HIPAA, when they’re yelling and you are yelling, the whole office can hear you yelling.

https://doi.org/10.1377/hlthaff.2022.00475

NCHPH
National Center for Health in Public Housing

# What is a disability?

The Americans with Disabilities Act (ADA)

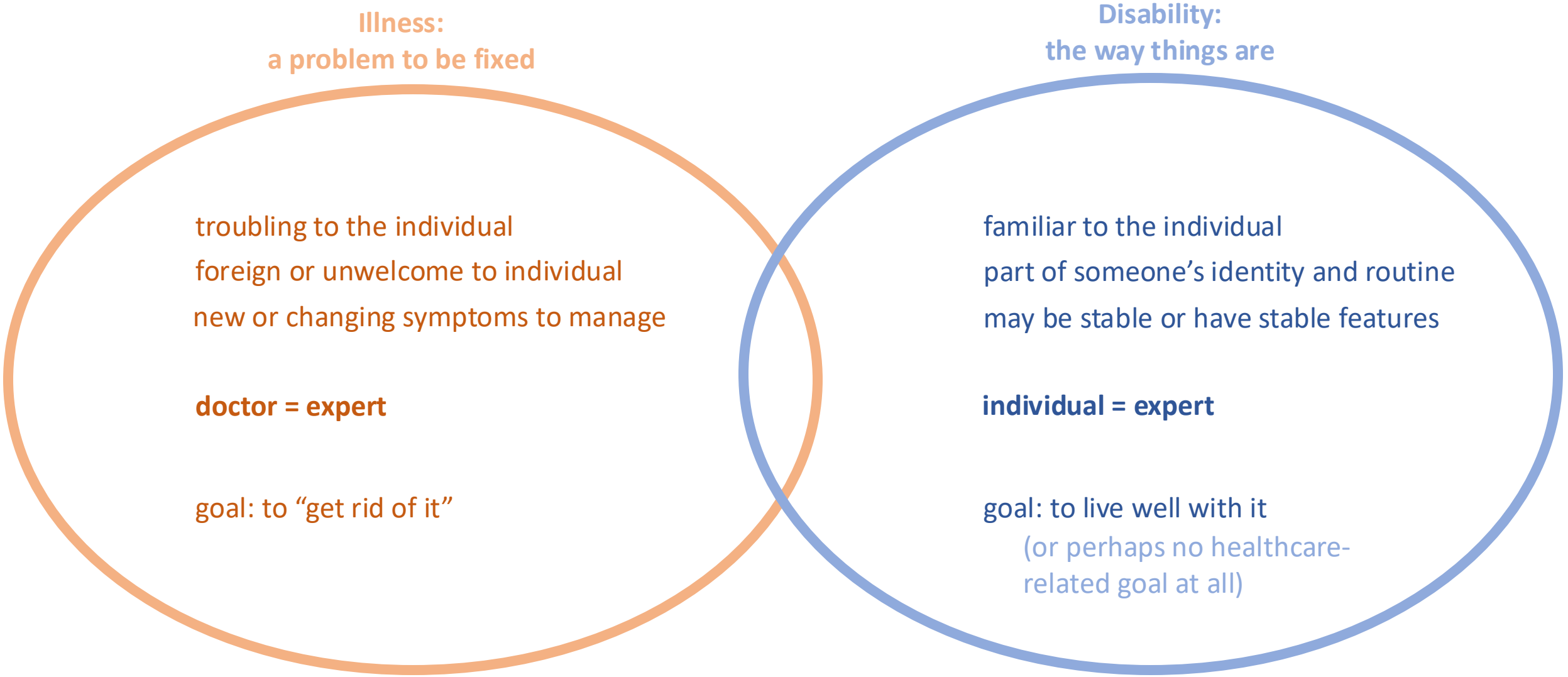
"a physical or mental impairment that substantially limits one or more major life activity"

Disability is **common** and **nearly universal**:

most of us will experience it at some time in our lives.

- What is the difference between **Illness** and **Disability**?

