SANFORD HEALTH

ACCESSIBLE PATIENT CARE

THE OFFICE OF HEALTH EQUITY & EXPERIENCE

AN IMPORTANT NOTE

Participation in this training opportunity is not required. While your participation is encouraged and a valuable part of development in caring for patients of all demographics, we want to emphasize that participation is voluntary and will have no impact on your job status, performance review, compensation or employment.

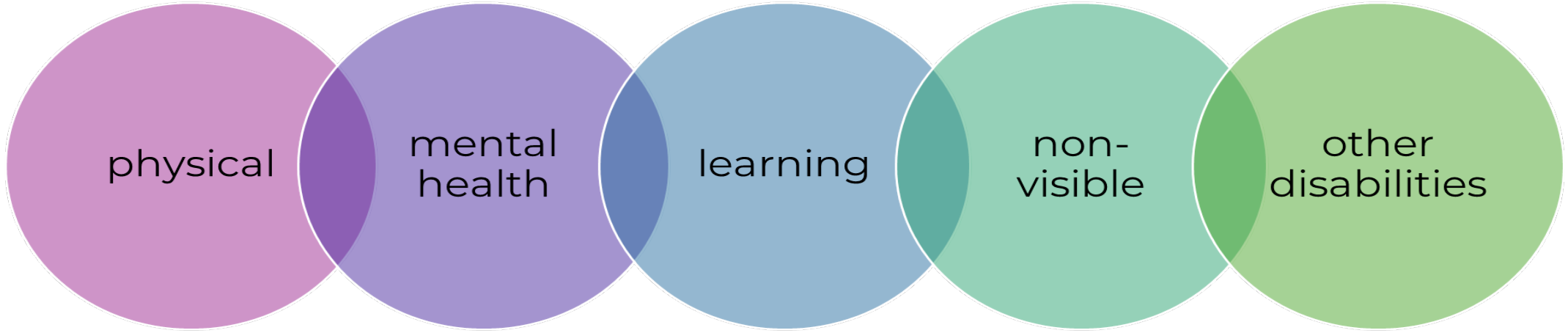
LANGUAGE CONSIDERATIONS



Put the person before their disability. However, individuals may have their own preferences on language
E.g. This would be to say, “My son Will has autism” whereas identity first language emphasizes the disability and would be “My autistic son Will.”

Language is ever-changing

TYPES OF DISABILITY



Physical disabilities -These can include loss of a limb, difficulty with mobility, or muscle control. Physical disabilities can be caused by accidents, brain injuries, infections, diseases, or other conditions.

