Beyond Access and Inclusion:
Belonging in Healthcare for Individuals with Intellectual and Developmental Disability

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Disclosures

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Conflict of Interest Statement
• No conflicts of interest to disclose
• No commercial interest/sponsorship to disclose
Learner Objectives

• To align the priorities of individuals with intellectual and developmental disability and their families/caregivers to the mission and vision of the academic medical center they are receiving care in.

• To increase the knowledge and comfort level of health care providers and all patient-facing staff in caring for persons with intellectual and developmental disability.

• To foster an healthcare environment of inclusion and belonging for individuals with intellectual and developmental disability and their families/caregivers.
The Why

200 million individuals

Perceptions

Passion
Who We Are
**Jefferson Health**

**Jefferson Center for Autism and Neurodiversity**
A programmatic and clinical practice center with the mission of designing and applying strategies to make healthcare and community settings more accessible to people with autism and other neurodiverse conditions is the priority.

**Jefferson Continuing Care Program**
A primary care program for adolescents, post-adolescents, and those well into adulthood with intellectual & developmental disabilities that provides a comfortable space for care teams to work with patients and help guide them as they continue to grow.

**Thomas Jefferson University**
Culture Shift

Health Enterprise and University Setting

People/Interdisciplinary
Education
Outcomes
Perspective
Learning
Environments
The Approach
Interdisciplinary and collaborative approach

Kotter’s Change Model

Create Urgency
Guiding Coalition
Vision & Strategy
Connect
Remove Barriers
Short term Goals
Build on Change
Make it Stick
Project Process

Population
- Intellectual and Developmental disability
- Students
- Faculty

Allys
- Internal
- External

Goals
- Equity
- Inclusion
- Belonging
- Access
Goals Achieved

• **Education**
  - Grand Rounds (Physical Rehabilitation, Palliative Care, Integrative Medicine, GI, Oncology, Nursing, Human Resources, DEI program, Security team)
  - Health Resume

• **Built Environment**
  - Furniture Design for the Honickman Specialty Care Pavilion
  - Immersive Art for Well Being-Waiting Room

• **Community**
  - Philadelphia Flower Show
  - Share the Showroom (Subaru dealerships)
  - Philadelphia sports teams (Union, 76ers and Phillies)
  - PHL17 Horticultural Program
  - Pennsylvania Supreme Court Autism Summit
  - Special Olympics

• **Academic Curriculum**
  - Standardized Patient simulations
  - Fashion Design Course
  - Medical Humanities course
  - Furniture Design Course
  - The Art Experience and Health
  - Architecture and the Built Environment Symposium
  - Office of DEI at Jefferson Health
  - Cybersecurity program
Inclusion and Belonging

- PHL 17 Summer Garden
- Pennsylvania Supreme Court - Foster Care
- Share the Showroom - Subaru event
- Health Passport
- Neurodiverse Friendly Specialty Care Pavilion
- COVID-19 friendly vaccine clinic for individuals with IDD/Neurodiversity
- Philadelphia Phillies baseball games
- Philadelphia Flower Show
COVID 19 Vaccine Clinic
Access and Equity
Jefferson Navy Yard
Honickman Specialty Care Pavilion
Belonging
Kambel Smith
Autisarian Network
Shifting Culture and Driving Policy

- Special Olympics and COVID
- CNN and COVID Vaccine Center
64 million medical records at 574 medical centers

Intellectual disability (ID) was the number 1 risk factor for getting COVID-19, well above other well known reasons like respiratory problems, obesity, diabetes.

It was second to age only for COVID-19 deaths

If you had ID you were over 30% more likely to die if your were inpatient but less likely to be admitted to ICU during your stay
People with Certain Medical Conditions

Disabilities

People with some types of disabilities may be more likely to get very sick from COVID-19 because of underlying medical conditions, living in congregate settings, or systemic health and social inequities, including:

- People with any type of disability that makes it more difficult to do certain activities or interact with the world around them, including people who need help with self-care or daily activities
- People with attention-deficit/hyperactivity disorder (ADHD)
- People with cerebral palsy
- People with birth defects
- People with intellectual and developmental disabilities
- People with learning disabilities
- People with spinal cord injuries
- People with Down syndrome
Lessons Learned

• It takes a village
• You need a champion
• The 3 P’s
  • Persistence
  • Patience
  • Passion
• Interdisciplinary team
Limitations/Challenges

• Covid-19 pandemic
• Burn out (staff and faculty)
• Size of organization
• Funding
Surprises

- Emergence of supporters and champions
- Increased membership on Advisory board
- Increased engagement of focus group members
- Feedback from employees
- Increased employment opportunities for students and IDD community (Cybersecurity)
diversity
is being invited to the party

inclusion
is being asked to dance

belonging
is dancing like no one's watching

Verna Myers
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References