# An individual's outlook and goals are different.

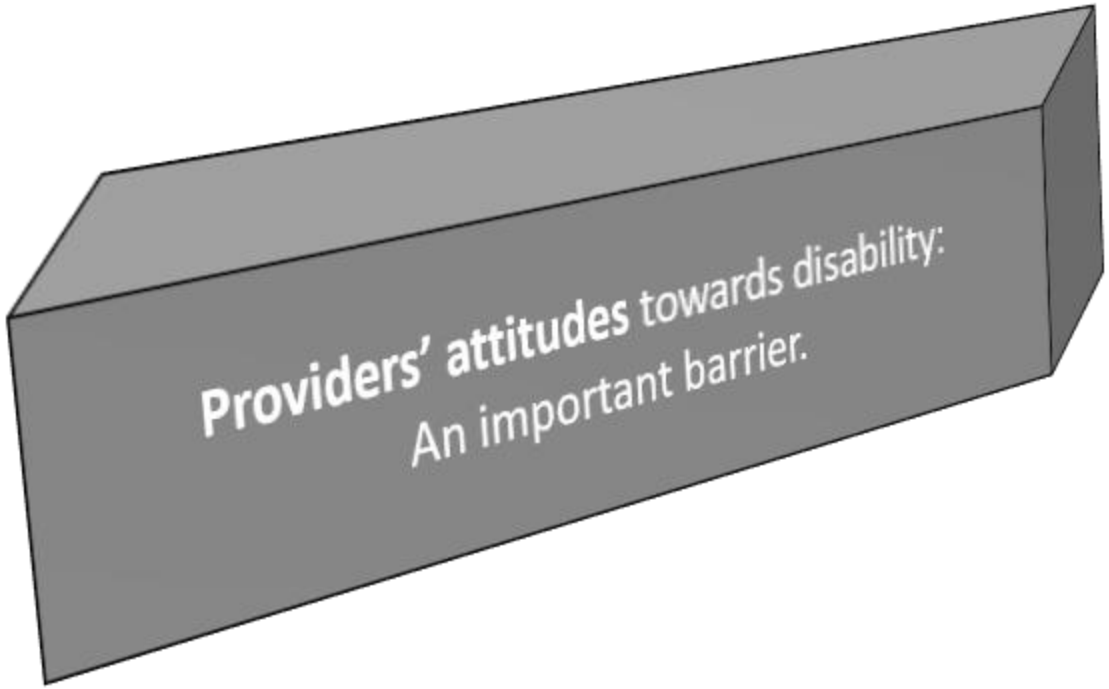



Often, the disability is **not** the patient's main concern when she comes to see the doctor.

NCHPH
National Center for Health in Public Housing

# Then, why is disability relevant to us as doctors?

People with disabilities
experience **barriers in healthcare access**.




Hearn SL, Hearn PJ. Working with people with disabilities

NCHPH
National Center for Health in Public Housing

**By understanding the potential challenges, and by applying mindfulness and consideration, we can help reduce these barriers.**


People with disabilities are more likely to perceive that the **physician does not**:

- listen to them
- explain treatment so that they understand
- treat them with respect
- spend enough time with them
- involve them in treatment decisions

analysis of nationwide survey data (2006 MEPS); (Smith 2009)

Negative provider attitudes sometimes result in:

- withholding of treatment
- provision of inferior treatment
- neglect in general and preventative care (e.g., birth control, tobacco use)

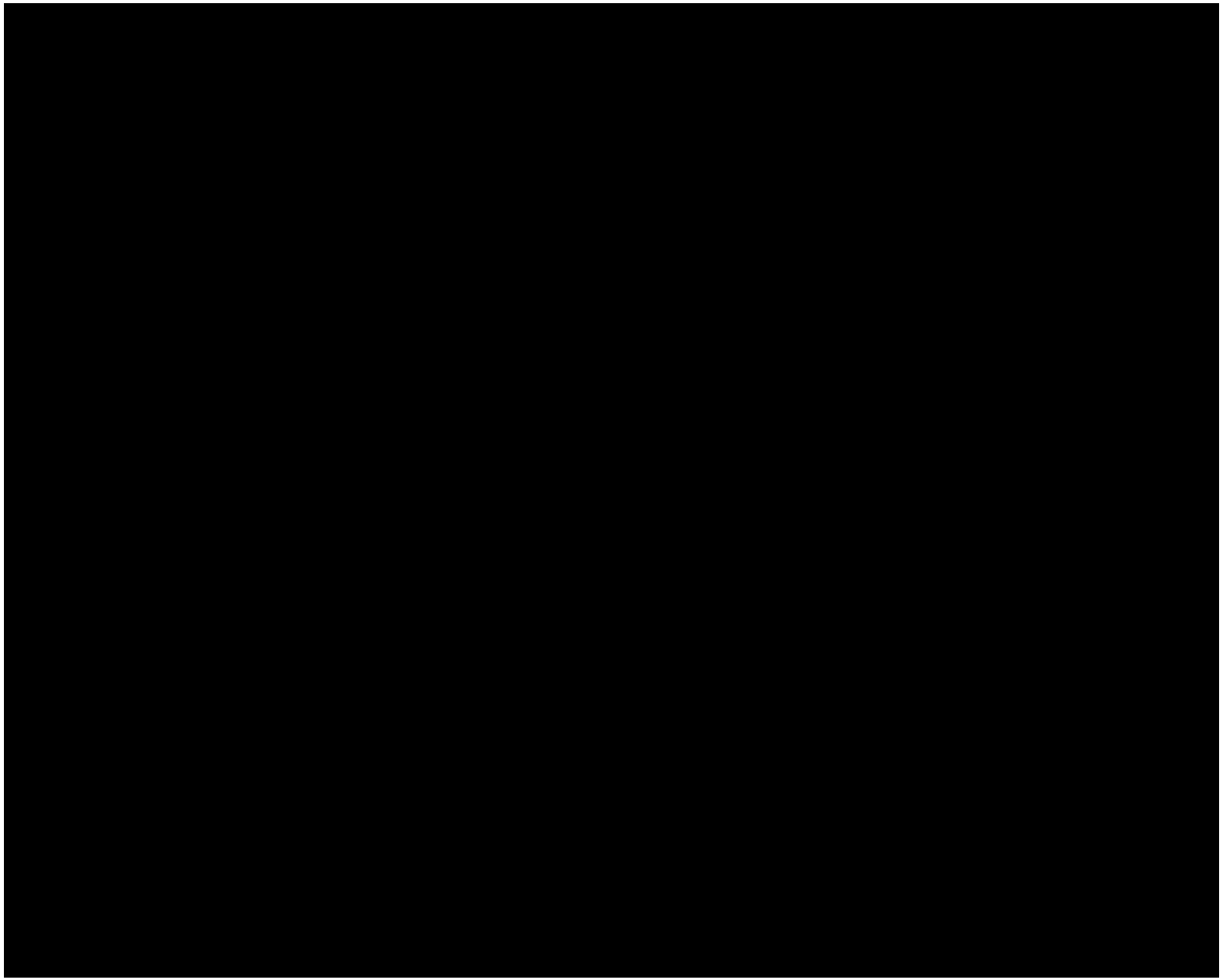
Patients' mistrust in providers may give rise to failure to seek needed care.

