Inclusive Services: Approaches to Improve Sexual and Reproductive Health Care for People with Disabilities

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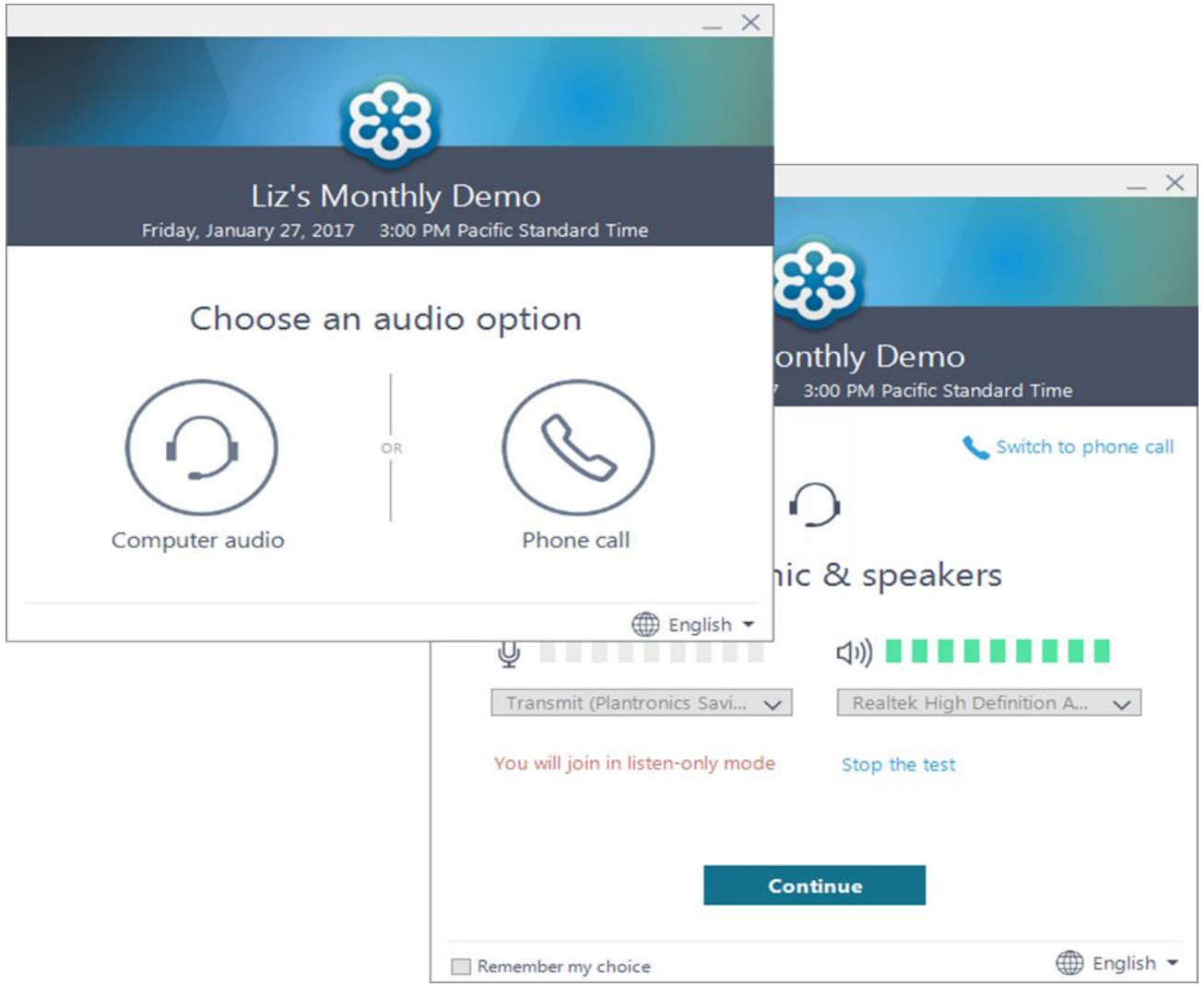

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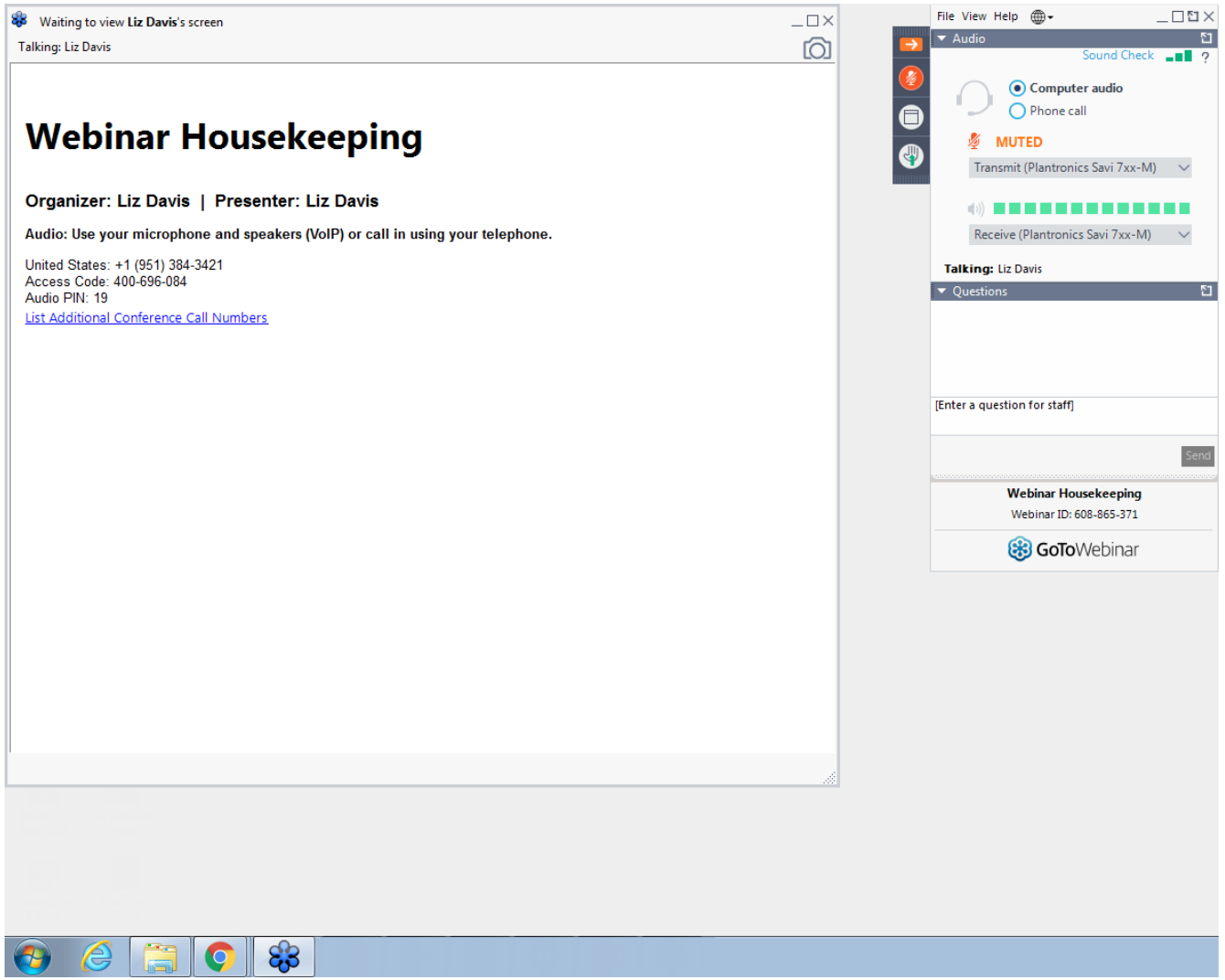

