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## Who Defines MY Quality of Life? Perspectives from People with developmental disabilities and their caregivers

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University of California  
San Francisco



Improving outcomes for people with developmental disabilities

# Who Defines MY Quality of Life?: Perspectives from disability advocates and their caregivers

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Office of Developmental Primary Care





Improving health outcomes for people with developmental disabilities.

# Acknowledgements

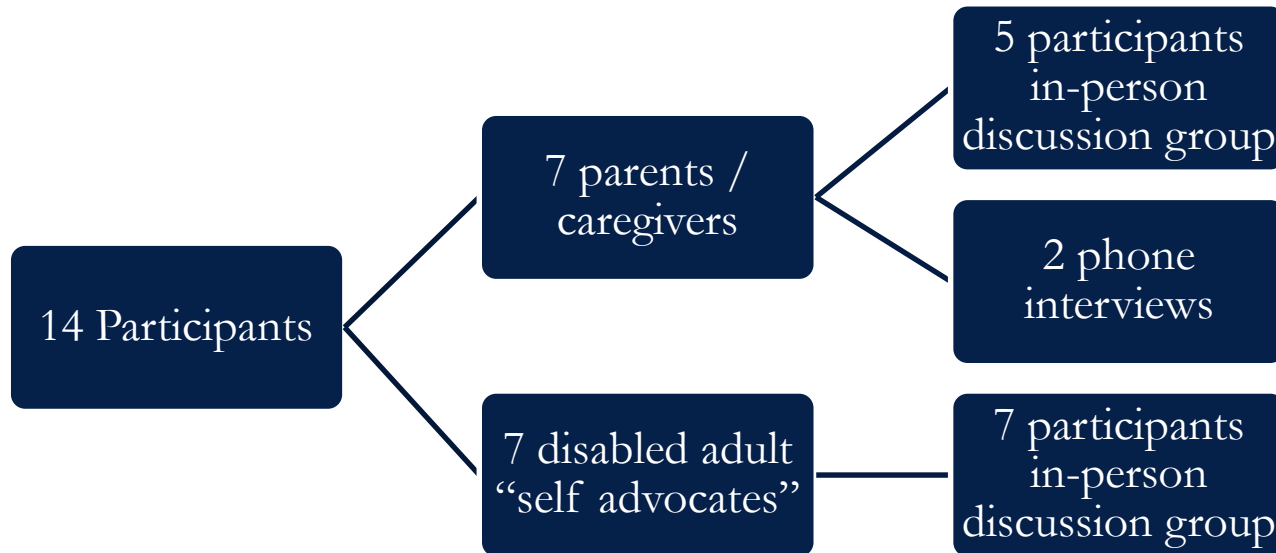
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# Quality Improvement Project Design

- Aim: Learn more about the experiences of people with disabilities and their families in accessing the health care system. Uncover how these interactions impact patient care, including goals of care and end of life conversations.



# Discussion Topics

- Communication
- Assumptions
- Changes in or loss of function
- Medical decision-making / Advanced Care Planning
- End of life care conversations



# Communication

“When I have brought others, especially my parents, the providers tend to direct their questions to them and not me. They take them more seriously. It’s frustrating.”

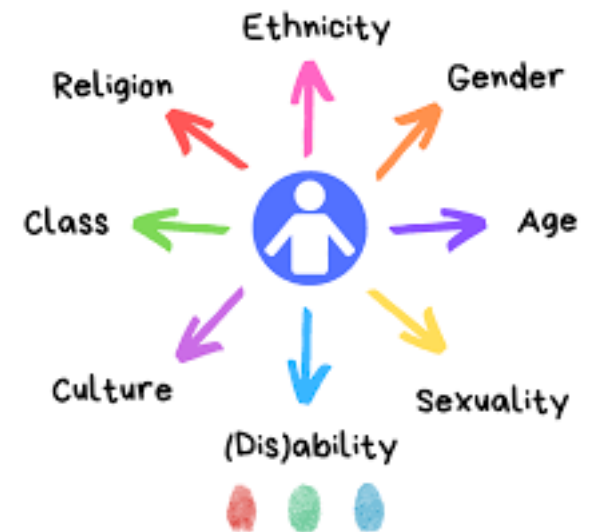
- Participants spoke of their frustration when medical providers directed questions and comments about their health to caregivers or family members.
  - Presume competence
  - Always address the disabled person
  - Explore different communication options, such as visual aids, slowing down the conversation, and using plain language



# Disabled & Beyond: Intersecting Identities

“My primary nurse practitioner sees me as a whole person, including my disability, sexuality, social life, and other medical needs unrelated to my disability.”