(Drainoni et al. 2006)

Hearn SL, Hearn PJ. Working with people with disabilities

NCHPH
National Center for Health in Public Housing

# Let’s meet Pamela.



NCHPH
National Center for Health in Public Housing

# Imagine Pamela is your next patient.

Let's pretend she is coming in to see you for headaches.
Your attending says you can "take a stab at this one!" and hands you her file.

Might you be a little nervous or unsure how to approach her?

(maybe more so than for a patient without a disability….)

**It's okay if the answer is yes.**
In fact, it's pretty normal.

**Why?**

NCHPH
National Center for Health in Public Housing

# We may feel uncomfortable when somebody is different and we don't know much about her.

There's so much I don't know about her!

- Will she understand what I am saying?
- Will I make her uncomfortable?
- How will she relate to me?

Is she sick from a vision standpoint, and am I supposed to fix it?

- Disability can appear, at first glance, like an illness.

I'm supposed to be the doctor. . . .

- But she is more familiar with her visual impairment than I am.
- What will she think of that?
- Will she trust me if I show I don't know how her visual impairment affects her?

There's no algorithm for her blindness!

- Disability crosses cultural and professional boundaries.
- There's no quick formula for approaching it; no one-size-fits all.
- Pamela's needs may differ substantially from those of the previous person with a visual impairment.

**Differences, and the unknown, can make us uncomfortable.**

NCHPH
National Center for Health in Public Housing

# Why might we feel uncomfortable working with individuals with disability?

Let’s pause and reflect.

NCHPH
National Center for Health in Public Housing

# Individuals with disabilities often lead very full lives.

What did we learn about Pamela?

- raised three children on her own as a single mom
- pursued and finished college in her late thirties
- works as a medical transcriptionist
- is socially connected, jokes around with colleagues
- has a visual impairment, and sees only variations in light

Healthcare providers routinely **underestimate quality of life** for individuals with disabilities, including ability to participate in society, pursue work, enjoy recreational activities, and nurture relationships.

Hearn SL, Hearn PJ. Working with people with disabilities

NCHPH
National Center for Health in Public Housing

# Equal Access to Information

- We have the obligation to provide people with disabilities information in a way that they are able to understand it.
- This is done through the provision of equipment or auxiliary aids and services.
- The choice of what to provide lies with the person with the specific disability.

Examples:

- A blind person receives information electronically instead of print;
- a sign language interpreter is scheduled for a deaf individual to attend a meeting

# Failing to offer standard care, thinking it irrelevant to someone “so disabled”.

A physician may neglect to inquire about sexual activity, assuming it must be out of the realm of the individual’s experience.

A physician might neglect to offer preventative care, thinking that the person’s quality of life is so low anyway.

NCHPH
National Center for Health in Public Housing

# Communication Tips for People with Intellectual Disabilities

- Get to know the person's communication method.
- Ask the individual to repeat if you do not understand their speech.
- Focus on one topic at a time.
- Demonstrate verbal instructions.
- Break down tasks into smaller pieces.
- Give timelines and inform people before transitions take place.
- Use pictures and other visual aids.

Hearn SL, Hearn PJ. Working with people with disabilities

NCHPH
National Center for Health in Public Housing

# Exercise Caution

- **DO:**
- Ask the person to repeat back what they understood, in their own words
- Check in with the person periodically to see how they are doing or if they need additional assistance

- **DON'T:**
- Ask "yes" or "no" questions
- "Baby talk" or talk down to people
- Assume that the person cannot make their own decisions

San Francisco Mayor's Office on Disability

# Communication Methods for People with Learning Disabilities

- •Ask the person how you can best relay information.
- •Demonstrate the task while giving verbal instruction.
- •Break learning down into smaller steps.
- •Try to minimize distractions.  Move person to a quieter environment, if possible.

# Communication Methods for People with Mental Disabilities

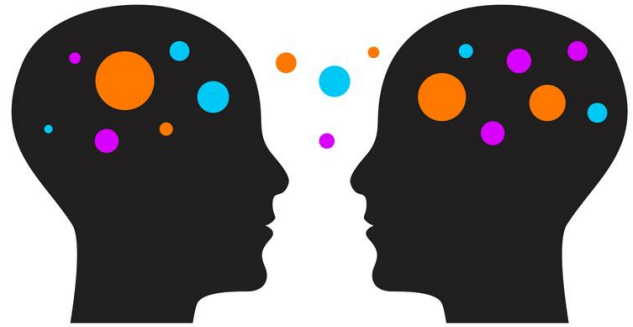
- Speak calmly and quietly
- Respond with quiet reassurance Slow down the pace
- Be willing to repeat yourself

EMPATHY

- Listen carefully and don't interrupt
- Be respectful
- Do not challenge delusions
- Make no sudden moves
- Be patient

# Communication Methods for People with Mental Disabilities

- Some people might experience hallucinations or delusions –this is their reality.
- Communicate that you understand but don't pretend that you experience it.
- Some people may be frightened; be mindful that they may need more personal space then you.
- Do not pass the person to another person just to get rid of them.
- Refer them to someone else only when it is an appropriate referral.
- If needed, set limits with the person as you would with anyone.
- If you are limited on time tell them, "I have only 10 minutes to talk with you".
- If they scream, say, "If you scream, I will not be able to talk with you".