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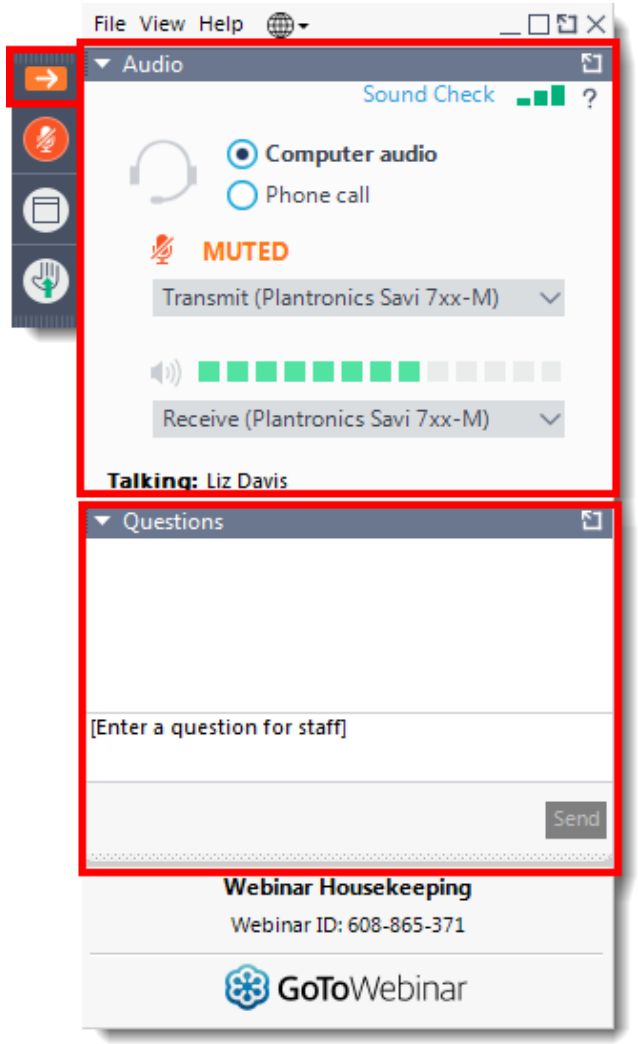

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Presenter

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- Clinical Professor Emerita at University of California, San Francisco

Presenter

Robin Wilson-Beattie (she/her)

- Disability Sexual and Reproductive Health Educator
- Certified by the American Board of Sexology and City College of San Francisco as a Sexual Health Educator

Framing this talk

"People with Disabilities" is a category that includes a very broad range of

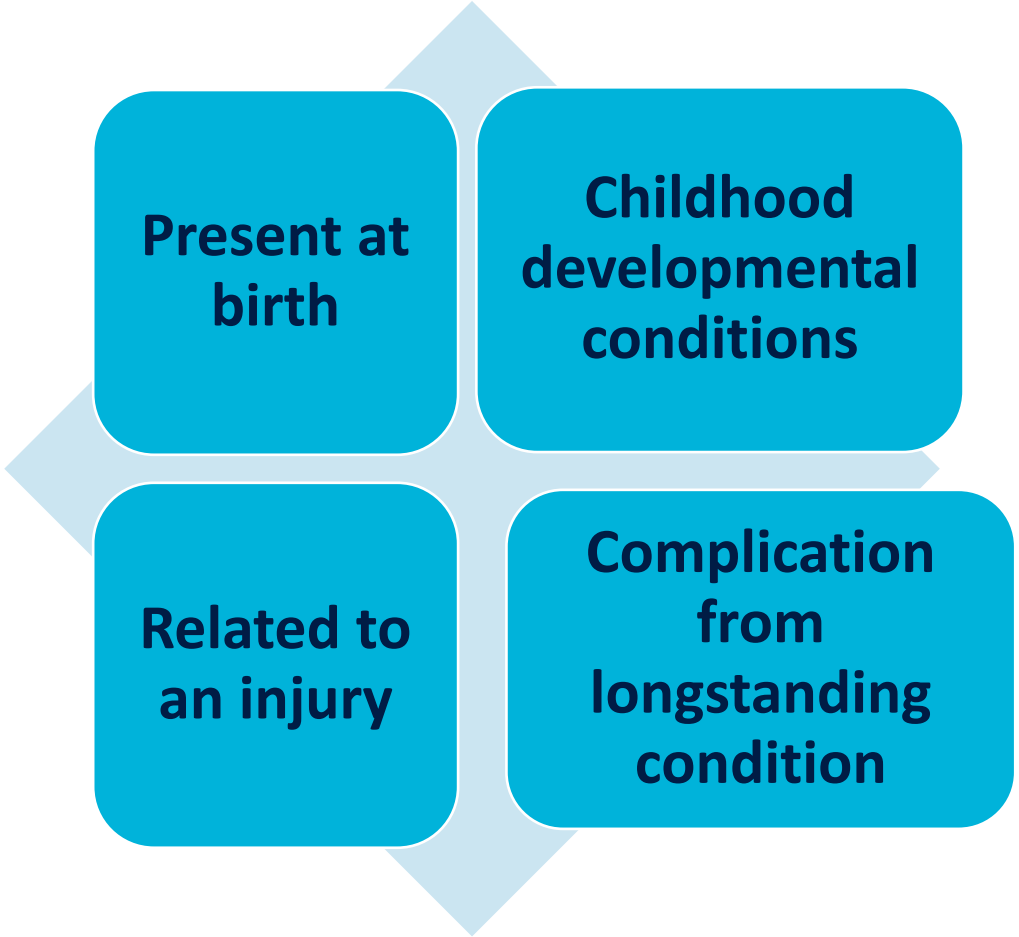
- Diagnoses
- Conditions
- Levels of function
- Strengths and challenges
- Needs for support/ facilitation

Framing this talk

This talk aims to be inclusive of this broad population

- It is challenging to define the population
- Diagnosis/condition does not define level of function
- Individualizing care is essential

