Transforming Healthcare Notes
Meeting 2 (August 27, 2025)
Building Disability Cultural Humility through Training

Summary

Respectful healthcare visits for people with IDD mean speaking directly to the patient, respecting privacy, believing their information, honoring accommodations, and allowing support people to be present without separating them. Barriers often come from rushed visits, lack of empathy from both providers and administrative staff, and assumptions about disabilities. Small but meaningful steps—like using plain, respectful language, answering questions, thanking patients for coming, and inviting providers into conversations that build understanding—can help create more humane and empathetic care.

Notes from the discussion with Advisory Board members

What behaviors show respect in a healthcare visit?

- Not having the right support during healthcare appointments can be challenging.
- Not assuming all of my disabilities; and to separate my disability from someone e's perception of my disability.
- It's important for healthcare providers to have more personal relationships with people with IDD.
- Respect my privacy and concentrate on my health.
- Saying terms such as, "thank you for coming. Do you need support?"
- Make sure we're not separate from our caregivers so they can give us support.
- Believe the information I'm providing.
- Be supportive of my accommodation requests.
- Speak to me, the patient, not just my caregiver.
- It's important for healthcare providers to not judge me and respect me for who I am.

What gets in the way of providers and patients with IDD understanding each other— especially when visits are short?

- Sometimes it's the administrative team at the healthcare facility. Creating a sense of safety looks like admin people in healthcare also showing more empathy during patient visits.
- Understanding what I'm saying. Creating more empathy means taking the time to understand the patient with IDD's physical and invisible disabilities.
- Showing humane care for people with IDD.

What's one small thing a provider (or patient) can do to show more empathy or presence in the moment?

- Inviting healthcare providers to conversations like these.
- Providers are not trained to interact with PWIDD—and that needs to change.
- Having someone who can speak in plain language and sensitive/positive language.
- It's important that healthcare providers answer my list of questions.

Advisory Board Members' Post-Meeting Feedback

What parts of the discussion and reflection questions were most helpful or meaningful to you?

- Services in Health Care
- As a provider it is helpful for me to hear from people with lived experience, as well as learn what other providers are doing in their practice.
- I like being able to build on what everyone else had said and come up with more complex answers together as everyone chimed in
- Everything was good.
- All of the discussion and reflection questions were excellent.
- I like the fact that it was led by a self-advocate, and it was organized
- The different options given to accommodate different needs an of an individual. Not everyone has the same experience or adaptive skills, so learning what has helped others was very helpful.
- Hearing feedback from everyone, providers and people with lived experience.

Please describe one aspect of cultural humility in healthcare that was discussed that you think is particularly important.

- Respect

- There were consistent themes that came up around communication barriers between providers and people with disabilities that I think should not be ignored
- We talked about respect for autonomy and what that looks like in practice. I think it's good though now there's little things providers can do, like talking to us directly, to show respect.
- Be patient and flexible
- The need to have a lived experience reflected among healthcare professionals.
- People's priorities
- Realizing that just because I can do one thing, doesn't mean the other person with a similar experience also has that same ability.
- Being short to separate the illness that the person is seeing that doctor for especially if it's not their Disability. I.e. a cold versus CP issues.

Do you have any suggestions for how the training or guidelines we create could be most useful for providers who work with patients with disabilities?

- I think the most important part is making sure it is accessible and widely distributed!
- We need to emphasize there are no exceptions. Providers need to show respect and humility to everyone regardless of their condition and how it presents.
- Don't discount people with disabilities.
- It will have to address the complex situations clinicians encounter, be specific, and address systems issues
- do not force a person-first or identity first language requirement. Let the person choose what they want to be called. Neither of them is wrong and it is not shameful to be a disabled person/person with a disability.
- Have some of the training aspects on video so the doctors or potential doctors can see the person discussing their own issues.

Is there any other feedback or ideas you would like to share?

- Happy to be participating!
- I feel like some of us participate, more than others, with myself being an individual that never shuts up. I don't know if this is the case, but maybe some people would prefer to submit their thoughts through writing ahead of time? Maybe present that as an option for those of us who are on the quieter side. I'm a very privileged disabled

person and I don't want to overshadow others. Feel free to give me a sign if I'm talking too much.

- Not at this time.
- Physicians and staff should be aware that there may be materials in the office on signs that not all patients will see. For example, I am visually impaired and I don't usually read to sign it because I can't see it well enough. I believe that if it is that important, someone will say something. I discovered recently there are things in Doctors' office that I'm not even aware of such as the OB/GYN area welcome concerns about abuse or neglect. Never knew that was there.