EMPATHY

# Case Study: Harry's Story

- Harry (45) lives in disability **supported accommodation**. He has intellectual disability, mental health concerns and needs communication support. Harry has an ingrown and infected toenail which might require a **medical procedure**. He is afraid of being in healthcare facility settings with people he does not know, especially as his past visits to clinics were not pleasant experiences.
- The staff at Harry's supported accommodation house are not sure about the health system and Harry's health needs. Harry does not have a regular general practitioner, but staff, after some effort, were able to get referrals to appropriate health specialists.
- Eventually Harry receives a letter to attend a clinic.
- Health staff in the clinic are unfamiliar with working with people with intellectual disability and their lack of confidence and communication skills unnerves Harry. He becomes anxious and wants to go home. In the confusion of the moment, there is no time for health staff to assess Harry's needs around **communication support, mental health and intellectual disability support.**
- There is no opportunity for health staff to explore ways in which Harry's needs could be managed. Security staff are called to contain the situation as Harry becomes more frightened and his behavior escalates. Staff are unsure what to do. They do not know where to access support and decide they are not trained to care for people with intellectual disabilities.
- Harry returns to his supported accommodation without being assessed. He refuses to consider attending the next clinic appointment.

NCHPH
National Center for Health in Public Housing

# Case Study Review

- Apply active listening and empathy to de-escalate tense situations
- Model the use of respectful language
- Maintain a composed tone during interactions with an autistic patient
- Identify and apply appropriate conflict resolution strategies
- Demonstrate collaborative problem-solving techniques
- Address the underlying issues contributing to anxious and overwhelming behavior

NCHPH
National Center for Health in Public Housing

# How to interact well with individuals with disabilities?

If we don't want to be hyperfocused or assume the worst . . .

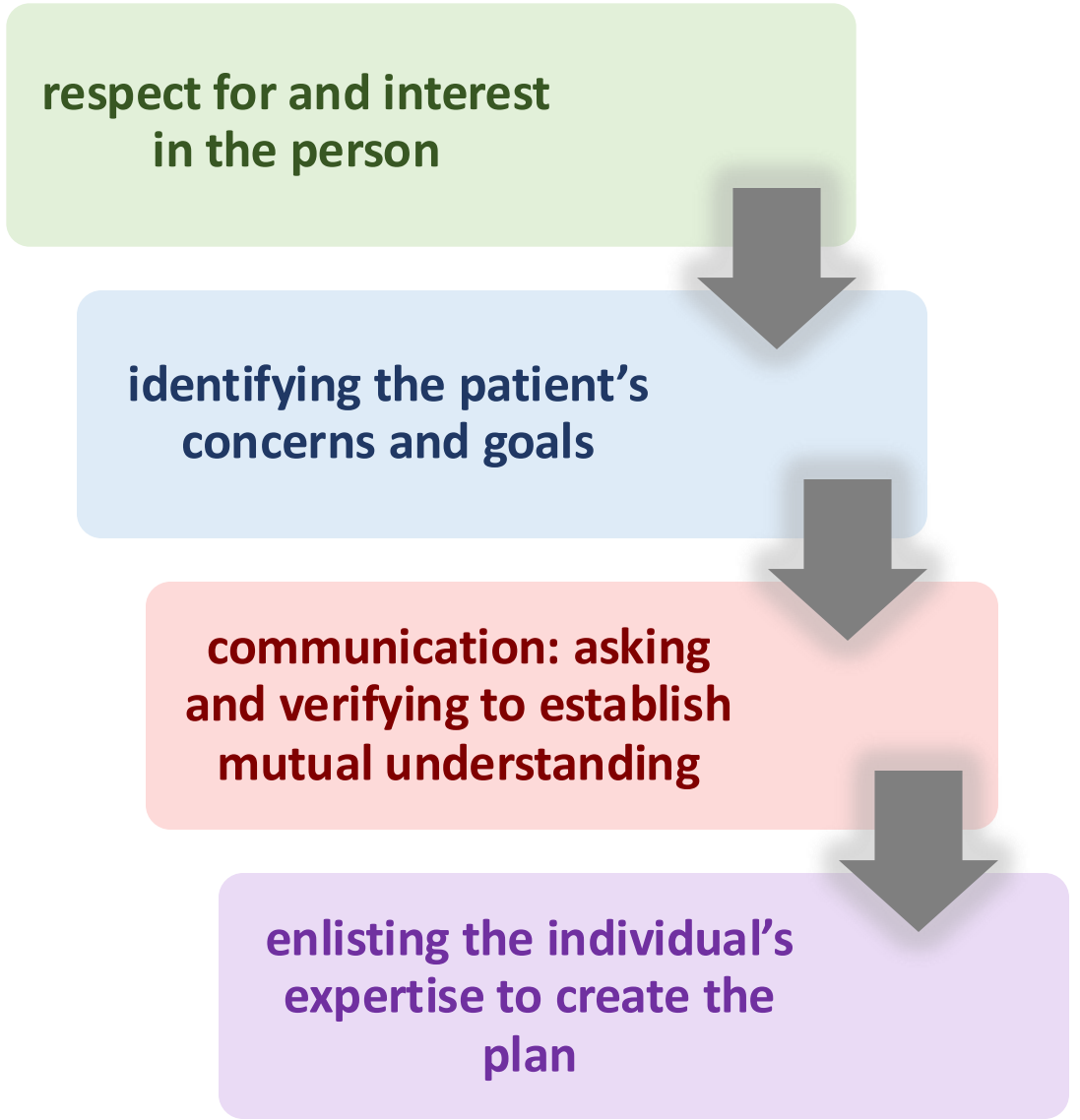
yet, we don't want to ignore the disability as we make recommendations . . .