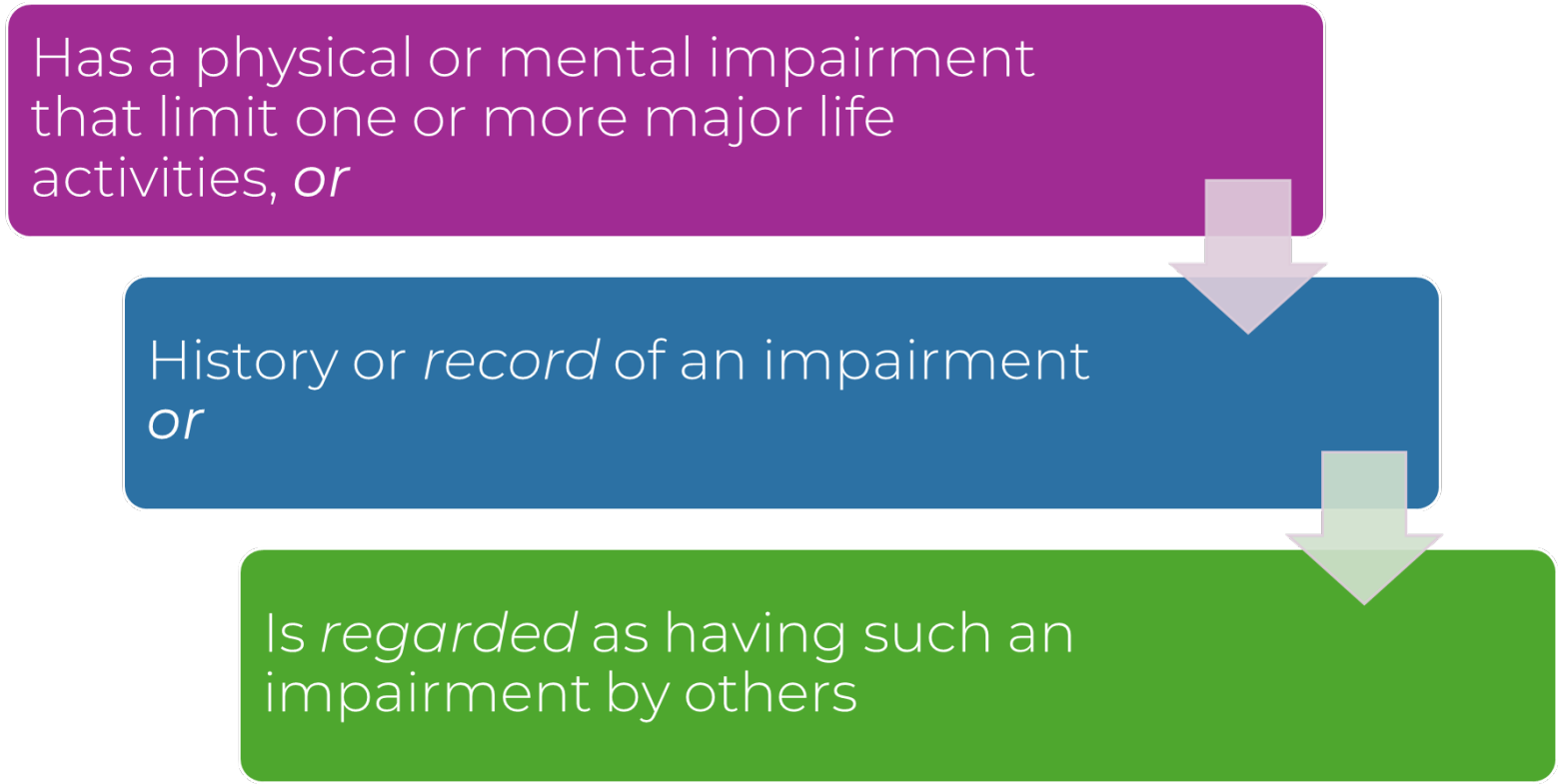
Mental health disabilities- These can include anxiety, depression, schizophrenia, and mood disorders.

Learning disabilities- These can include dyslexia, dysgraphia, and dyscalculia. Dyslexia is a learning disability that affects reading, while dysgraphia is a learning disability that affects writing.

Non-visible disabilities -These can include mental health conditions, hearing loss, sensory and processing difficulties, and cognitive impairment.

Other disabilities- These can include autism spectrum disorder, intellectual disability, speech and language disability, and multiple disabilities.

AMERICANS WITH DISABILITIES ACT (ADA)



The ADA defines a person with a disability as someone who:
•Has a physical or mental impairment that substantially limits one or more major life activities, or
•Has a history or *record* of an impairment (such as cancer that is in remission), or
•Is *regarded* as having such an impairment by others even if the individual does not actually have a disability (such as a person who has scars from a severe burn that does not limit any major life activity).

MAJOR LIFE ACTIVITY

- Actions like eating, sleeping, speaking, and breathing.
- Movements like walking, standing, lifting, and bending.
- Cognitive functions like thinking and concentrating.
- Sensory functions like seeing and hearing.
- Tasks like working, reading, learning, and communicating.
- The operation of major bodily functions like circulation and reproduction.
- The function of individual organs like the heart, lungs, or pancreas

Major life activities are basic activities that most people can perform with little or no difficulty. Some examples of major life activities are listed on the slide:

Source: https://adata.org/factsheet/ada-definitions

WHO – 3 DIMENSIONS OF DISABILITY

Impairment in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss.

Activity limitation, such as difficulty seeing, hearing, walking, or problem solving.