Disability can be…



- Hidden or visible
- Progressive, static or intermittent

CDC, Disability and Health Overview, 2020

Models of Disability

Medical

Social

Identity

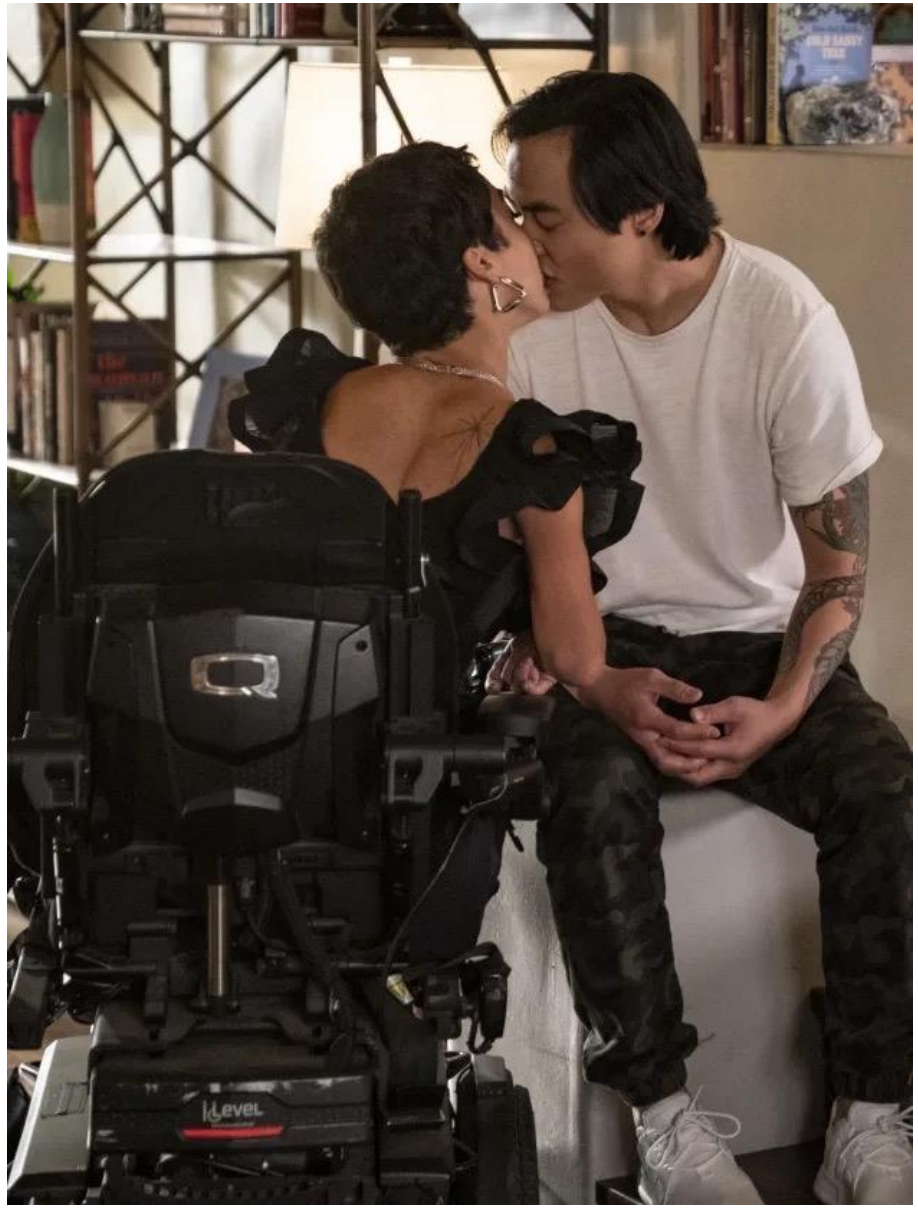
Charitable

Religious/Moral

[Models of Disability: Medical, Social, Religious, Affirmative and More…]

Intersectionality

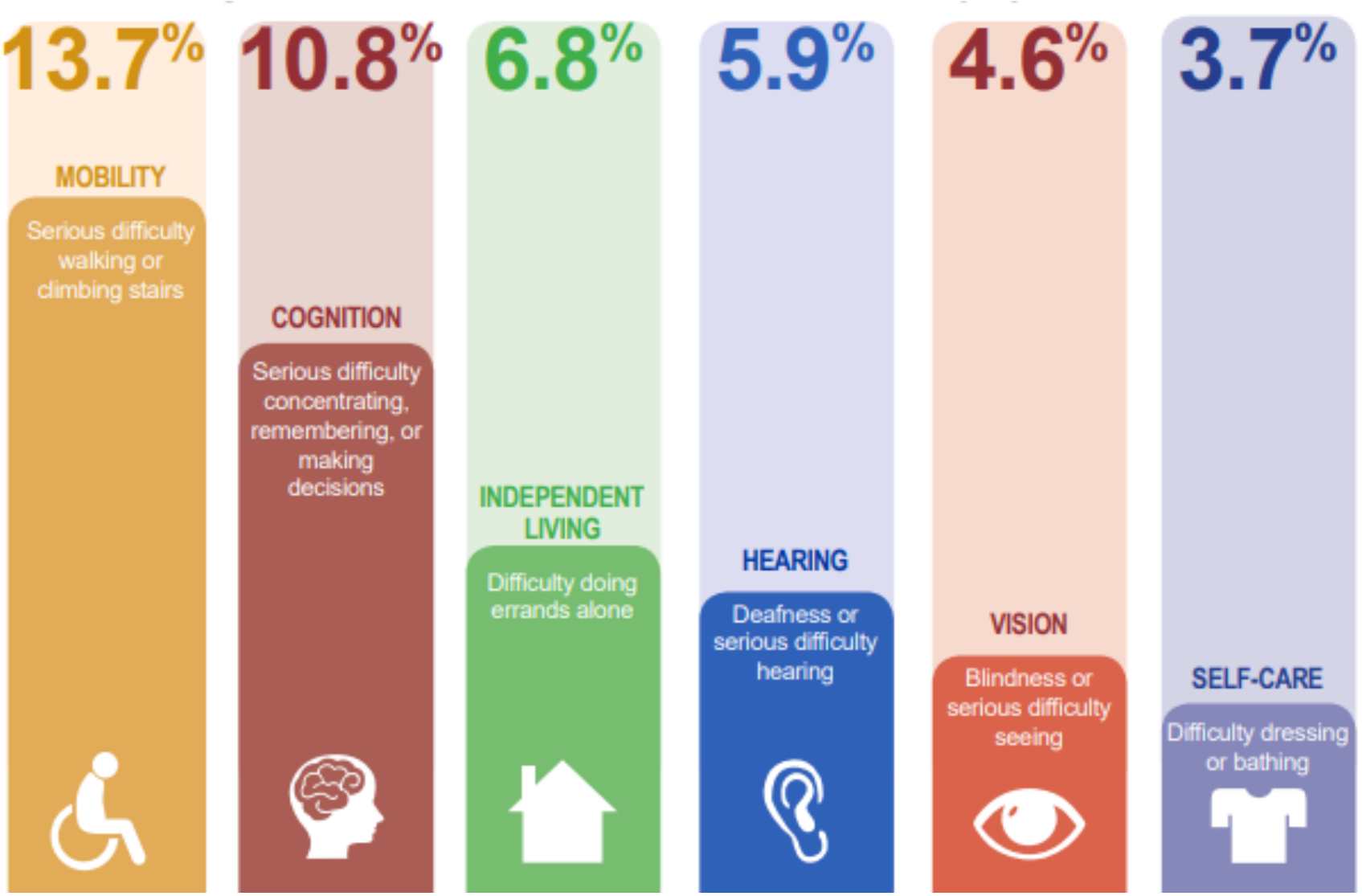
- People don’t live single-issue lives
- Race, Gender, Sexual Orientation, Economic Status, Education
- Unconscious bias in health care



“Disability Impacts All of Us” CDC Infographic

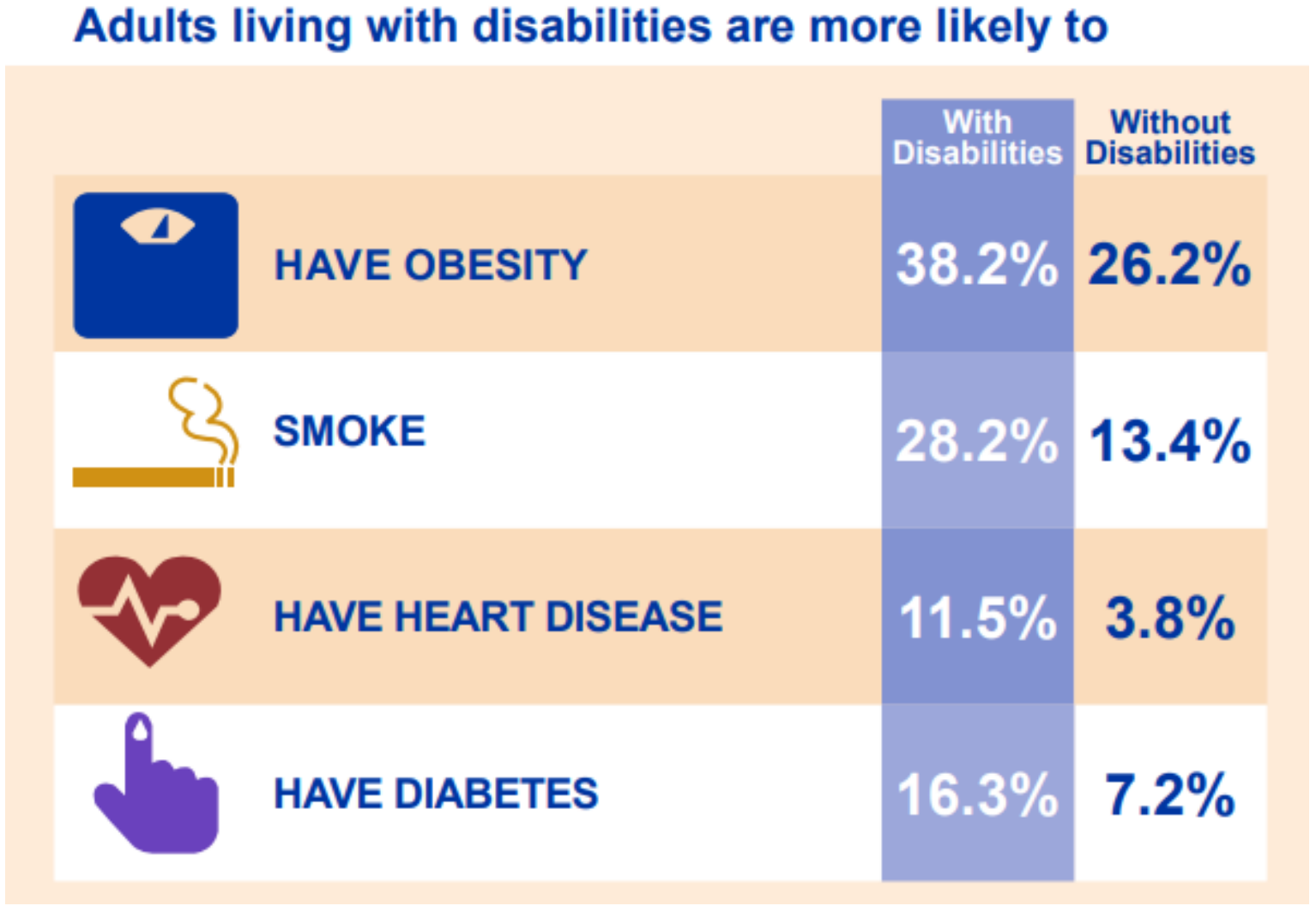
CDC, Disability and Health Overview, 2020; Okoro et al 2018, PMID: 30114005