**How do we avoid feeling like we are walking a tightrope?**

Hearn SL, Hearn PJ. Working with people with disabilities

NCHPH
National Center for Health in Public Housing

# Consider the following foundation for care:

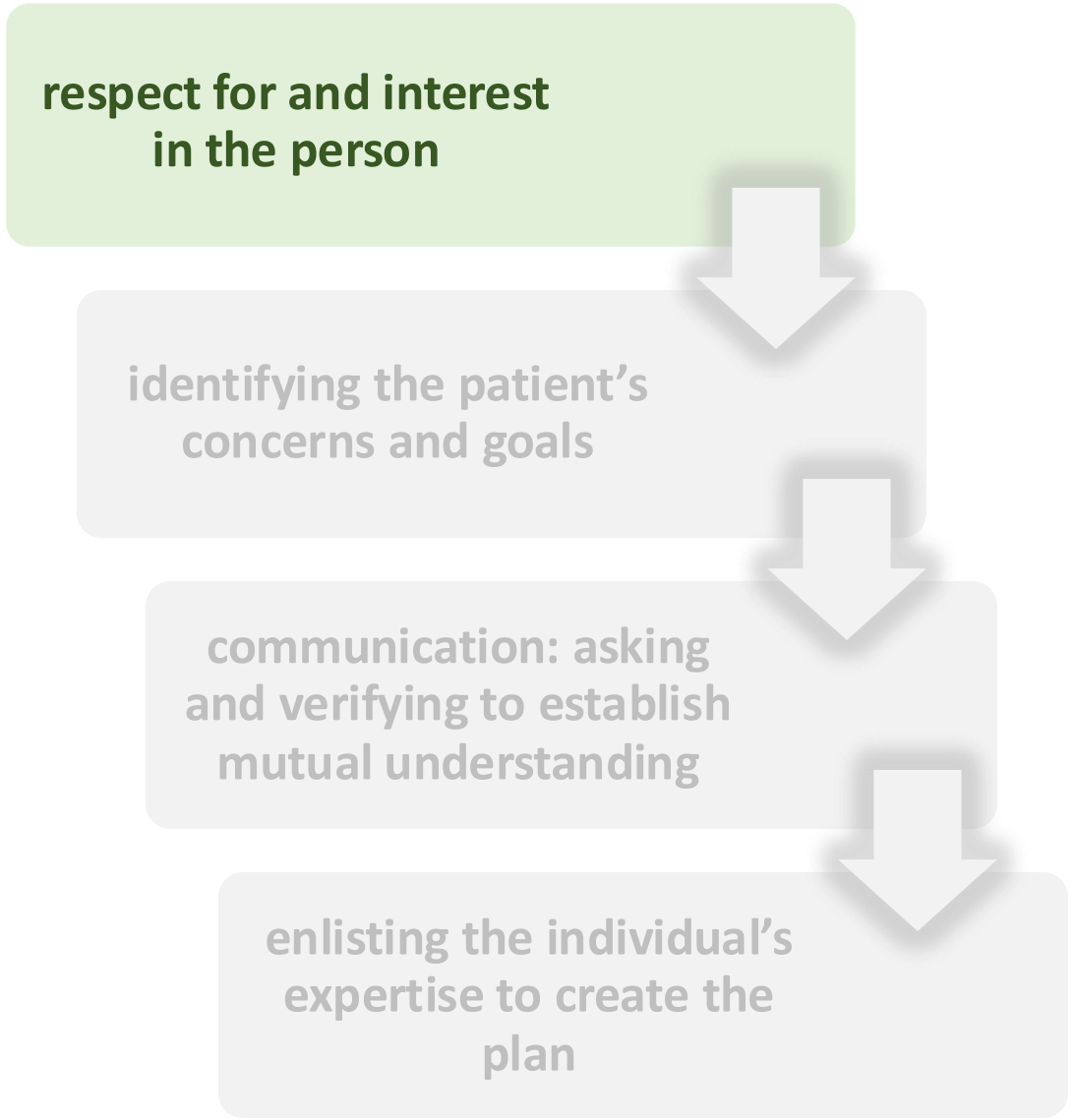



framework built from components from Rider and Keefer (2006)

# Some practical tips . . .

## respect for and interest in the person

- Make an effort to shake hands.
- For the visually impaired, introduce yourself when you enter a room; let him know when you leave. Let him know before making physical contact and ask permission.
- Talk at eye level.  If needed, grab a seat or crouch down.
- Respect personal space: treat wheelchairs, prosthetic limbs, and gait aids as extensions of the person's body.  Do not lean on these items or touch them without permission.
- Don't overly praise normal tasks or use a child-like voice with adults.