Participation restrictions in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services.

The World Health Organization defines disability as having three separate dimensions to it.
Resource: CDC Disability and Health Promotion site
https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html#:~:text=Impairment%20in%20a%20person's%20body,%2C%20walking%2C%20or%20problem%20solving.

CAUTION



Lots of definitions



Who is defining?



Who is being asked?

Do you notice the complexity of these different definitions? Among federal statutory definitions of disability, a report found 67 different definitions. Note **who** is defining…and **who** is being defined. The definitions on the previous slides are based in a medical framework for understanding disability. They are also founded in a deficit framework, rather than a strengths framework. Perhaps we should consider something different…

THE SOCIAL MODEL OF DISABILITY

- Most accurate to understand lived experiences of people with disabilities.
- Distinguishes between *impairments* versus *disabilities*
- Impairments are what is difference of the person's body or mind. Disabilities are the social responses to the impairments one has.

Example:

A person might use a wheelchair because of a spinal **impairment**, but what **disables** them is a society without ramps and elevators, and culture with stigma and discrimination in education, labor, and so on.

Disabilities scholars have long suggested we look at disabilities from a social model. Note the distinction between impairments and disabilities.
Source : https://jamanetwork.com/journals/jama-health-forum/fullarticle/2819894

INEQUITIES ASSOCIATED WITH DISABILITY POPULATIONS

In 2023 the NIH designated disabled people as a health disparity population

People with disabilities experience increased rates of chronic health conditions

3 times more likely to experience diabetes, arthritis, or heart attack

5 times more like to experience depression, COPD, or stroke

Often decreased preventative care or health maintenance.

People with disabilities consistently report higher rates of obesity, lack of physical activity, and smoking. Some also have higher rates of newly diagnosed cases of diabetes, and their percentages of cardiovascular disease are 3 to 4 times higher. Although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly less likely to receive preventive care. As an illustration, people with cognitive limitations are up to 5 times more likely to have diabetes than the general population while potentially receiving less adequate management care. Inclusion of people with disabilities is critically important as agencies coordinate efforts[51] to prevent and manage chronic diseases and conditions like diabetes, cardiovascular disease, and hypertension.

Reference articles:

https://pmc.ncbi.nlm.nih.gov/articles/PMC4355692/#:~:text=People%20with%20disabilities%20consistently%20report,of%20physical%20activity%2C%20and%20smoking.&text=Some%20also%20have%20higher%20rates,3%20to%204%20times%20higher

https://jamanetwo

REPRODUCTIVE HEALTH GAPS

- Caesarean birth rates
- Less choice in birthing plans
- Higher risk of pre-natal health concerns
- Less timely prenatal care
- ~20% of deliveries are to birthing parents with disabilities
- Barriers to contraceptive care
- Lack of clinician knowledge
- Dobbs

Caesarean birth more likely for people with disabilities, even as rates of c-sections among non-disabilities populations rise and fall. Birthing parents with disabilities were more likely to have c-sections even in the absence of circumstances we generally look for to indicate a c-section is needed – per review of chart coding.

Qualitative studies show increased responses from birthing parents with disabilities reporting that they were not given a choice of birthing plans and are often assumed to be high risk based solely on their identity of having a disability. C-sections of course bring greater risk due to surgery and longer length of stay, followed by greater need of support upon discharge, which based on SDoH may or may not be available to them.

Birthing people from the disability population have higher rates of tobacco use, experience higher rates of obesity, diabetes, and hypertension, and have less social support and poorer mental health.

When studies used self reported data, rather than trying to extrapolate from coding data, 1 in 5 births are to birthing parents with disabilities

Barriers to contraception including physical barriers to getting in the clinics, lack of ASL interpretation, lack of written information in alternative formats, lack of appropriate education for IDD patients, lack of insurance coverage as many folks with disabilities are on Medicare before age 65, however as that insurance coverage is designed for a majority elder population many plans don't cover contraceptives, or limit types covered

Lack of research means lack of clinical knowledge on how some types of hormonal contraceptives will interact with their types of disabilities, medication interactions, etc.

