

The 3rd Annual Shifting the Autism Narrative: The Impact of Stigma on Health

Webinar presented by Mel Houser, M.D., Executive Director, All Brains Belong VT (4/16/2024)

Part 1: The status quo of healthcare is failing Autistic patients

Autistic Adults struggle to access healthcare

- 79.8% difficulty accessing primary medical care (Doherty et al 2020)
- 63-69% untreated health conditions (Doherty et al 2022)

Types of barriers to healthcare (Raymaker et al 2017; Doherty et al 2020; Doherty et al 2022)

- Environment
- Provider knowledge, skills, attitudes
- Systemic barriers

Autistic patients are dying

- Life expectancy 36-54 years
- Leading causes are premature cardiovascular disease and suicide

Part 2: The healthcare system's role in driving the stigma of autism

The way doctors are trained to think and talk about autism leads to a deficit-based paradigm

- How did we get here? Doctors generally do not know the history of how autism made its way into the Diagnostic Statistical Manual (DSM) and medical education was shaped. This history is presented in detail.

Language matters. The words professionals use often lead to patients and families mistrusting the professional. Language often reflects the paradigm the professional is working from.

- Example video of "typical" doctor discussion after the diagnosis of a child
- Example language used in a consult note from an evaluator
- Examples of pathologizing terms vs. neurodiversity-affirming terms

Why does any of this matter?

- Autistic people grow up stigmatized and "othered."
- Autistic people receive the message that their way of thinking, acting, communicating, etc. is broken.
- If healthcare providers view patients through this deficit-based lens, they won't feel comfortable.

Part 3: Shifting the narrative

Definitions

- Neurodiversity: We all have different brains. Different brains do things differently: sensing, processing, thinking, behaving, communicating, learning.
- Neurodiversity paradigm: There is no one correct type of brain.
- Universal design (offering everything in multiple different ways) is best practice.

Autism redefined in the neurodiversity paradigm

- Differences in thinking, attention, processing, communicating, and motor coordination
- Defining access needs and the social model of disability
- Neurodiversity-affirming resources are offered

Part 4: All Brains Belong VT

All Brains Belong is pioneering a new model for neurodiversity-affirming healthcare.

- Healthcare is more than medical care: social connection, employment support, community education
- 'One size fits all' does not work for all: universal design for healthcare
- Ask the community what they need, and change the system from the ground up.
- Connection is the path to health

Check out [Practical Strategies for Delivering Neuroinclusive Healthcare](#): ideas for any healthcare setting.