Hearn SL, Hearn PJ. Working with people with disabilities

NCHPH
National Center for Health in Public Housing

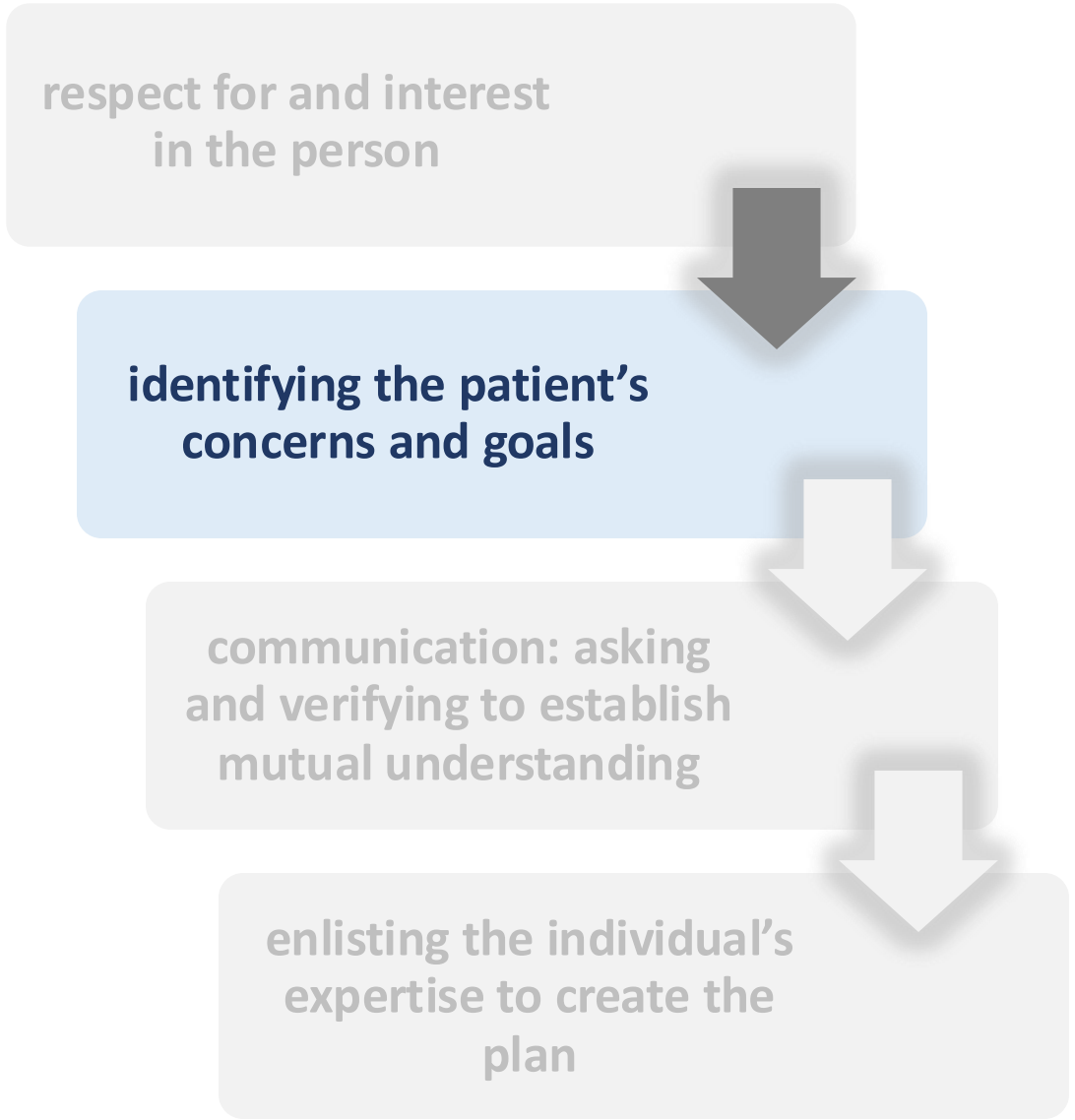
# Some practical tips . . .

## identifying the patient's concerns and goals

- Unless pertinent to presenting medical issue, consider deferring inquiry into the origin of disability .

  (perhaps at all, perhaps until more of a relationship has been established)

- Focus the encounter on the patient's needs.