With the decision of Dobbs vs Jackson, has significantly limited abortion availability which often means that folks with need of an abortion must travel farther and pay more to try to receive this treatment. As people within the disability population have statistically lower economic wellbeing, greater challenges related to mobility, and more potential for chronic health condition, they have had even greater difficulty navigating this health challenge.

Resource: Podcast – "Inlcuded The Disability Podcast" from John's Hopkins University Disability Health Research Center

IMPACT OF COGNITIVE SHORTCUTS



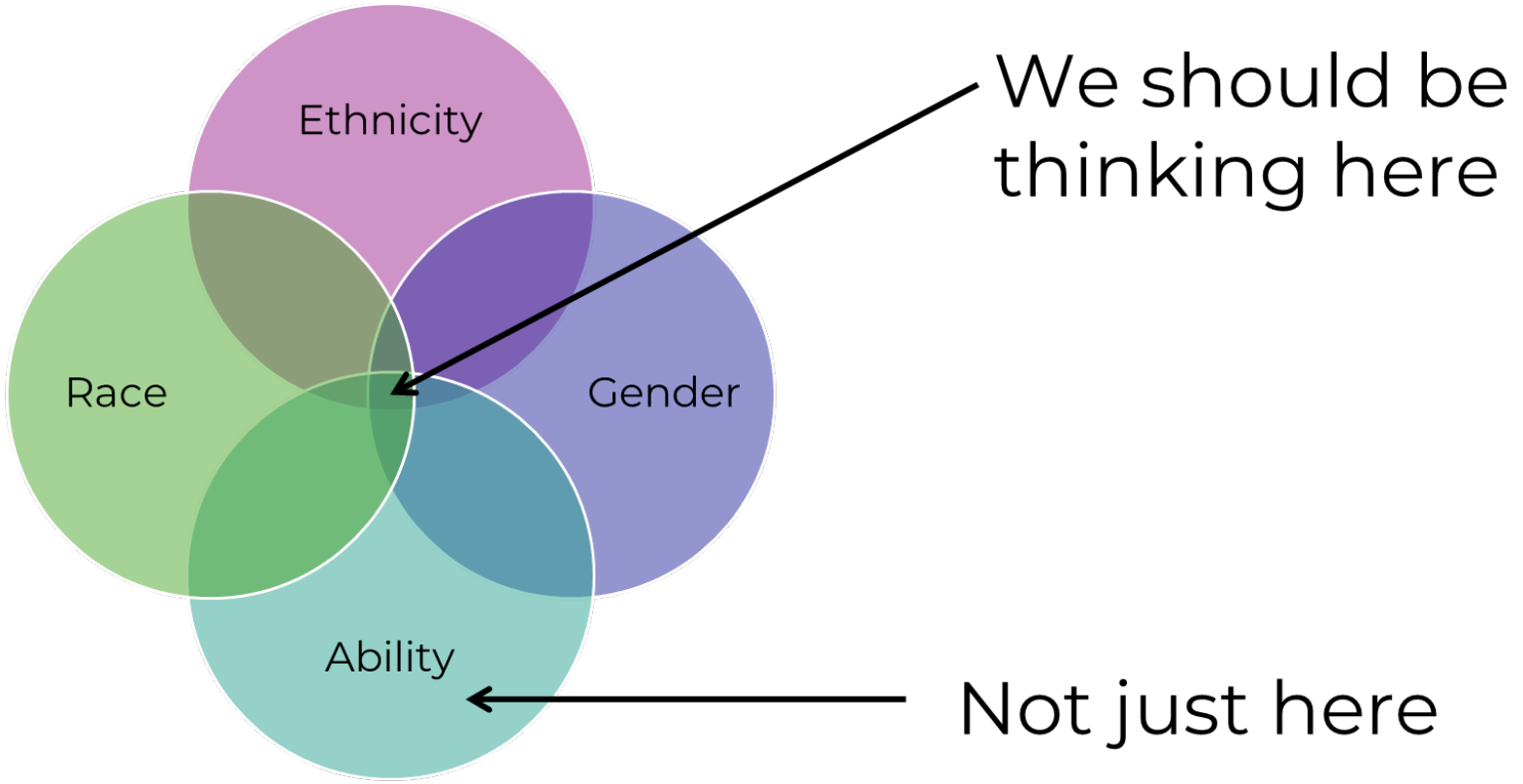
In a 2021 study 714 physicians surveyed showed that 82.4% believed that people with “significant disability” have worse quality of life (QoL) than people without disabilities. This is a troubling when compared with social scientific research exploring disability and QoL over the last 30 years has shown that people with any type of disabilities, significant or not, have similar levels of QoL as those without disabilities. Disability is often linked to an assumption of experienced pain and suffering which can mislead clinicians into assuming that disabled patients are, overall, living terrible lives.
A health disparities framework instead suggests that most disabled people instead face adversity because of the chronic lived experience within a culture that is inaccessible, discriminatory, ableist, and stigmatizing for people with disabilities.

