Autism, Neurodiversity, and Ableism: What Clinicians Need to Know

Part 2: Disability Models, Shifts in Clinical Practice, and Being an Ally

April 29, 2021

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My Professional Background

- Worked with disabled people in my youth

- Dream: write about science

- Began autism advocacy after my own diagnosis 2002

- Personal experiences led me to want to help

- Master's in Rehabilitation Counseling 2009

- Division of Rehabilitation Services (DORS) 2007-2009

- Towson University Certificate in Autism Studies 2010

- Towson University Hussman Center 2013-present

Review

- Ableism – discrimination against disabled people
- Disability as socially constructed concept
- How we define and respond to autism evolves over time and varies by culture
- Neurodiversity – neurological differences
- Neurodiversity Movement – value the differences

Questions

- How do we balance real-world deficits/challenges with philosophical idea to value differences?

- How do help families embrace a child who may really be struggling, especially very young children?

- How do we honor families from other cultures/ other situations who may have very different views on disability, difference, childhood, etc?

Section 1: Models of Disability – The Basics

What is a "model"?

- A model is like a "map" of how members of a society think the world operates
- We use these models to guide what we do, how we react, what we assume…
- If every single situation was totally new, it would be hard for society to function
- Models are built up over time and we rely on them in unconscious ways
- Models influence what we think, say, do, and feel, usually without even noticing!

Example of a Model

Dominant European "model" of the Earth until the 1500s C.E. (or thereabouts): The Earth is flat and has a mysterious edge. We could fall off.

Consequences:

- No robust shipping industry

- Countries did not have massive navies

- Children did not grow up dreaming of being sailors

- Trade mostly restricted to land routes

What Is a Disability Model?

- How society "thinks" about disabilities or "operates" regarding disability

- Unconscious models guide reactions to and understandings about disabilities

- Disability models inform what society "does" about disability

- Disability models have an enormous impact on the lives of disabled people.

(Dirth & Branscombe, 2017; Retief & Letšosa, 2018; Zaks, 2019)

Disability Model #1: Medical Model

- Disability is not normal.

- Disability is a burden and a tragedy.

- A world without disability is viewed as a good thing.

- The disabled person needs to be cured, fixed, or eradicated.

Disability Model #2: Professional Model

- Related to the medical model.

- Because the disabled person is "broken" they need a professional.

- Professional experts will fix the disabled person and make the disabled person "normal".

- Professional experts know what is best for the disabled person and will decide on a course of action to make the disabled person as normal as possible.

Disability Model #3: Social Model

- Happiness and quality of life are not dependent on "normalcy".

- Disabled people have problems because of society.

- If we provide accommodations, then disabled people would not have problems.

- We should fix society, not the disabled person.

Disability Model #4: Neurodiversity Model

- Disability is a human diversity and a natural variation.

- Autistic traits benefit society.

- Society gets different ways of living, unique skill sets, unique interests, new means of human connection, and specialized expertise from diverse brains.

- Society should utilize, appreciate, and protect neurodiversity.

- Parallel seen in physical disability community: "empowerment model" or "diversity model of disability"

Other Models of Disability Exist

- Moral model – disability is caused by sin, the disabled person is evil

- Gift model – the disabled person is sent by God, is an angel...

- Financial model – disability is a financial burden; the burden should be reduced

- Custodial model – disabled people must be taken care of for their own good

Discussion: Remember the "Normal" Exercise?

Considering the medical/professional; social; and neurodiversity models of disability, how do you think each model makes a disabled person feel?

Section 2: Models of Disability & Clinical Practice

Medical Model is NOT the same as Medicine & Therapy

- The medical model is called "medical model" because it was first used by doctors in the 1900s

- In some ways, it is an unfortunate name because most people are AGAINST the medical model but NOT AGAINST medicine, therapy, or health care that can help disabled people deal with their functional limitations, learn skills, and reach their goals

(Zaks, 2019)

"Medical Model" Versus Medicine + Therapy

Medical Model

- normalization
- segregation (institutions)
- eradication (prenatal screening, eugenics, forced sterilization)
- shame and blame
- personal responsibility to cope, not society's responsibility to accommodate or help

Medicine, therapy, health care

- can help disabled people reach their personal goals, relieve pain, and learn skills
- can help disabled people live in society, go to school, work, and join their communities
- health care for "regular" health issues and for disability related issues is a human right
- society is responsible for helping

