

COLLEGE OF NURSING

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

Jane Tobias, DNP, CRNP, CPNP-PC
Assistant Professor
College of Nursing



Disclosures

Jane Tobias, DNP, CRNP, CPNP-PC

- Thomas Jefferson University
 - Assistant Professor
- National Association of Pediatric Nurse Practitioners
 - Executive Board- Member at Large

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



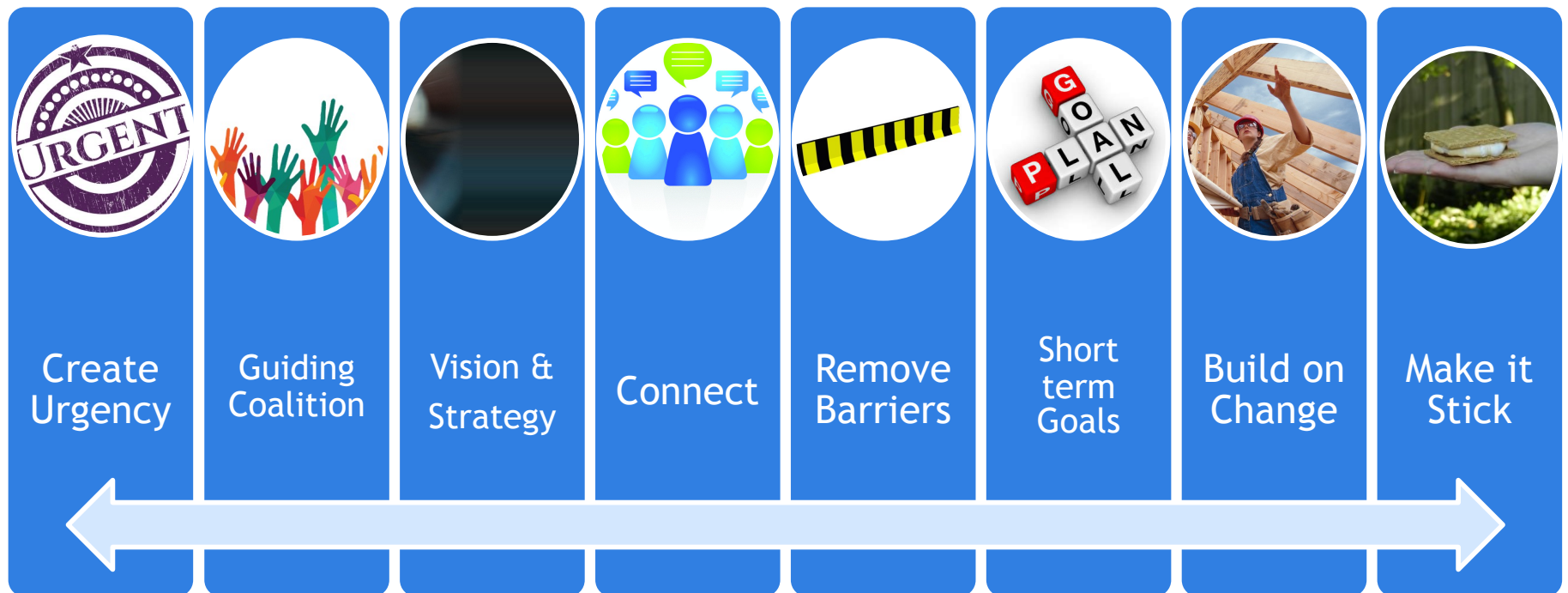
Health Enterprise
and
University Setting

- People/Interdisciplinary
- Education
- Outcomes
- Perspective
- Learning
- Environments