Structural inequities can be everything from how our healthcare facilities are designed, to how we complete the business of healthcare. In many clinical practices how the departments are run, how appointment times are structured, etc are based on the assumption of a patient without disabilities. In surveys with physicians only 40% reported being very confident they could provide the equitable care to patients with a disability. Only 56.5% strongly agreed that people with a disability are welcomed within their practices.

SDoH – increased rates of disabilities within lower socioeconomic populations, and harder on those populations because they require greater amounts for assistance, so the gap between what they have and what they need can be wider. (lack of celiac safe food at food pantries, etc)

Resource:
https://jamanetwork.com/journals/jama-health-forum/fullarticle/2819894

INTERSECTIONALITY



- first described by legal scholar Kimberlé Crenshaw in 1989
- defined as the interconnected nature of social categorizations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination of disadvantage

INTERSECTIONALITY IN DISABILITY POPULATIONS

Statistic Black Americans with Down Syndrome

The life expectancy within Down Syndrome population

Being a part of a second marginalized identity

Ethnic or racial minority group members with mobility limitations

Disabilities within the LGBTQIA2S+ community

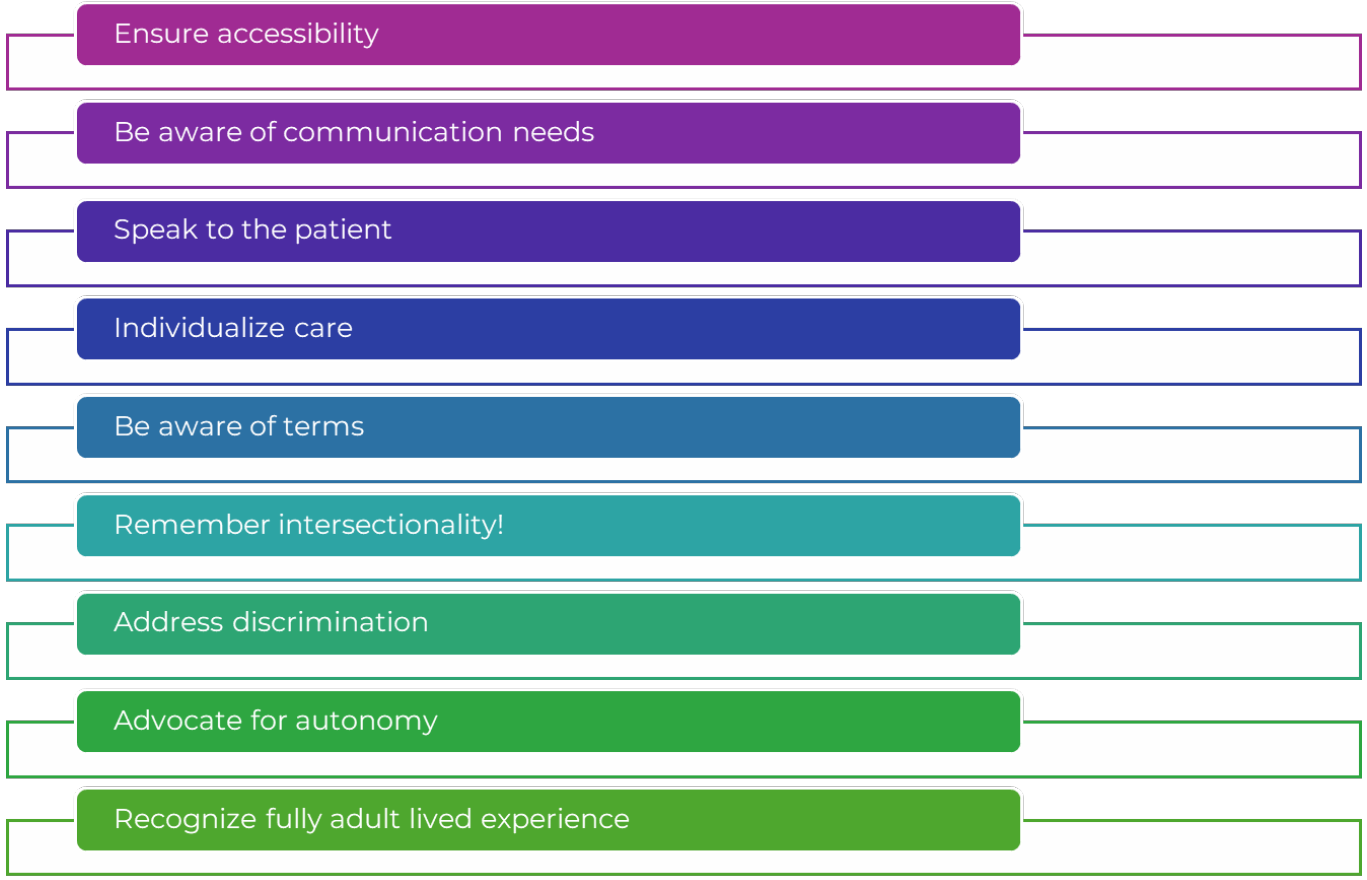
Transgender identity within ASD population

•Blacks Americans with Down syndrome are greater than 7 times as likely to die by age twenty than their White Americans to die by age 20.
•The life expectancy for White people with Down syndrome is around 55 years, and only 25 years for patients with Down syndrome who are Black.
•Being a part of a second marginalized identity while having a disability exposes you to greater disparities than White individuals with disabilities.