Social Model Medicine, Healthcare, and Therapies

- If medication, healthcare, & therapy helps the disabled person reach personal goals, get healthy, feel better, gain skills, then the disabled person can access life

- Medication, healthcare, & therapy are "therapeutic accommodations" so the disabled person can go to school, make friends, work, live in the community

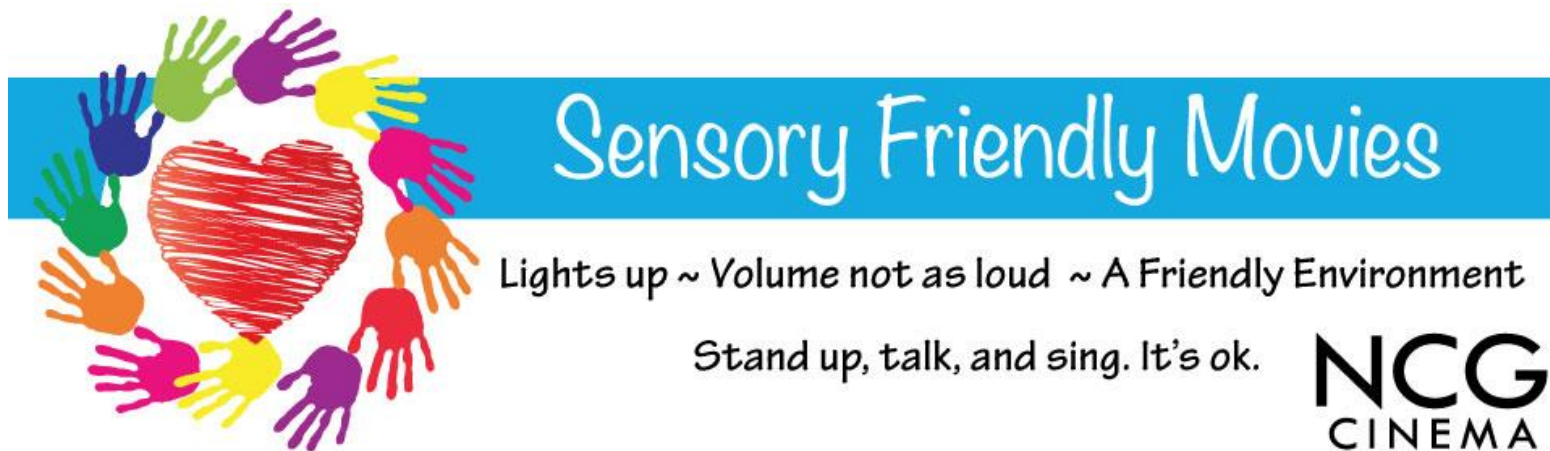- Access and accommodations = Social Model!

(Zaks, 2019)

Social Model: Accommodations We Can See

- Architectural: ramps; elevators; doors with "open buttons"
- Physical: wheelchair lift on the bus; a lower counter at the restaurant
- Environmental: dimmers on lights; flashing alarms; headphones to reduce noise
- Legal: anti-discrimination laws
- Informational: Braille signs; ASL interpretation; picture instructions
- Communication: speech devices; text or chat feature; mobile apps to order coffee
- Scheduling: more time on tests at school; time off work for medical treatments

Social Model: Fix Society

- We don't make the physically disabled person walk; we build a ramp

- We don't make the neurodiverse person change the nerves in their ear; we give them headphones to use at the mall or turn off the music

- We don't make the autistic child act more normal; we change the movie theater and offer "Sensory Safe Movies" on Saturday mornings that allow children to move, rock, walk, and make noise if they need to.

Sensory Friendly Movies

Lights up ~ Volume not as loud ~ A Friendly Environment

Stand up, talk, and sing. It's ok.

NCG CINEMA

Ad for NCG Cinema Sensory Safe Movies

The Most Important Accommodation Is Invisible

Attitudinal accommodations: we change YOUR attitudes, not the disabled person

In this case, we fix "you" (as opposed to a building, a bus, or the lights)

(Zaks, 2019)

Examples of Attitudinal Accommodations

Donel was always talking about air conditioners. Instead of teasing him, his classmates encouraged him to review a new air conditioner each month in the school newspaper. They appreciated his fascination.
(We changed the students' viewpoints, not Donel's traits).