Impacts on Function



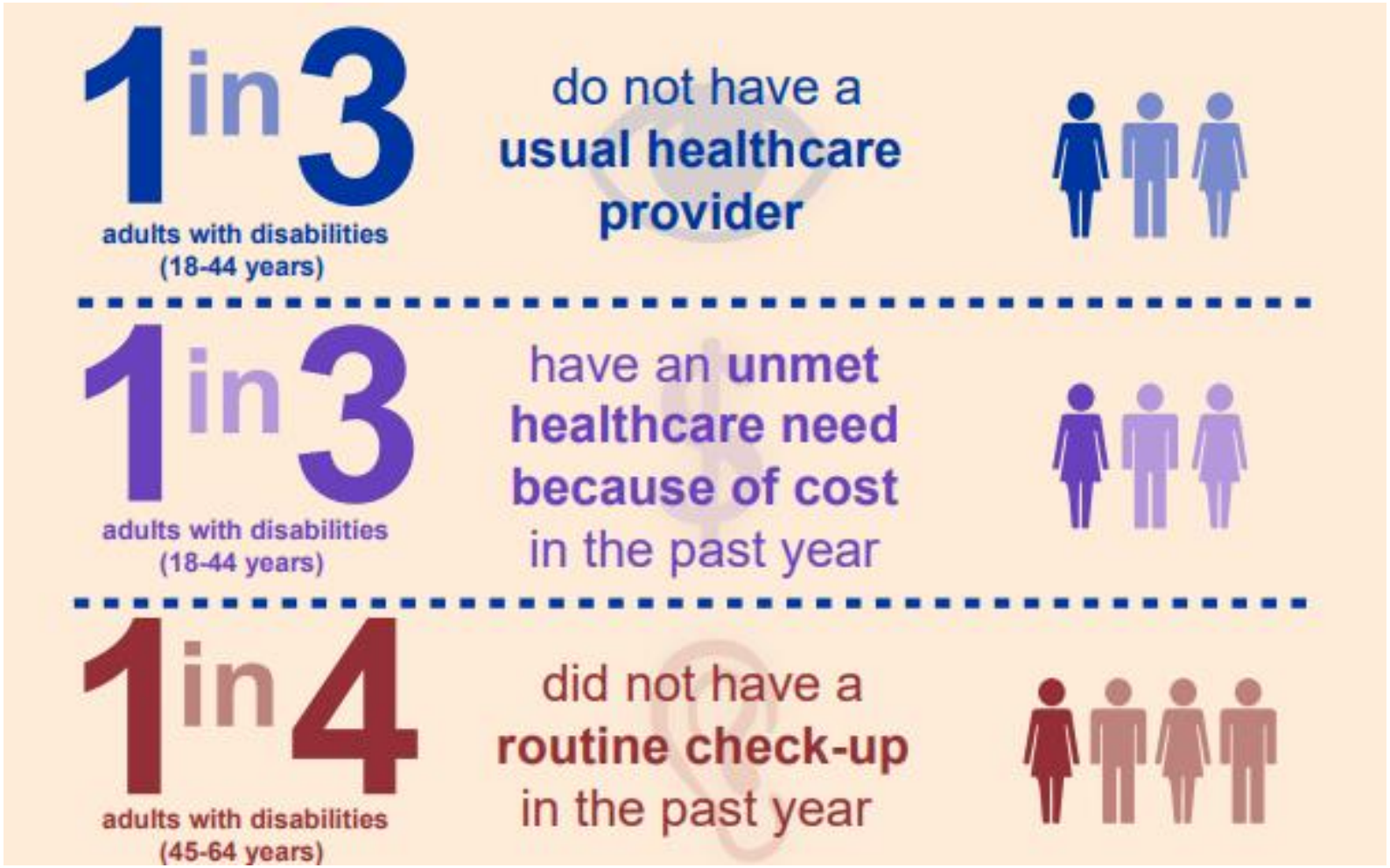
CDC, Disability and Health Overview, 2020; Okoro et al 2018, PMID: 30114005