•Adults with intellectual and developmental disabilities who identify as Black or Latino have increased rates of reporting fair or poor physical and mental health than Whites with disabilities.
•Ethnic or racial minority group members with mobility limitations are more likely to experience depression or have diabetes, hypertension, or vision impairment than White people with mobility impairments.
•People living with disabilities who are members of the LGBTQIA2S+ community are more likely to report diminished health-related quality of life.

RESOURCES

- Special Olympics
- American Association for People with Disabilities
- The ARC of the United States
- Occupational Development Center
- Inclusive school programs
- Community support groups
- Religious affiliation support groups
- Many, many, more

IMPLICATIONS FOR CLINICIANS



Ensure accessibility within the healthcare facility you work
Be aware of communication needs including items like large print, Braille, appropriate reading level, etc.–
Speak to the patient
Individualize care get to know that patients as individuals, not just their disability
Be aware of terms – older terms such as “slow”, “handicapper”, “special needs”, “crippled”, wheelchair bound”, “mental retardation”
Remember intersectionality – their experience is so much more that the disability on their diagnosis list. They have Ethnic identities, religious affiliations, racial identities, sexual orientations, gender identities, and on and on
Address discrimination – speak up if you witness inequitable treatment
Advocate for autonomy – Having a disability does not immediately disqualify a person from participating in their decisions on their care. Ensure that your patients are being given all choices that those without disabilities would have, unless there is a concrete clearly documented reason medical reason not to do so.
Recognize fully adult lived experiences – There is a lot of data to show that people with disabilities can have challenges living full life experiences, especially regarding physical intimacy.