Sheila constantly paced, repeated dialog from the *Finding Nemo* movie, and sometimes sat under tables. Barbara still invited her to the pool party. No one wants to be left out.
(*We changed Barbara's ideas of friendship, not Sheila's traits*).

At the office, Musaf never says hi and eats lunch alone. Instead of viewing him as anti-social, everyone acknowledges that Musaf is a very hard worker, very caring in other ways, and very devoted to the team.
(*We changed co-workers' notions of expected behavior at work, not Musaf's traits*).

Neurodiversity Model: Not A Pedestal

- Disabled people are not "special" just because something is different about their bodies or minds

- Disabled people are not here to inspire non-disabled people: there is nothing inspiring about brushing your teeth, playing soccer, going to school, or getting a job – many humans do these things

(Young, 2012)

Neurodiversity Model: Not Rose-Colored Glasses

- functional limitations can be very frustrating

- but limitations drive innovation

(Zaks, 2020)

(Austin, 2012)

That Tricky Word *Value*

"I value disabled people" does not necessarily mean you are using a Neurodiversity Model!

Value as in respect: "I value you as a human being" or "I value all different types of people"
- this is an attitude, a viewpoint, a feeling of respect and concern
- falls under social model – attitudinal accommodations
- even those who use a medical model can *value* others

Neurodiversity model *value*: "Disability traits are valuable to humanity"
- requires a paradigm shift
- valuing traits goes beyond *respectful attitude*
- the traits themselves must be conferring some benefit to humanity
- it's not about your values – it's about disabled person's traits

(Zaks, 2019)

Neurodiversity Model "Value"

I'm Dr. Smith. I *value* Wang Lie as a human being. I *respect* him. I believe in the Medical Model and I will get Wang Lie to use speech so he can be normal like other boys.

I'm Dr. Chen. I *value* Wang Lie as a human being. I *respect* him. I believe in the Social Model and I will give Wang Lie a communication device so he can communicate by typing.

I'm Dr. Johnson. I *value* Wang Lie as a human being. I *respect* him. I believe in the Neurodiversity Model and I will partner with Wang Lie to discover new ways of self-expression and new ways of connecting because while not speaking can be frustrating, I value Wang Lie's traits has having creative potential that benefits humanity.

This is Wang Lie. He is autistic. He does not use speech.

The World Is Changing

- Medical model: pathologizes autism; pressures neurodiverse people to become as "normal" as possible; oppresses individuals who can't conform to society's expectations; pities and tries to prevent divergence

- Professional model: various therapies such as occupational therapy, speech-language therapy, behavior training *USED TO BE* provided to disabled people to make them more normal

- Professionals are questioning making disabled people normal at all costs – clinical practice is changing rapidly!

(Klein, 1995; Raghavan, 2018)

Section 3: Applying Disability Models

Disability Models: Practice Case A

Explain how the medical, social, and neurodiversity models might respond to Samantha.

Samantha is on the autism spectrum and lives in her grandmother's basement. She finished college a number of years ago but doesn't hold down a steady job. She makes small objects out of wires and shiny objects she finds on the street and sells these creations on Etsy. She says she has no friends and feels lonely. Samantha only wears items that are purple, including her favorite purple sneakers. She collects purple stuffed animals, as well, and has over 1,000 in her collection. People stare sometimes because she walks around with one or two of her stuffed animals everywhere she goes.

Disability Models: Practice Case B

Explain how the medical, social, and neurodiversity models might respond to Dominique.

Dominique is in second grade. He loves animals. He spends hours lining up his toy animals in long rows. At school, he tries to line up the toy animals in his classroom, too, and rarely interacts with other kids. He loves to look at books with pictures of animals in them, though he does not appear to be able to read and is behind on all of his academic skills. His mother says that at home, Dominique will try to feed the cats. He pours their dry food into bowls, and it spills all over the floor, but he is so happy and proud of himself that his mother doesn't care and lets him be "in charge" of this job.

Discussion

- What model(s) do you use in clinical practice?

- How might you switch to a social model or neurodiversity model?

- Why switch?

- Is this one way to change the paradigm for families?