- Both advocates and caregivers asked that clinicians acknowledge and respect them as whole people when considering the impact of potential treatment.
- Disability as a cultural identity





# Assumptions

“I wish medical students had to work in the community so they could see for themselves what our lives can be. I would like them to see ‘life’. That it’s not all medical – we have fun!”

## Instead of . . .

1. People with disabilities want clinicians to avoid basing treatment options on assumptions about their quality of life
2. Negative messages regarding disability can be found everywhere, including medical literature
3. Members of both groups cautioned clinicians not to confuse a patient’s health status in a hospital setting with their typical baseline
4. Participants expressed the need to respect privacy and personal boundaries

## Try these techniques instead!

1. Ask patients what brings value to their lives
2. Refer patients to peer-led groups and/or websites that promote positive disability identity
3. Ask patients to describe their baseline
4. Tell patients what they can expect to happen before starting an exam

# Decision-Making

“I brought in her communication device and they were shocked that she could do anything like that. They had assumed that she was a little lump.”

- In medical decision-making, disabled patients need as much autonomy over their bodies as possible.
- Disabled patients should be able to choose trusted supporters to help them make medical decisions.
- Rather than assuming that disabled people cannot make decisions, consider what supports or accommodations can optimize a patient’s capacity to participate in decision-making.



# Cultural Humility & Respecting Patient Experiences

“Believe me. I may not have medical training, but I know a lot about my disability. Don’t give up on me.”

- Disabled people and their caregivers asked that medical professionals recognize them as experts in their care and abilities
- Group members requested that clinicians trust the information and history they provide and correct errors that may exist in the medical chart
- Everyone has unconscious bias – be willing to revise your ideas of what it means to be disabled



# Adapting to Change in Function

“About 10 years ago, I became spinal cord injured. It’s common with CP (cerebral palsy), but no one spoke to me about it. I had to relearn things. It was heavy.”

- All people have the capacity to adapt to change and evolving circumstances – people with disabilities and their families are used to adapting to new circumstances and know what they can handle
- Many members of the advocate group spoke of how aging with a significant developmental disability can be full of unknowns
- Clinicians can help patients by educating them on any disability-specific progressions based on literature and clinical experience



# Visits to the Emergency Department

“People I see more than once are almost always okay. The problem is the ED or people who work in the hospital. They don’t know who we are. They only see us for our problems and that’s a real problem.”

- Emergency visits pose unique challenges to disabled patients
  - Physicians and medical personnel may be unfamiliar with a patient’s disability, medical history, baseline, or communication style
  - Sensory overload due to bright lights and loud noises can impair a disabled person’s capacity to communicate
  - Some disabled people are survivors of medical trauma
- Accommodations to consider
  - Reduced wait time
  - Better coordination between departments
  - Streamlining discharge



# Advanced Care Planning

“Afterward, they kept talking about it, when I was doing well. A social worker came to my house and her first question was, “Do you want a DNR?” This is when I was doing fine. All I wanted to do was move away from that conversation.”

- Parents and caregivers reported that they want to know that their options are based on neutral medical advice
- Patients want to know that their lives are valued: Learn what your patients value, what’s important in their lives, and how to support their goals in the context of their environment
- Disabled people need opportunities to make decisions about what happens to them during a medical emergency and at the end of their lives



# End of Life

“I really appreciated how hard they tried to save her. They gave value to her life.”

- All lives have value and all deaths will be grieved, regardless of one’s level of functioning at the time of death.
- Disabled people reported concerns that their wishes would not be followed at the end of their lives. Clinicians can discuss these fears with patients and identify themselves as advocates in ensuring that their wishes are followed.
- Along with disability status, many factors impact patients’ relationship to the death and dying process, e.g. religion, family structure and legacy of access to medical care.



# Thank you!

Any questions?





# Resources

Office of Developmental Primary Care: <http://odpc.ucsf.edu>

Ability Bias in the Health Professions:

<https://odpc.ucsf.edu/training/access-diversity/ability-bias-in-the-health-professions#pdf>

My Health Passport:

<https://odpc.ucsf.edu/clinical/tips-for-organizing-visits/health-passport>

Supported Decision-Making:

<https://odpc.ucsf.edu/advocacy/supported-health-care-decision-making>

What I Wish My Doctor Knew About Non-Traditional Communicators:

<https://odpc.ucsf.edu/advocacy/advice-from-self-advocates/non-traditional-communicators#pdf>

What I Wish My Doctor Knew About People Who Accompany us to our Medical Appointments:

<https://odpc.ucsf.edu/advocacy/advice-from-self-advocates/the-people-who-accompany-us-to-our-medical-appointments#pdf>





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