For example a 2022 Journal of American Nursing Association article showed that previous models of care in group housing settings restricted or repressed behaviors related to sexuality within the intellectual and developmental disability population, particularly for those of the LGBTQIA+ population. However, meaningful, consensual, healthy relationships can assist adults with finding love, building resilience, decrease psychopathology, and improve health.

Echezona-Johnson C. Support of LGBTQ+ People with Intellectual and Developmental Disabilities in Group Homes. *Journal of the American Nurses Association - New York (JANANY)*. 2022;2(2):35-42. doi:10.47988/janany.444764667081.2.2

AUXILIARY AIDS AND COMMUNICATION

The type of auxiliary aid or service necessary to ensure effective communication depends on:

- The method of communication used by the individual;
- the nature, length, and difficulty of the communication taking place; and
- the complexity of what is being communicated.

Auxiliary aids and services must be provided in accessible formats, in a timely manner, and in a way that protects the privacy and independence of the individual with a disability. A public entity or private business cannot impose a surcharge on an individual with a disability to cover the costs of the auxiliary aid or service provided.

Aids and Services may include:

- Accessibility features in electronic documents and other electronic and information technology that is accessible (either independently or through assistive technology, such as screen readers, speech-to-text programs, and text-to-speech programs).
- Assistive listening systems and devices.
- Computer Aided Real-time Translation (CART).
- Documents in large print or electronic formats.
- Laptop magnification software, screen reader software, and optical readers.
- Microsoft Teams captioning.
- Qualified readers.
- Sign language interpreters (on-site or video remote).
- Videophones
- Height-Adjustable Exam Table
- Transfer Board
- Low Stimulation Environment

https://www.ada.gov/resources/effective-communication/

PARTNERING WITH PATIENTS & THEIR DESIGNATED SUPPORT PERSONS

SUPPORTING PATIENT-CENTERED CARE WHILE RESPECTING PATIENT AUTONOMY

During the Visit:

- ✓ **Ask the patient first**
  - ✓ "Would you like your support person to be involved in today's visit?"
  - ✓ Document the patient's preference
- ✓ **Speak directly to the patient**
  - ✓ Maintain eye contact with the patient – not only the support person.
  - ✓ Use the support person to enhance communication, not replace it.
- ✓ **Invite participation**
  - ✓ Support persons can help by:
    - ✓ Explaining medical history
    - ✓ Clarifying questions
    - ✓ Taking notes
    - ✓ Reinforcing treatment plans
    - ✓ Assisting with medication management
    - ✓ Supporting follow-up care
- ✓ **Confirm understanding**
  - ✓ Before ending the visit:
    - ✓ Review the care plan with the patient.
    - ✓ Include the support person (if authorized).
    - ✓ Ask both if they have questions.

It's about **asking the patient who they want involved**, documenting that preference, and involving designated support persons in examinations, counseling, and treatment planning while continuing to communicate directly with the patient whenever possible.

SCENARIO

Mrs. Jones has early dementia and brings her daughter to appointments.

Instead of saying: “Does she take her medications?”

Say: “Mrs. Jones, can you tell me how you’re taking your medications? If it’s okay with you, I’d also like to hear your daughter’s observations.”



This approach:

- Keeps the patient at the center of the conversation.
- Encourages support person involvement.
- Respects patient autonomy.
- Demonstrates person-centered care.

UNIVERSAL DESIGN

Universal design is a process of considering all people , with and without disabilities in the design and creation of products.



- Sidewalk curb cut outs, automatic doors, zero step entries, hoor handles instead of knobs, etc.
- Ramps work for all those who can use stairs, but stairs cannot be used by all who can use ramps





- Plain language patient education is good for patients with intellectual disabilities and those with English as a second language. They also work for those without these challenges as well.

POSITIVE OUTCOMES

Although not guaranteed, for many folks who live to elder ages may experience impacts of aging that qualify as disability such as hearing loss, vision loss, inability to perform activities of daily living, cognitive changes, etc.

According to the U.S. Census Bureau more than 30% of U.S. citizens over the age of 65 have a disability. By age75 that number increases to 50%.

SANFORD HEALTH

THANK YOU