

Lives Worth Living

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Who decides?

Hello!

- Julia Bascom
- Autistic Self Advocacy Network

- Nothing About Us, Without Us!



Lives Worth Living

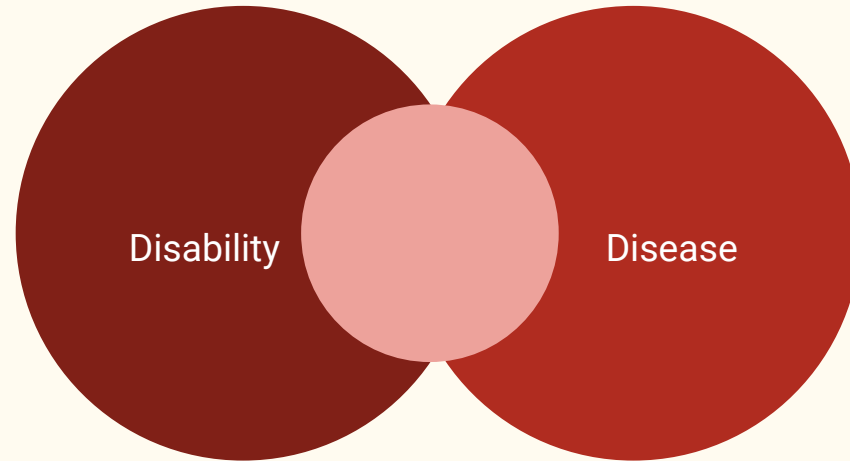
- “Patient” vs disabled person
- Much of what our society thinks it knows about disability is wrong.



Models of disability



But what about...



Medicine does not happen in a vacuum

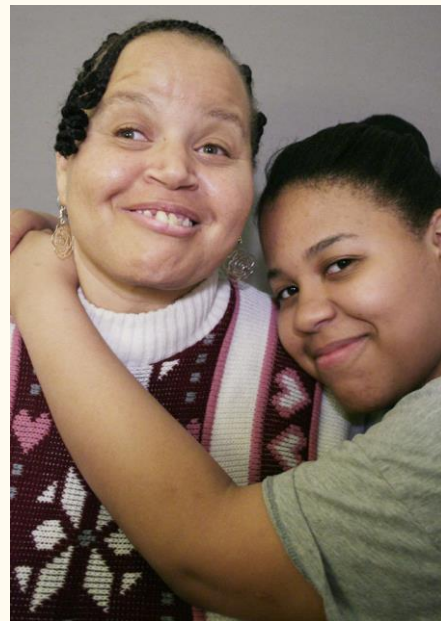
- Doctors and researchers internalize problematic ideas about disability
- Doctors and researchers conflate disability and disease
- Bias can actually change the facts about a disability



Things we think we know are wrong

- As researchers
- As clinicians
- As patients

This makes informed consent extremely difficult.



The past isn't over

Disability communities are having these conversations:

- In the legacy of Oral Method and eugenics
- In the current context of ABA, guardianship, and Ashley X

These conversations are a part of that history and current reality.



How do we move forward ethically?

- Slow down
- Take a close look at our assumptions and what we mean
- Make room for nuance
- Ask: who are we making decisions on behalf of?
 - One patient group or another?
 - Gene therapy vs heritable genetic modification?

Make sure that the people making decisions about a given community are actually that community.

Foundational questions we need to answer:

- What does it mean to do meaningful patient engagement?
- What percentage of our time and resources are we devoting to this technology vs to addressing structural inequities? In other words, what work are we doing to make sure that informed choice will actually be a real option?
- We aren't going to eliminate disability--we're just going to morph it. What are we creating?