Impacts on Health



CDC, Disability and Health Overview, 2020; Okoro et al 2018, PMID: 30114005

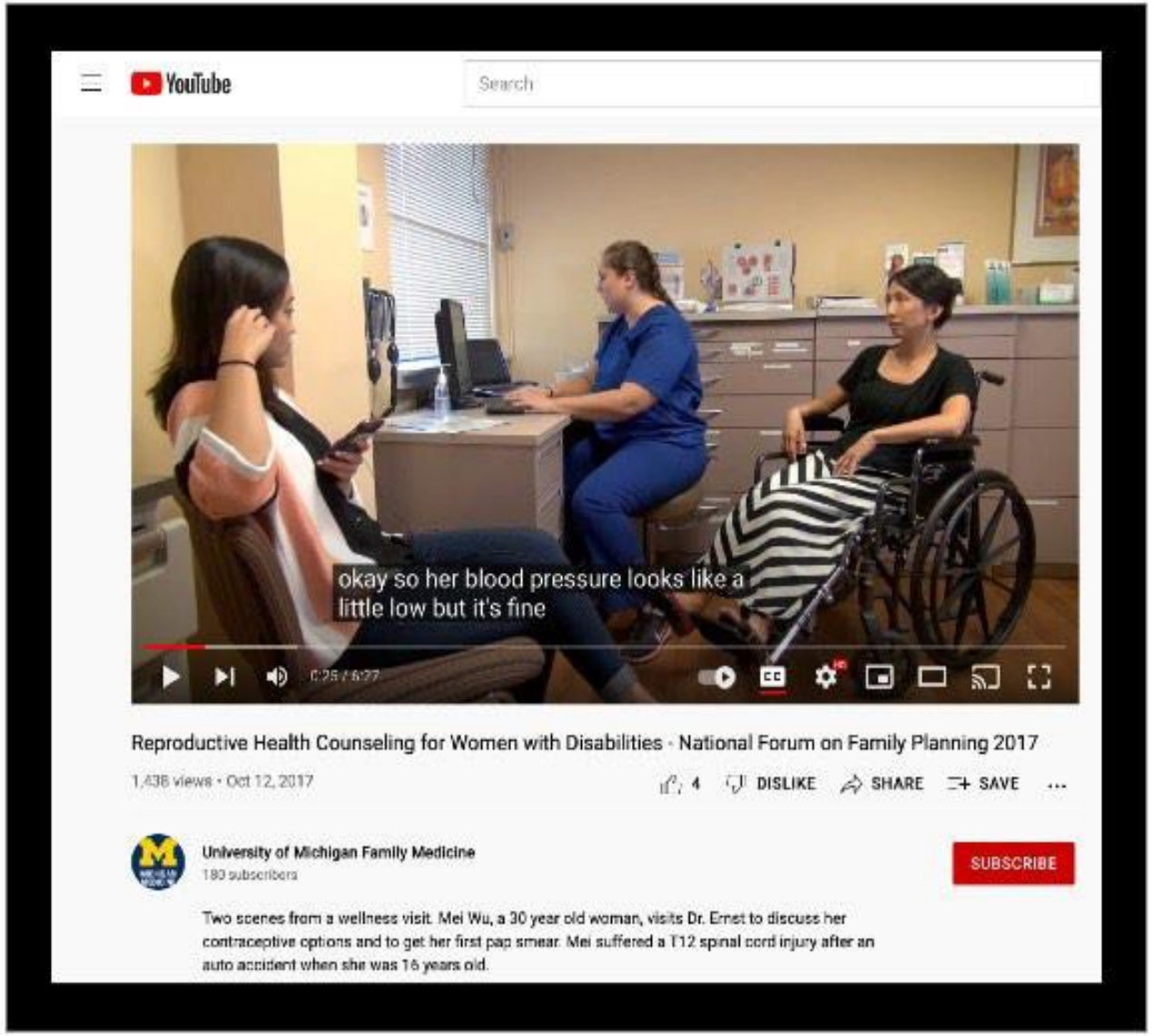
Impacts on Access to Care



CDC, Disability and Health Overview, 2020

A Tale of Two Visits: Video

Reproductive Health Counseling for Women with Disabilities - National Forum on Family Planning video



Family Planning Challenges for People with Disabilities

- Inaccessible health care facilities and equipment
- Stereotypes and discrimination
- Inaccessible family planning clinics
- Programmatic inaccessibility
- Transportation barriers to accessing facilities

Anderson & Kicthin, 2000

Family Planning Challenges for People with Disabilities

- Limited coverage of health care
- Providers who lack disability-related training or sensitivity and/or fail to recognize the woman as a person with sexual and reproductive health care needs
- Problematic interactions between hormonal methods of contraception and some disability-related medications
- Difficulties using barrier methods due to limitations in manual dexterity, loss of sensation, contractures, or spasticity

Anderson & Kicthin, 2000

Sexual and Reproductive Health Among People with Disabilities

- **Approximately 12-18% of reproductive-aged women have a disability**
- **Historical and societal biases about sexuality and reproduction among people with disabilities impact on attitudes about**
  - Sexual activity and behaviors
  - Ability to have consensual sex
  - Ability to become parents
- **Compared with women without a disability, women with a disability are as likely to**
  - Desire a future pregnancy
  - Be sexually active
  - Experience pregnancy

Okoro et al 2018; Bloom et al 2017; Haynes et al 2018; Mitra et al 2019

Barriers to Healthcare Access Among People with Disabilities

- **Limited availability/training of providers**
  - 81% of medical students have no training in disability care
  - 75% of medical residences have no experience in disability care
  - 44% of ob/gyn clinics report being unable to provide for people with mobility disabilities
  - 41% of physicians feel confident in their ability to provide for patients with disabilities

Holder et al, 2009; Lagu et al, 2013; Sonalkar et al, 2020; Iezzoni et al, 2021

Sexual/Reproductive Health Disparities Among Women with Disabilities

- Unmet needs for contraception, preconception, and pregnancy counseling
- Lower utilization of reproductive health care
- Higher rates of pregnancy complications (e.g., cesarean delivery, preterm birth) and adverse birth outcomes (e.g., low birth weight)
- Higher rates of physical abuse and sexual assault
- Higher rates of STIs
- Lower rates of cervical and breast cancer screening
- Less likely to receive pelvic exams at regular intervals
- Higher rates of female sterilization/hysterectomy
- Higher rates of mortality from breast cancer

Mitra et al 2019; Sonalker et al 2020; Holt et al 2021; Mitra et al, 2015; Iezzoni, 2011; Steele et al, 2017; Mosher et al, 2017; Wu et al, 2017; Horner-Johnson et al 2019

Justine Ross, Michigan Medicine

Sexual and Reproductive healthcare for women with disabilities

Family Planning Challenges for Women with Disabilities

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Anderson & Kicthin, 2000

Key Principles of Communication

- Focus on abilities, not disabilities. Talk respectfully; do not shout; explain what is happening; take time
- Greet the person first, before addressing the accompanying relative or support person
- Invite new patients to bring any existing personal health records
- Paid support staff may be unaware of vital elements in a person's medical history; encourage them to make and keep notes and to bring these for subsequent consultations

Edwards, 2013

History Taking Considering Verbal Capacity

- Ask how your patient communicates best
- Assess your patient's verbal capacity
  - Potential imbalance between receptive and expressive language skills
  - Your patient may give clear answers even when she does not understand the question
- If a patient has limited or absent verbal skills
  - Assume competence
  - Establish contact with the person first, and ask if he or she will allow the accompanying person to interpret
- Obtain the medical history as far as possible from the patient; otherwise an accompanying person should complete it