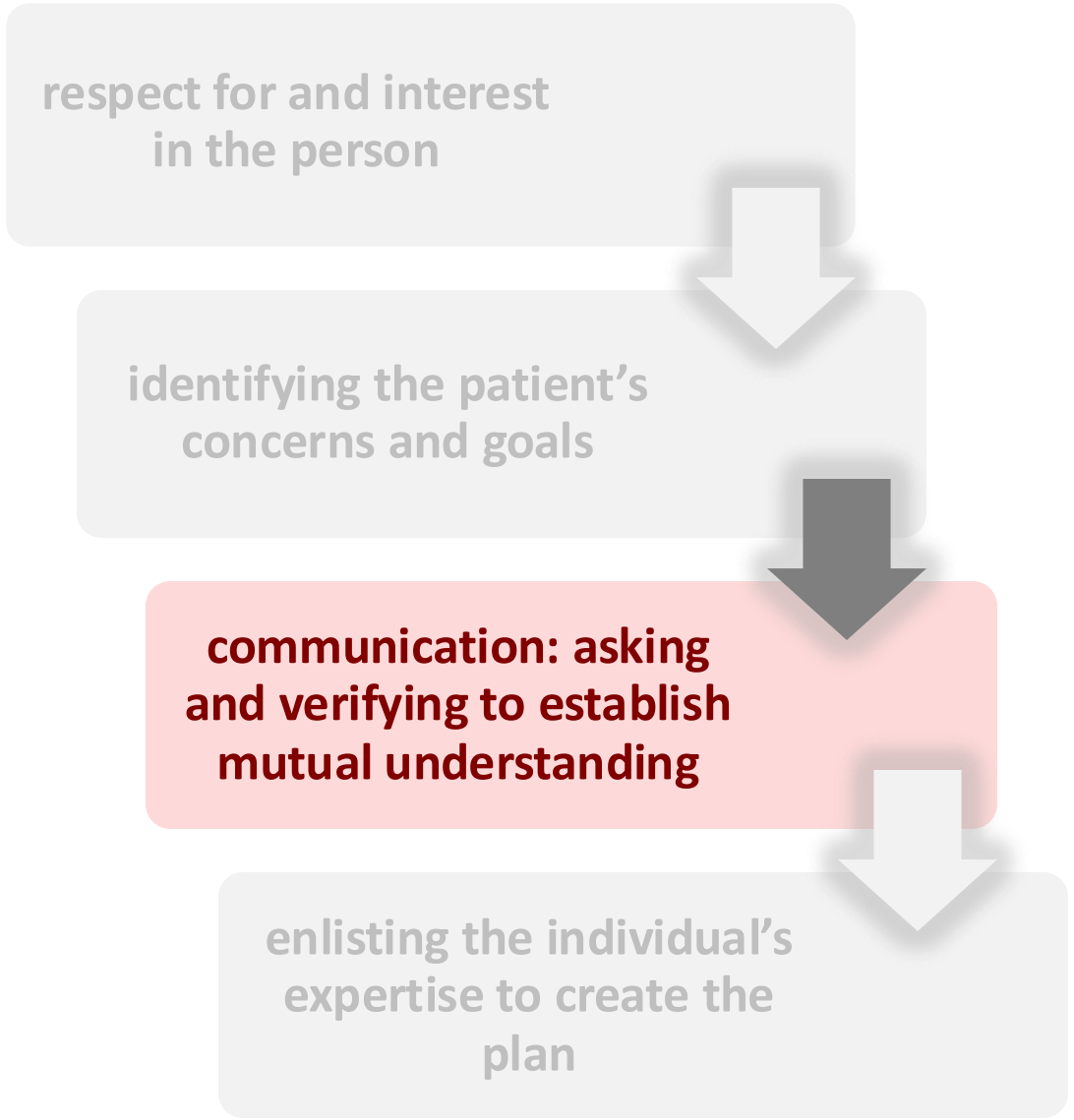



NCHPH
National Center for Health in Public Housing

# Some practical tips . . .

## communication: asking and verifying to establish mutual understanding

- Be patient if they take longer to speak/communicate.
- Talk to the patient, not the caregiver or interpreter.
- Ask for clarification if you cannot understand.
- If you are not sure if communication is working, ask. For example: “Am I speaking at a good volume?”

