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Neurodiversity: How to Support Agency and Self-determination

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Speaker Bio

- Joleen R. Fernald, PhD, CCC-SLP was awarded Board Specialty Recognition in Child Language from the American Speech Language Hearing Association. Dr. Fernald follows Greenspan and Wieder's model, DIRFloortime® , when working with children and families. She has a special interest in the social emotional development of young children and its impact on their speech and language skills. As a speech-language pathologist, Dr. Fernald works with children who have a variety of communication disorders. She partnered with Easter Seals NH in 2006 to begin an assessment and treatment clinic specifically for children with selective mutism and has recreated the model in the Tampa Bay area of Florida as well. Joleen enjoys public speaking and has presented nationally on the topics of childhood apraxia of speech and selective mutism.



Disclosures

- **Presenter Disclosure:** Financial: Joleen Fernald was paid an honorarium for this presentation. Joleen is a Training Leader and Expert DIRFloortime provider and has a private speech-language pathology clinic. Non-financial: No relevant relationships to disclose.
- **Content Disclosure:** This learning event does not focus exclusively on any specific product or service.
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Learning Outcomes

After this course, participants will be able to:

- Define neurodiversity.
- Explain why Applied Behavioral Analysis and other behavioral interventions are traumatic.
- List three adjustments to clinical practice that will support agency and self-determination.



Introduction / Background

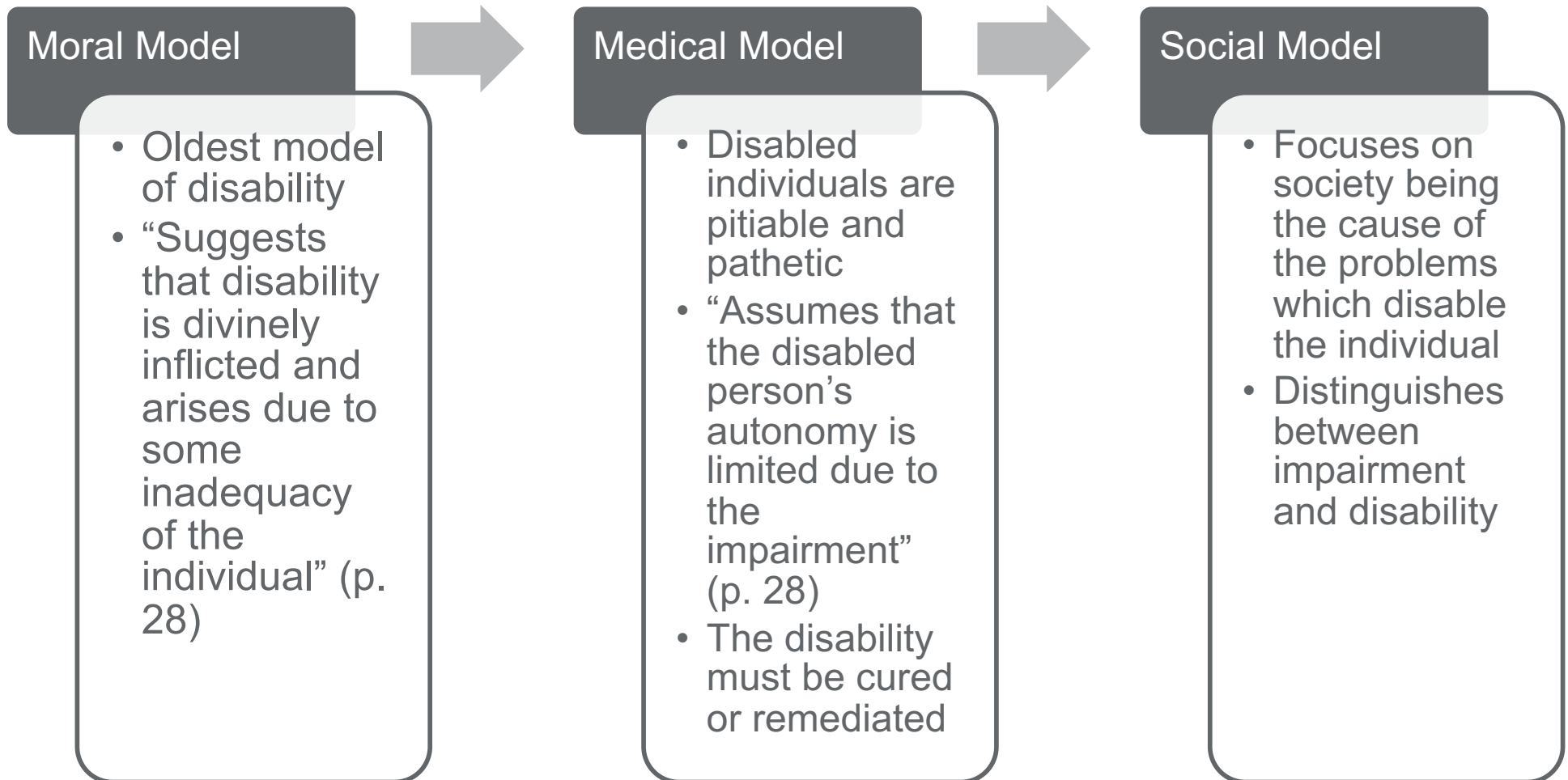
- Clinician for 25 years
- Within the past three years, I have become more aware of the neurodiversity movement
- Neurodiversity and supporting agency and self-determination, human rights is not specific to autistics