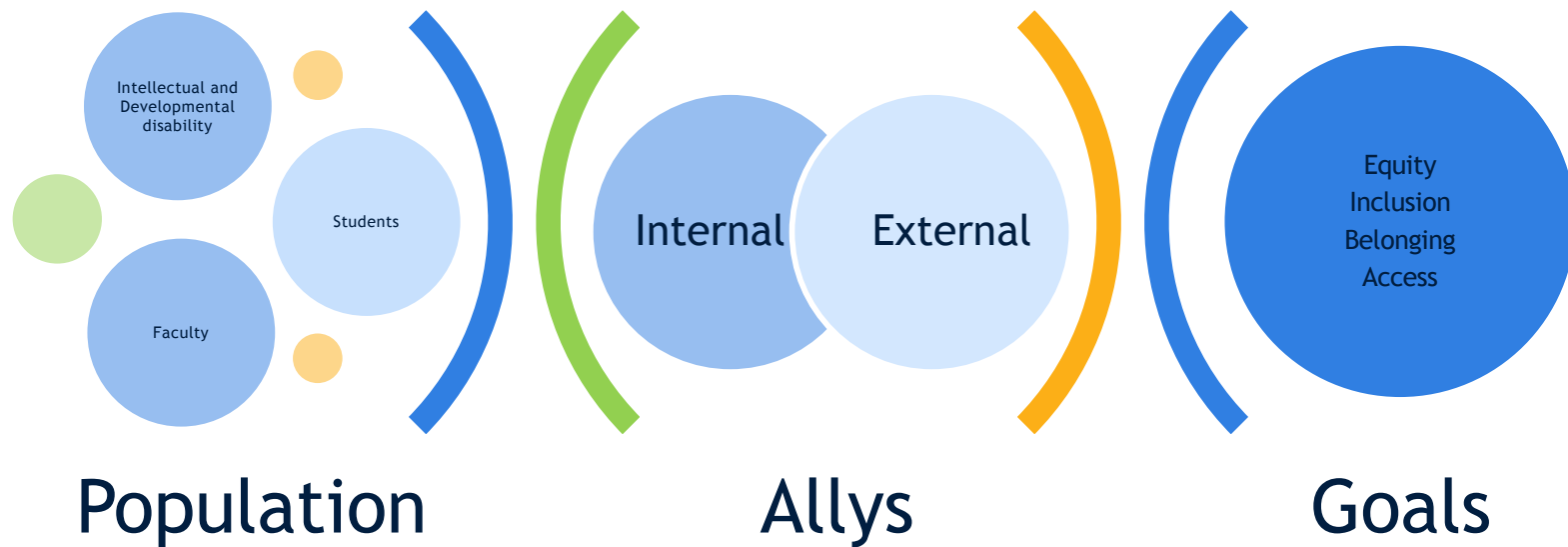
The Approach

Interdisciplinary and collaborative approach

Kotter's Change Model



Project Process



Goals Achieved

- **Education**

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

- **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

- **Built Environment**

- Furniture Design for the Honickman Specialty Care Pavilion
- Immersive Art for Well Being-Waiting Room

- **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

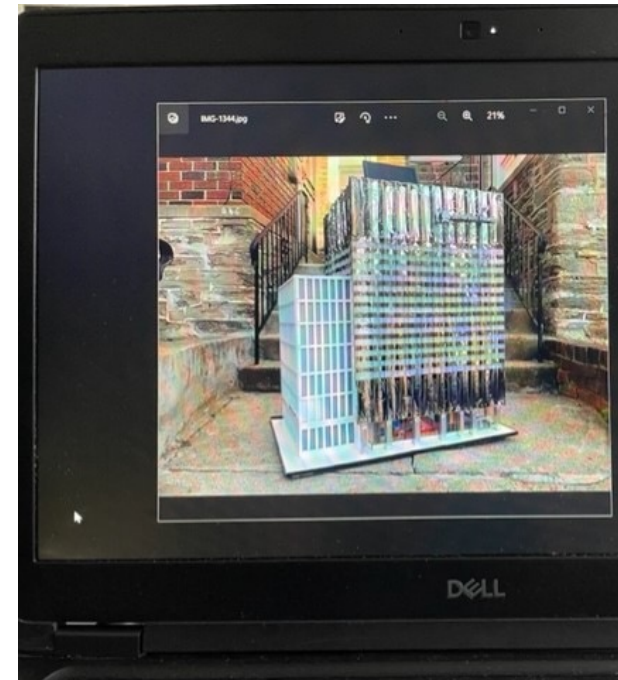
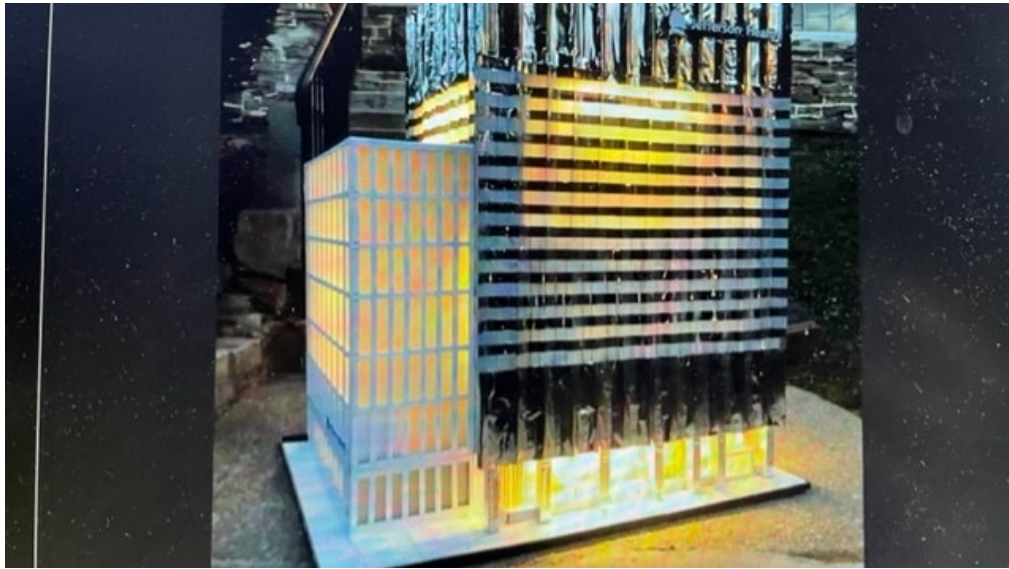
Inclusion and Belonging