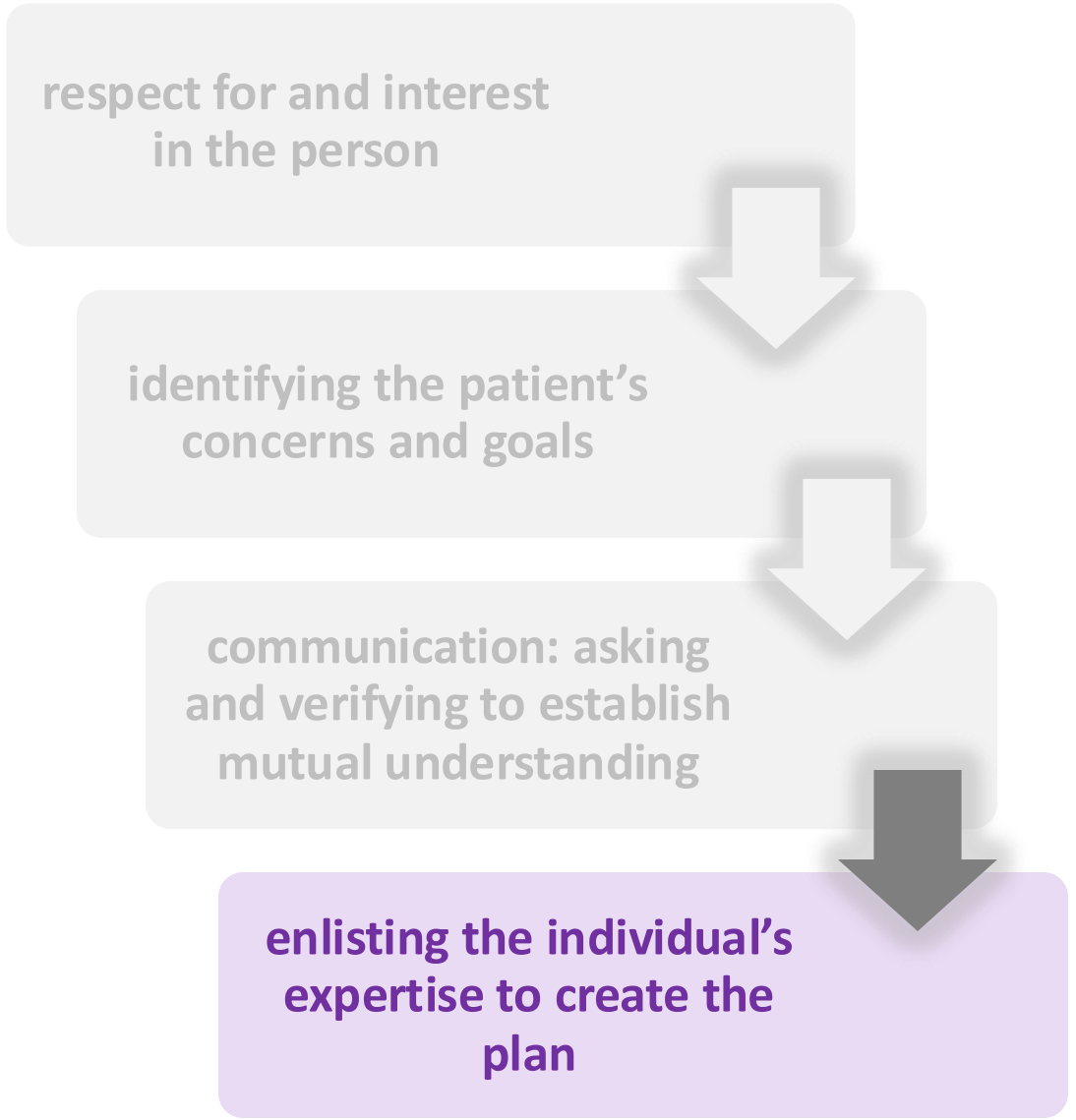



NCHPH
National Center for Health in Public Housing

# Some practical tips . . .

## enlisting the individual's expertise to create the plan

- Acknowledge person's expertise in this particular disability, and his/her ability to be innovative with it. Problem solve together with the patient!
- Don't be afraid to ask—what her needs are, how we can help, what she prefer, etc.
- If you don't know how to help the patient, know where you may be able to turn for more expertise:
  - Physical Medicine and Rehabilitation consultation
  - physical and/or occupational therapy
  - neurocognitive testing
  - social work department




NCHPH
National Center for Health in Public Housing

# Refer to people with disabilities as people first.

Consider **People First Language**.

a person
a lady
a gentleman

*with*

*who uses a*

. . . .

| **say:** | not: |
| --- | --- |
| person with Down syndrome | mongoloid |
| person with a disability | the disabled, handicapped |
| person with multiple sclerosis | afflicted by MS |
| person who uses a wheelchair | wheelchair bound |

Reference: Centers for Disease Control and Prevention

# In summary. . . .

**Disabilities may make us nervous.**

- because they represent differences, and the unfamiliar or unknown
- understanding our reactions is important so we can be mindful in our behaviors

**We want to be mindful about disabilities, without letting our assumptions dominate the encounter.**

**Unfortunately, health care provider attitudes can create barriers, by:**

- making assumptions about the disability
- getting too focused on or distracted by disability
- neglecting standard care
- pushing recommendations that are not feasible

**When working with patients and disabilities:**

- respect and focus on the individual
- address his/her concerns and goals
- communicate (ask and verify) to establish understanding
- involve the patient in establishing a plan

NCHPH
National Center for Health in Public Housing

# A Quick Review

It's always a good idea to ask people how they receive information.

- Find out which learning technique, such as hearing, reading, viewing, or doing, works best for the person.
- Present complicated information in a variety of ways during the course of an interaction.
- Ask if you don't understand a person. Don't pretend to understand if you don't.

- Not every disability is visible

- Provide a quiet environment free of distractions.
- Be flexible and try different methods to make yourself understood.
- Ask open-ended questions.
- Break complicated instructions into single steps.

# A Final Word RELAX!

Respectful and compassionate attitude is key to effective communication


Source: CDC.gov


## Inclusive Healthy Communities Model

The **Inclusive Healthy Communities Model** uses a phased approach to create local-level change by using community coalitions to plan and implement sustainable healthy living improvements. Through policy, systems, and environmental (PSE) changes, this model focuses on increasing access to healthy living opportunities, such as

- Healthy eating;
- Physical activity;
- General accessibility improvements; and
- Tobacco use prevention or cessation.

Source: CDC.gov

# Inclusive Healthy Communities Model Resources

CDC's Resources on this Slide

- Inclusive Physical Activity
- Inclusive Climbing Wall
- Park Project for People of all Abilities
- Inclusive Healthy Design Workshop
- Accessible Streets
- Making the Monday Mile
- New Adapted Bikes
- Better Nutrition and Physical Activity
- Building an Accessible Downtown
- First Mobility-charging Device

NCHPH
National Center for Health in Public Housing

# Q&A Session

# Complete our Post Evaluation Survey

National Center for Health in Public Housing

# Contact Us


**Robert Burns**
Program Director
Bobburns@namgt.com

**Jose Leon, M.D.**
Manager of Clinical Quality
jose.leon@namgt.com

**Kevin Lombardi, M.D., M.P.H.**
Manager of Policy, Research, and Health Promotion
Kevin@namgt.com

**Fide Pineda Sandoval, C.H.E.S.**
Training and Technical Assistance Manager
Fide@namgt.com

**Chantel Moore, M.A.**
Manager of Communications
Cmoore@namgt.com

Please contact our team for Training and Technical Support
703-812-8822


NCHPH
National Center for Health in Public Housing

# Thank you!