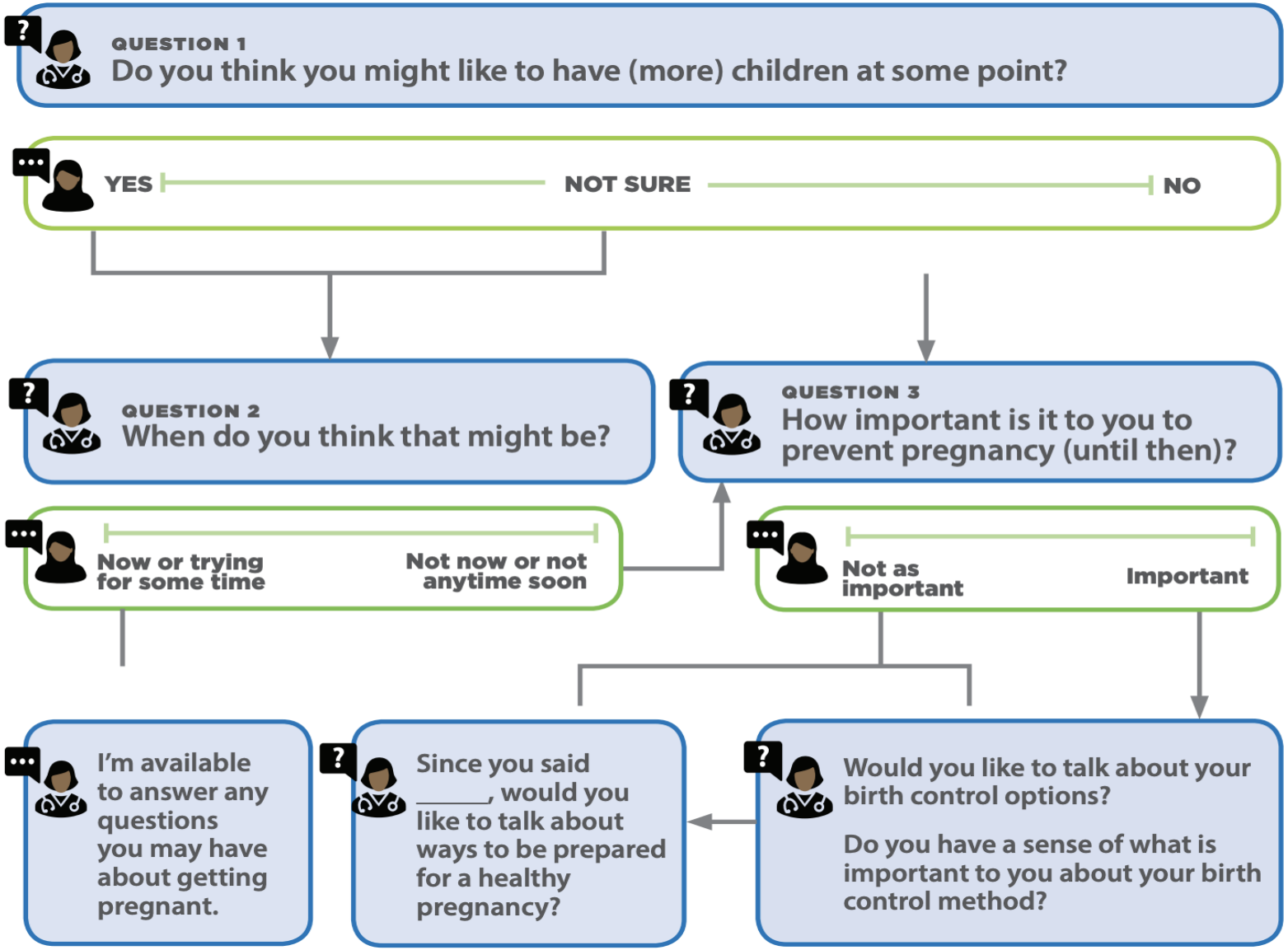
Edwards, 2013

Confidentiality and Communication

- Make clear that if the patient wants the accompanying person to leave at any moment during the consultation, they can do so
- For people who are non-verbal, find other ways to communicate:
  - body language such as gestures and facial expressions
  - sign language
  - pictorial materials
  - electronic devices
- Establish if the patient normally uses any communication devices or system
  - if the patient does not use a communication system, ask the accompanying person how they know what the patient wants

Edwards, 2013

PATH Questions



Competency and Decision-Making

Capacity Assessment

- Provider
  - Presents relevant facts for a decision
  - Assesses patient's understanding of the facts
  - Asks for the person's choice
  - Assesses their appreciation and reasoning about that choice
  - Reassesses the choice, paying attention to the logical consistency of the choice based on the reasoning provided

Karlawish, 2021, UpToDate

Decision-making Ability	Definition	Sample questions
Understanding	Ability to state the meaning of the relevant information (diagnosis, risks/benefits, indications, options for care)	”Can you tell me in your own words what I just said about …(fill in topic disclosed)?
Expressing a Choice	Ability to state a decision	Based on what we just discussed about …(insert the topic) what would you choose?
Appreciation	Ability to explain how information applies to oneself	Diagnosis- “Can you tell me what you see as your medical problem? Benefit/risk- “Regardless of what you choose, do you think that it is possible that the medication can benefit/harm you? (as 2 separate questions)
Reasoning	Ability to compare information and infer consequences of choices	Comparative reasoning- “How is *x* better than *y*”? Consequential reasoning – “How could *x* effect your daily activities

Chart adapted from Karlawish, 2021, UpToDate

C. Informed, Voluntary Consent Checklist and Sample Questions [a]

Inform the patient that you will be doing a capacity assessment with him/her. Do not assume that the patient will understand the connection between the illness and some consequent intervention.

Use the categories below to guide your assessment, and the examples below them if helpful.

- For each category of question, check **Yes**, **No** or **Unsure**.
- If the answer is No to any of these questions, the patient is not capable.

1. Does the patient understand that you are offering an intervention for a health problem? ☐ Yes ☐ No ☐ Unsure

e.g., What problems are you having right now?
What problem is bothering you most?
Do you know why you are in the hospital/clinic?

2. Does the patient understand the nature of the proposed investigation or treatment and the expected benefits, burdens, and risks? ☐ Yes ☐ No ☐ Unsure

e.g., What could be done to help you with your (specify health problem)?
Do you think you are able to have this treatment?
Do you know what might happen to you if you have this treatment?
Do you know if this treatment can cause problems? Can it help you live longer?

3. Does the patient understand possible alternative treatment options and their expected benefits, burdens, and risks? ☐ Yes ☐ No ☐ Unsure

e.g., Do you know different ways that might make you better?

4. Does the patient understand the likely effects of not having the proposed investigation or treatment? ☐ Yes ☐ No ☐ Unsure

e.g., Do you know what could happen to you if you don't have this (*specify*) done?
Could you get sicker or die if you don't have this (*specify treatment*)?
Do you know what could happen if you have this (*specify treatment*)?

5. Is the patient free from any duress (e.g., illness, family pressure) or pain or distress that might impair his/her capacity regarding the particular decision? (Note that a relatively minor illness can cause significant anxiety.) ☐ Yes ☐ No ☐ Unsure

e.g., Can you help me understand why you've decided to accept/refuse this treatment?
Do you feel that you're being punished? Do you think you're a bad person?
Is anyone telling you that you should or should not get this treatment?

6. Is the patient free from a mental health condition (e.g., mood disturbance or psychiatric illness) that may influence his/her capacity to give consent? (Note that having mental illness is not in itself an indicator of permanent incapacity. This factor may change once the mental health condition is treated.) ☐ Yes ☐ No ☐ Unsure

e.g., Are you hopeful about the future?
Do you think you deserve to be treated?
Do you think anyone is trying to hurt and/or harm you?
Do you trust your doctor and nurse?

Assessment:

DATE: _____ PRINT NAME: _____ SIGNATURE: _____

a. Questions adapted from: Etchells E. Joint Centre for Bioethics-Aid to Capacity Evaluation **www.utoronto.ca/jcb**

CAPABLE	NOT CAPABLE	UNSURE
If "YES" to ALL of the above, and the patient can remember the information long enough to make a decision (verify by asking him/her to explain the information to you), then consider that capability exists to consent to or refuse the proposed treatment.	**If "NO" to ANY of the above,** then repeat the questions; you may need to repeat this process several times to ensure that the patient understands. **If the patient still does not understand**, he/she is incapable and a legal Substitute Decision Maker (SDM) should be assigned (see below).	**Consult family, if not already done** **Consider seeking a second opinion from:** • **Designated "capacity assessor"** (e.g., for admission to long-term care and/or personal assistance services) **www.ccboard.on.ca** • **Hospital ethicist/bioethics committee** if available • **Provincial regulatory College or Medical Association**, especially if the decision is related to reproduction, genetic testing, chemical restraints, procedures, or end-of-life issues

Essential Relationship Skills: Where does capacity fit in?

- Ability to say “no”
- Ability ***to hear*** “no”
- Knowledge that having unprotected sex can result in pregnancy or STI
- Ability to differentiate appropriate and inappropriate times and places to engage in intimate relations
- Ability to recognize persons or situations that might be a threat

Facilitating a gyn exam

From “Margarita with a Straw”

Preparing for the Appointment

- Schedule a longer appointment
- Select the most accessible exam room and have necessary equipment available
- Practice with staff
  - Ask for patient's preferences
  - Providing assistance
  - Safe transfer techniques
- Flag the chart to indicate patient requires accommodation

ADA Requirements for Office Adaptation

- If the health care site does not provide an examination table that can be accessed, the office must provide assistance to help patients onto the high tables, including lifting them if necessary.

- Such measures must be undertaken in a safe manner to avoid injury to the patient and to preserve the dignity of the patient as much as possible.