Vocabulary and Terminology

- Neurodiversity
 - diversity of human minds, the infinite variation in neurocognitive functioning within our species
- Neurodiversity Movement
 - a social justice movement that seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent.
- Neurodivergent
 - sometimes abbreviated as **ND**, means having a brain that functions in ways that diverge significantly from the dominant societal standards of “normal.”

Models of Disability



Impairment vs. Disability

- Attributed to functional limitation characterized by a physical or cognitive/mental impairment
- Linked to the loss of opportunities in society caused by society's failure to break down the barriers (physical and social)

Identity First vs. Person First Language

- Identity First (Autistic person)
 - Recognizes, affirms, and validates an individual's identity as an Autistic person
 - Recognizes the value and worth of that individual as an Autistic person
 - Being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual's potential to grow and mature, to overcome challenges and disability, and to live a meaningful life *as an Autistic*.
 - Ultimately, we are accepting that the individual is different from non-Autistic people—and that that's not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference.

- Person First
 - Person with autism,” it *does* have an attitudinal nuance. It suggests that the person can be *separated* from autism, which simply isn’t true. It is impossible to separate a person from autism, just as it is impossible to separate a person from the color of his or her skin

How Do You Know?

- Ask
 - If you ask, use the person's preference.
 - If you aren't sure of the preference and can't ask, go with the majority of the community
 - If you're referring to a group of people who have different preferences, use the language of the majority of the group



Ableism

- subscribing to the idea that the neuromajority are superior to those who are neurodivergent; therefore, those who are neurodivergent should participate in therapy to be more like the neuromajority
- In language, ableism often shows up as
 - metaphors (“My boyfriend is *emotionally crippled*.”),
 - jokes (“That comedian was *hysterical*!”), and
 - euphemisms (“He is *differently abled*.”)



How Ableist Language Influences Us

- Reveals our unconscious biases
 - “our attitudes towards disability show up in the language we use.”
- Causes us to internalize harmful biases about disability
 - “spreads the idea that it’s acceptable to dehumanize and stigmatize someone with a disability. Depending on your circle or friend group, you could even be enabling others to do the same.”



How Ableist Language Influences Us

- “a disabled person may end up internalizing those tropes themselves.”
- Stigmatizes already marginalized people
 - “distracts attention from the point you’re trying to make and normalizes the idea that disabilities equate to insults”



Ways to Avoid Ableist Language

- Acknowledge the disability around you - Don't try to fix disability; instead fix the oppression.
- Education - Educate yourself, and don't rely on others to teach you.
- Don't make assumptions about other's disability - Golden rule is: When you're unsure of someone's identity, just ask.
- When you make a mistake, apologize - This isn't about your opinions; it's about how the other person feels.



Masking

- Camouflaging is the difference between how people seem in social contexts and what's happening to them on the inside (Lai et al., 2017)
- calls for constant and elaborate effort to conform to other's social behavior with the goal of fitting in
 - suppressing repetitive behaviors known as stimming
 - reduction in talking about obsessive interests
 - pretending to follow a conversation or imitating neurotypical behavior.



Masking

- Not gender specific
- More frequent in females than males
- Upwards of 70% of the autistic population mask (Cage & Troxell-Whitman 2019)
- often motivated by a sense of alienation and threat, and frequently represents an attempt to avoid ostracism and attacks' (Mandy 2019)



Masking in Females

- Impacts ASD diagnosis
 - three to four times as many boys as girls are diagnosed as Autistic.
 - It might also account for why girls diagnosed young tend to show severe traits, and highly intelligent girls are often diagnosed late
 - Girls seem more anxious/depressed
 - Autistic girls tend to stay close to other Autistic girls (Dean et. Al, 2017)
- Women with high intelligence are excellent at camouflaging

Trauma – Pay Attention

- Negative impacts on autistic people's mental health (Livingston and Happé 2017, Cage & Troxell-Whitman 2019,
- Physical exhaustion and extreme anxiety
- Lead to “increased stress responses, meltdown due to social overload, anxiety and depression, and even a negative impact on the development of one's identity” over time (Lai et al. 2016).
- Suicidal ideation (Healle 2018)



Assessment To Support Neurodiversity

- Better assessment process
 - Be aware of masking
 - Remove ableist language in report writing
 - Use identity first language in report writing
 - Include a section for strengths and talents
 - Reframe to be positive

https://elishabidwell.com/why-strengths-based-evaluations-of-neurodivergent-kids-matter/?fbclid=IwAR1VY1C67vLAb6QeKlch9xF4SrjcuqIX9H8YJLhzMfYW5tmp_k1BgeIB-4s



Goals To Support Neurodiversity

- Better goal writing
 - Not compliance-based
 - Presume competence
 - No Social Skills Training – it's dehumanizing
 - No Eye Contact and No Teaching Emotions
- Goals should support...
 - human rights and dignity
 - self determination
 - advocacy

DO Write Goals For...