Section 4: Controversies

Decolonizing Medical Model

==Western society / Western self-advocates==:

normalization is horrible

stop using medical model

ABA is abusive

==Global South / non-Western scholars & advocates==:

colonial practices disabled people (imperialism, industrialization, war…)

normative functioning is needed to survive

restoration of normative function is justice

(Connell, 2011: Grech, 2009; Grech, 2015; Lynch, 2019; Meekosha, 2011; Meekosha & Soldatic, 2011; Sandoval-Norton & Shkedy, 2019; Soldatic & Grech, 2015; Walker, 2012)

Decolonizing Social Model

Western society / Western self-advocates:

disabled people have a human right to exercise autonomy

accommodations are a civil right

accommodations and access enable independence and autonomy

Global South / non-Western scholars & advocates:

autonomy & independence are Western inventions inflicted on interdependent indigenous ways of life and not something to aspire to

"accommodations" can destroy local social fabric & disrupt relationships

indigenous / non-Western societies have a right to self-determination and their goals may be juxtaposed to Western desires or expectations

(Haegele & Hodge, 2016;

Decolonizing Neurodiversity Model

Western society / Western self-advocates & many indigenous worldviews:

diversity is natural

diverse traits sparks innovation

diverse traits, however frustrating in the moment, are valuable to the functioning of the community

Global South / non-Western scholars & advocates:

too much focus on the individual

the collective is more important

not being able to contribute to the collective can impinge survival

(Connell, 2011: Grech, 2009; Grech, 2015; Hickey & Wilson, 2017; Meekosha, 2011; Meekosha & Soldatic, 2011; Soldatic & Grech, 2015; Walker, 2012)

What Is a Clinician Supposed to Do?

Being an Ally: A Process Not an Answer

- An ally is not part of the group that has a problem

- An ally wants to help the group change the conditions the group is contending with

- An ally listens to and follows the group as the group determines what needs to happen

- An ally has privileges that the group does not have and that the ally can use to help change the conditions in question, but in ways determined by partnering with the group

(Abes & Zahnei, 2020; Carey et al., 2020; Evans et al., 2005; Forber-Pratt et al., 2019; Klein, 1995; Raghavan, 2018)

"A major role that allies can play is questioning accepted practice... [and]..critically examining the assumptions and expectations of society about how things are done." (Evans et al., 2005)

"The work of an ally is as much internal as external. Actively deconstructing one's biases, understanding one's privileges and...ableism, reading and listening, being accountable and doing better every day is our job as...aspiring allies,"

(Raghavan, 2018)

"...practitioners hold immense power in settings that serve disabled individuals... which puts the practitioner in a unique role... To critically and consciously enter into this space...practitioners must explore their own potential biases, worldviews, and meaning making around and about disability... This action is demonstration of allyship."

(Forber-Pratt et al., 2019)

The work [of being an ally] is not easy but it is real and rewarding. The process of learning to become an ally Will bring you back to the reasons you chose to become a...therapist in the first place, and make you an even better one.

(Klein, 1995)

Reflecting On Ourselves

- An ally does not have the answers but is willing to ask the questions

- What issues do you want to raise to a conscious level in your clinical practice?

- What questions do you want to be asking?

- How will you be an ally?

Conclusion

Summary

- Models of disability influence what we do & how we respond
- Self-advocates in the West have pushed back against the medical model
- Professionals are abandoning medical model ideals
- No easy answers: clinicians must "hold" seemingly competing priorities, needs, perspectives, value systems all at once
- Clinicians also answer to many stakeholders: the client, the client's family, the client's community, self-advocates, society, colleagues

Allyship: An Antidote & A Path Forward

We tend think of the tensions in binary ways:
fixing / helping
normalizing / accepting
frustration / diversity
self-advocates / professionals
autonomy / interdependence
individual rights / collective good

Concluding thought:
Being an ally is all about embracing the paradox!

Questions

Part 3: Finding the Balance Between Support and Acceptance –

How Do We Really Help Children with Various Conditions?

More to Explore

Sue Austin TED Talk: [Deep Sea Diving in a Wheelchair](#)

Dr. Ragahavan: [Trying to Be an Ally…As a Mental Health Professional](#)

Stella Young TED Talk: [I'm Not Your Inspiration](#)

Jim Sinclair: [Don't Mourn for Us](#)

Aiyana Bailin: [Clearing Up Some Misconceptions About Neurodiversity](#)

Wendy Lu: [These Things Might Not Seem Ableist But Are](#)

The Guardian: [Seven things you should stop saying and doing to disabled people](#)

Edith Sheffer: [The NAZI History Behind Asperger](#)

Gary Pisano, Harvard Business Review: [Neurodiversity as a Competitive Advantage](#)

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