Source: ADA 1990 [1]

Access is a Legal Right

- Healthcare providers must have an accessible facility that meets the 2010 ADA Standards for Accessible Design .
- https://www.adapacific.org/healthcare

Preparing for the Pelvic Exam

Determine	Before the exam, determine if your exam is for preventive care only, or adds to the diagnosis of a presenting problem
Assure	Assure that the patient feels safe, well supported, and confident that she will not fall
Consider	Consider extra padding on exam table, use pillows and blankets liberally

Transferring to the Exam Table

- Be prepared to assist patients with transfers to the exam table
- Consider adapting the office with an electric table for ease of transfers, also helpful for other patients with mobility issues
- Do not perform exams in the wheelchair (including breast exam) unless it is preferred by the patient and no other option is available

Slide adapted from: Susan D. Ernst, MD & Mary Milkey, CNM – University of Michigan

Transfer Assistance

Several options are available to transfer the patient who uses a mobility assistance device to the exam table

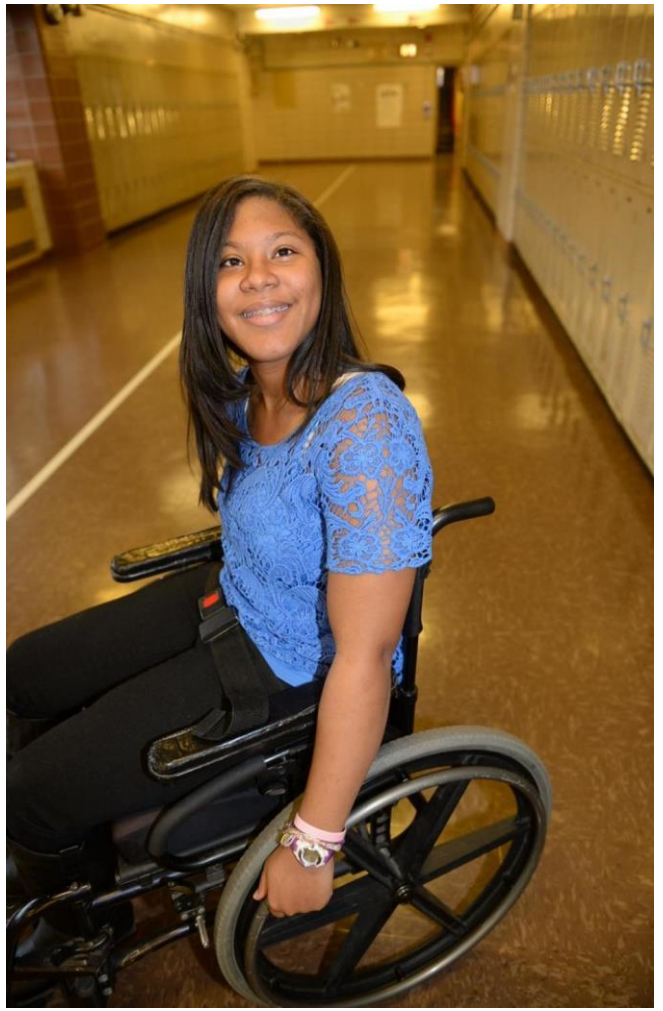
Some women need assistants, use of a transfer board or a lift

Adapt transfer strategy for each patient and situation

Positioning on the Exam Table

Be aware of:

- Impaired balance, weakness
- Spasticity
- Skin pressure, especially over the sacrum
- Contractures



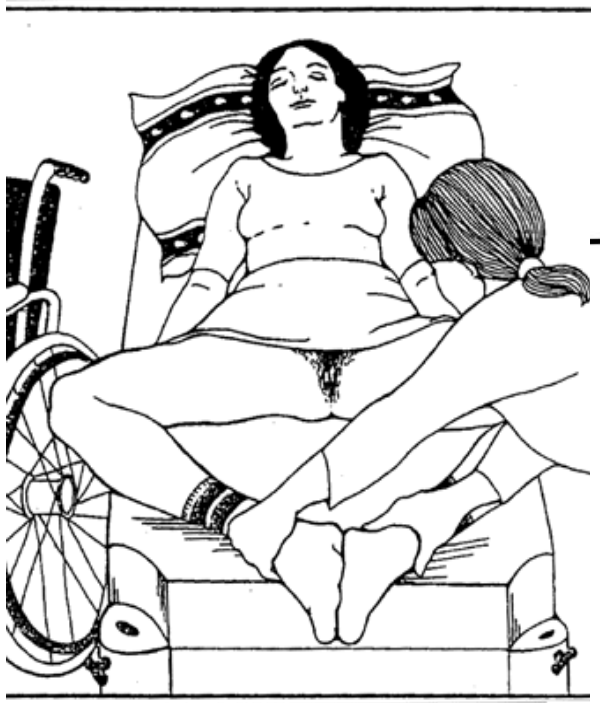
Pelvic Exam: Managing Spasticity

- Slow, gentle positioning can minimize spastic activity
- Consider use of diazepam, tizanidine or baclofen
  - Ask patient what has worked best in the past
- A local anesthetic gel may be helpful in minimizing discomfort and unintended stimulation
- Hot packs post-procedure

Important Tips for the Pelvic Exam

- Empty bladder first
  - A trip to the bathroom may take additional time
  - Consider specimen collection (even if unsure whether submitting)
- Alternative positions can be used to facilitate the exam. Let the patient help you!
- Smaller, narrow speculum may be helpful (eg. Pederson)
  - Can insert speculum with handle facing upwards
- Blind PAP smear
  - Slide over finger into cervical os – decreased rate of endocervical cells
- Urine or vaginal swab for STI screening/diagnosis
  - Alternatives to speculum exam

Positioning Options



Source: Simpson, Table Manners and Beyond, 2001[2]

Dr. Anna Tirado

Dr. Anna Tirado talks with patient Denzil Benton

Accessing Care and Equipment

[Most OB-GYN Practices Fall Short In Caring For Women With Disabilities]

Contraceptive Considerations

Combined Hormonal Contraception

- Contraceptive efficacy in combination with some anti-seizure medications
- Seizure disorders common with numerous conditions causing DD
- Prolonged immobility/limited mobility and thromboembolic risk for women with spinal cord injuries, traumatic brain injuries, cerebral palsy and other conditions
- May be useful for mood regulation if cyclic behavioral issues are present
- May be useful to treat painful menses or other problems related to the menstrual cycle management in some women

Combined Hormonal Contraception

- Adherence challenges for women with intellectual disabilities
- Extended cycling as an appropriate option for menstrual management
  - Contraceptive patch or ring may be used in a continuous fashion as well
  - Breakthrough bleeding is the most common side effect
  - Complete amenorrhea at 1 year in half of patients and another 26% experience only occasional spotting

Drug–Drug Interactions

Decrease OCP Efficacy

- Carbamazepine (Tegretol)
- Clobazem (Onfi)
- Felbamate (Felbatol)
- Phenytoin (Dilantin)
- Phenobarbital
- Primidone (Mysoline)
- Oxcarbazepine (Trileptal)
- Topiramate (Topamax)

Do Not Affect OCP

- Gabapentin (Neurontin)
- Levetiracetam (Keppra)
- Lamotrigine (Lamictal)*
- Tiagabine (Gabitril)
- Valproate (Depakote)
- Zonisamide (Zonegran)

Zupanc, ML Neurology 2006; 66 (supp 3)

Estrogen and VTE Risk in Persons with Disabilities

- Related to immobility
- Minimal info on DVT in adult wheelchair patients
  - Suggests small increase
- VTE in teens is rare
  - 4/10,000 in COC users- 2.1/non-users
  - Think about other risk factors (obesity, family history)
  - Progestin choice- 1st and 2nd generation slightly lower risk
- COC category 3 in women with MS with prolonged immobility 2º to an approximately threefold increased risk of VTE or DVT

Arpaia G, et al , 2010; Lohiya GS. et al , 2006 ; Pillai P, et al , 2013; 26 (3) 186-188 , Zapata LB et al.,2016

Progestin-Only Contraception

- Consider issues of bone density and weight gain in women who use DMPA, particularly in adolescence
- Progestin-only IUDs are an appropriate option for both contraception and menstrual management, but insertion may be challenging
  - Consider insertion to coincide with other procedures, such as dental care, that might require light anesthesia
- Bleeding patterns with the implant may be problematic for women who cannot independently manage pads/tampons

Menstrual Suppression with Progestins

- **Progestin-Only Pill**
  - 20% rate of amenorrhea with norethindrone 35mcg
    - May be higher with drosperinone 4mg
  - Breakthrough bleeding with POP
  - Can use other progestins – norethindrone 2.5-10mg
  - Mood changes
- **Depot Medroxyprogesterone Acetate (DMPA)**
  - Amenorrhea rates of 60% at 1 year
  - Issues with decreased bone density
  - Issues with weight gain
- **Implant**
  - 20% rate of amenorrhea
  - Irregular bleeding
  - Insertion needs cooperation
  - Not recommended as first line
- **LNG IUD**
  - Amenorrhea rate of 70% in small study of 105 young women with disabilities
  - Overall rate of 60+% with “long term use”