- Self-Advocacy
- Perspective Taking: Self and Others
- Interoception for: Self-Regulation, Self-Awareness, Flexibility of Thought, Intuition, Perspective Taking, Problem Solving, Social Understanding
- Teaching how one's body sensations correlate to emotions
- Figurative Language: Metaphors, Similes, Personification, Hyperbole, Symbolism
- Building upon strengths

DON'T Write Goals For...

- Treating Autism
- Eye Contact with Communication Partner
- Quiet Hands and Whole Body Listening
- Extinguishing perceived neurodivergent social deficits
- Teaching social scripting that encourages masking (feelings, emotions, stimming, sensory needs, quiet hands, compliance for rehearsed role-play, etc.) "Social Stories*" that are written and used in a manner that is meant to compel compliance
- Social skills goals that focus on making the client appear indistinguishable from their neurotypical peers

Interventions to Support Neurodiversity

- Don't get caught up in one model or philosophy, instead be aware of what upholds the dignity of the individuals who cross your path
- Developmentally, Relationship-based Models without a behavioral connection
 - DIRFloortime
 - SCERTS
 - Hanen
- Autism Level Up (<https://autismlevelup.com/>)



DO

- Honor and use whatever communication method is preferred by the user (Augmentative and Alternative Communication)
- Model language
- Ask permission before touching
- Use hand under hand

DON'T

- Use Picture Exchange Communication System® (PECS)
 - Relies on operant conditioning (e.g. withholding an item if the person doesn't use the picture exchange methodology)
- Physically restrain/touch without permission
- Use Hand Over Hand



We say NO to:

Play-based ABA
ABA + relationship-based therapy
"New" ABA
Verbal Behavior (VB)
VB-MAPP
The Lovaas Approach
Pivot Response Treatment (PRT)
Natural Language Paradigm (NLP)
Early Start Denver Model (ESDM)
Early Intensive Behavioral Intervention (EIBI)
Discrete Trial Training (DTT)
Incidental Teaching
Intensive Behavioral Intervention (IBI)
Positive Behavior Support (PBS)
Relationship Development Intervention (RDI)
Positive Behavioral Interventions and Supports (PBIS)
The PEERS® Program
Social Skills Training
Whole Body Listening

Therapist Neurodiversity Collective International

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<https://therapistndc.org/>

Human Rights & a Paradigm Shift

- Presume competence.
- Provide access to robust AAC without prerequisites.
- Respect and uphold self-determination for quality-of-life decisions.
- Support client needs first and foremost, including unrestricted access to the accommodations, modifications, and supports that work for them.

- Practice therapy models focused on building upon and expanding individual strengths.
- Advocate for equitable access and inclusion.
- Teach self-advocacy skills.
- Refuse all behavioral methodologies or behaviorally-derived therapy practices or programs.

- Reject neurotypical 'Social Skills Training' therapy models, materials, and commercial programs. (Clinical outcome objectives intended to mask autistic characteristics, e.g. changing behaviors such as stimming, forcing eye contact, or make autistic children or adolescents look 'less autistic'.')
- Accept behavior as a possible communicative attempt, while working diligently towards understanding, rather than extinguishing or ignoring the behavior.

- Focus communication therapy on expanding the client's preferred manner of communication (e.g. Spoken, Robust AAC, Sign, Self-directed Spelling, Gestures, Actions, Body Language, Behavior).
- Respect body autonomy. (e.g. Will not physically manipulate client, without client consent. Use hand underhand and only with client consent, and only when necessary. Will not force-feed.)
- Never withhold access to emotional comfort, physical comfort, food, drinks, favorite items, activities, personal belongings as a way to manipulate or control.

- Commit to continued research/reading into the personal experiences of a wide range of Neurodivergent people.
- Commit to reading current research, and studying humane and trauma-informed best practices in my area of expertise, my provider setting, and population: Pediatric, Adult, Geriatric.
- Strive for Autistic children and adolescents to have a strong support base of Autistic peers and mentors.

- Use identity-first language, noting its consistency with the neurodiversity paradigm and preferences expressed within Autistic Culture.
- Promote Human Rights, respect Civil Liberties, uphold Human Dignity for all humans, especially including non-speaking, intellectually disabled, all neurodivergent people, marginalized neurodivergent populations, traumatically brain-injured, neurologically involved, and those with Mental Illness, Dementia, Alzheimer's, or otherwise disabled.

PATHOLOGY



POTENTIAL