Healthy Relationships and Abuse Prevention

Risk of Sexual Abuse

- More vulnerability with dependency on others & communication difficulties
- With mild developmental impairments, victimization due to the need to “fit in”
- Abuse occurs more frequently with family & caregivers (14% abused by a “stranger”)
    - NPR report of DOJ data
- American Academy of Pediatrics data:
    - Overall incidence is 2-10X higher than for the general population without disabilities
    - 68-83% of women with developmental disabilities will be sexually assaulted

What Contributes to Vulnerability

- Factors influencing these statistics
  - Less able to defend themselves
  - Often not alert to potentially dangerous situations
  - Do not know to report abuse
  - Seek approval and affection
  - With mild ID may be more vulnerable due to desire to “fit in” with peers
  - May be exposed to a large number of caregivers for intimate care
  - Taught to be compliant to authority

In their own words…

"We are taught to trust grown-ups more than anyone else would be because when you have a disability, people are always telling you, do as that person says; do as this person says and all of this other stuff."

Thomas Mangrum, Washing, DC interviewed by Joseph Shapiro for NPR

In their own words…

"It happens to people like us, and why is because we're easy targets to take advantage of. We think that the people that we're around, we can trust them, but you don't know that by looking at 'em. You can't judge a person by their looks."

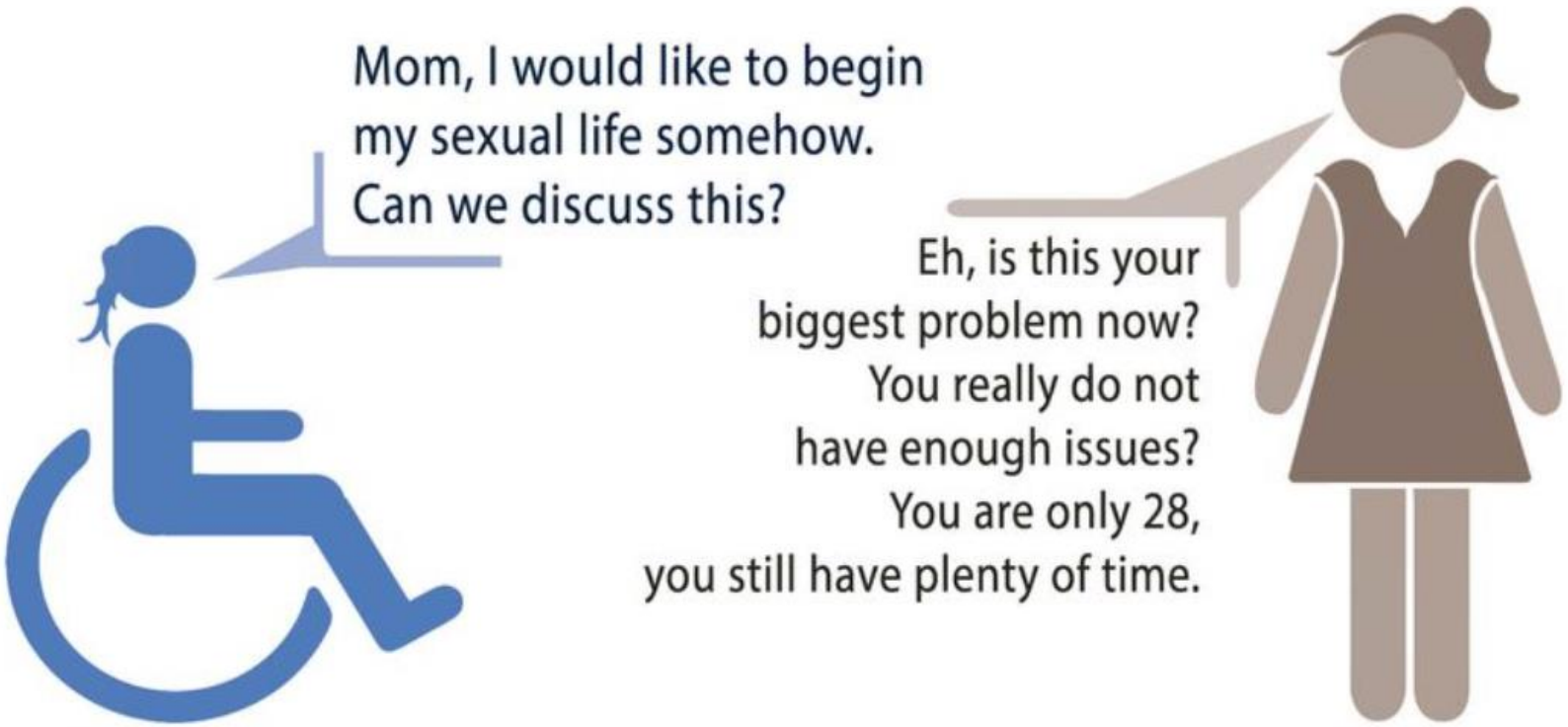
Cindy Whitaker, Austin, Texas interviewed by Joseph Shapiro for NPR

In their own words…

"I was thinking maybe it was a relationship, a bad one. I was just in denial. … I had to figure out that it's not my fault. I had to go through all the memories and name it, and open up the box you really don't want to open up, Pandora's box."

Debbie Robinson, Philadelphia interviewed by Joseph Shapiro for NPR

discrimination begins in the family



too many people find it very difficult
to openly discuss sexuality
with disabled people,
instead, they choose to suppress or ignore it

WHAT'S YOUR EXCUSE?

Social and Communicative Impairments

- Impact on development of friendships and romantic relationships
- Diminish opportunities to learn about sexuality from peers
- Influence one's judgement to apply sexuality in a socially acceptable way or in interpreting (sexual) intentions of others
- May result in literal or incorrect interpretations of information relating to sexuality
  - Information about sexuality and sexual codes might not be clear to people on the autism spectrum

Gabriels and Van Bourgondien (2007)

Universal Healthy Relationship Education

- Characteristics of healthy and unhealthy relationships
- Educate sexually active adolescents and adult women about sexual coercion and the importance of consent
- Create a safe environment to discuss relationships

Relationship Challenges for People with Developmental Disabilities

- Negotiating relationships is a learned skill
- People with developmental disabilities
  - have fewer opportunities to “practice” through friendships
  - have fewer social outlets and higher levels of adult supervision
  - desire romantic relationships, but have no models among their peers
- Sexual decision-making requires abstract thinking skills
  - Individuals with ID may not develop abstract thinking

Teach boundaries and consent: The right to say “NO!” and to say “YES”

Teach the right to refuse

- People with disabilities can sometimes be trained to be quite compliant.

Remember that context is everything!

- How does the information fit into their real life? Discuss social situations as examples

Its not all about “NO”

- Adults and Youth with disabilities desire and seek relationships, including romantic relationships

Tips adapted from “Sex Education for Youth with Disabilities" www.sexualityandU.ca

And finally…a word about pleasure

"Access to pleasure is the real accessibility issue. Full inclusion means access to pleasure. It means a reasonable chance for relationships."

Sexuality and Disability: The Missing Discourse of Pleasure Mitchell S. Tepper, Ph.D., M.P.H (2000).

https://www.sinsinvalid.org/

Provider Resources

- Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations
  - https://nisonger.osu.edu/wp-content/uploads/2016/11/TableMannersandBeyond-1.pdf
- Simple language health education materials:
  - http://www.nswcid.org.au/
  - https://www.fpnsw.org.au/justchecking/easyenglish (videos, social stories, plain language materials)
- The Ultimate Guide to Sex and Disability

  Miriam Kaufman, MD, Cory Silverberg and Fran Odette
- Edwards P. Therapeutic guidelines. Management guidelines: developmental disability. Aust Prescr 2013;36:161.