- 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](#)

New England Journal of Medicine Catalyst

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

 NEJM Catalyst | Innovations in Care Delivery

COMMENTARY

The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States

Jonathan Gleason, MD, Wendy Ross, MD, Alexander Fossi, MPHc, Heather Blonsky, MAS, Jane Tobias, DNP, RN, MSN, CPNP-PC, Mary Stephens, MD

Vol. No. | March 5, 2021

DOI: 10.1056/CAT.21.0051

A cross-sectional study of 64,858,460 patients across 547 health care organizations reveals that having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality. Screening for Covid-19, care coordination, and vaccination efforts should be intense within this population that is less able to consistently use masks and socially distance.



COVID-19



Your Health

Vaccines

Cases & Data

Work & School

Healthcare Workers

Health Depts

Science


More

People with Certain Medical Conditions

Updated Feb. 25, 2022 Languages Print

Disabilities

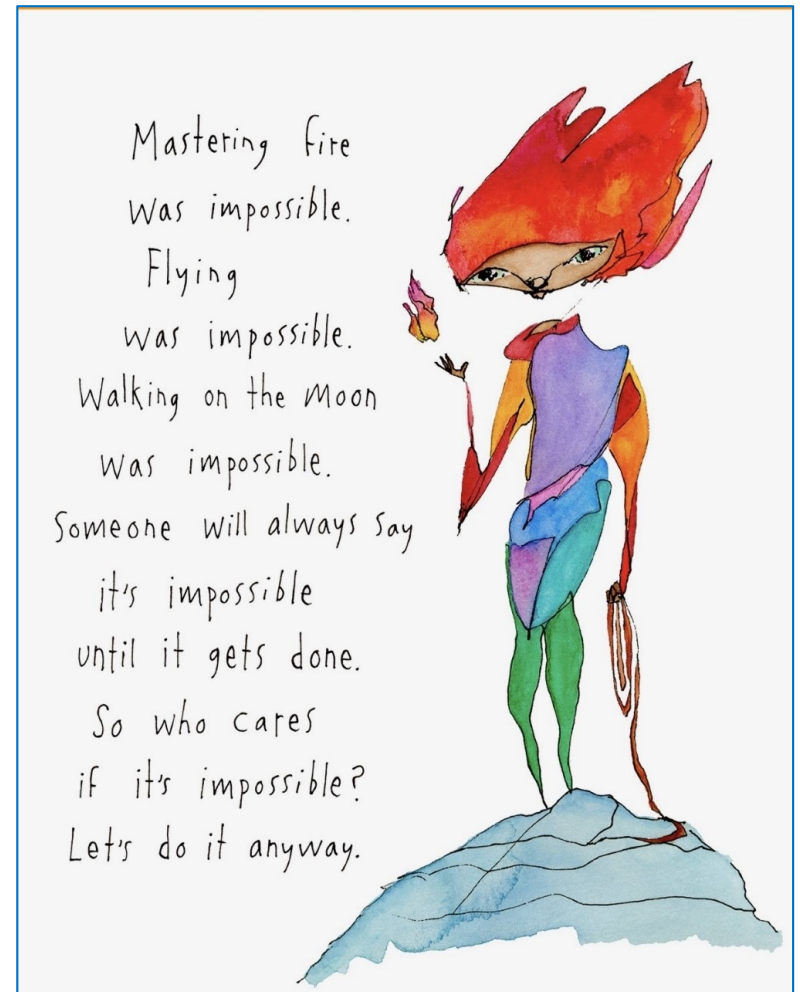
People with some types of disabilities may be more likely to get very sick from COVID-19 because of underlying medical conditions, living in congregate settings, or systemic health and social inequities, including:

- [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)



Verna Myers

Acknowledgements

- The Golisano Institute of Intellectual and Developmental Nursing faculty
- Shirley McMillan, RN, PhD, CDDN~ Clinical Nurse Specialist, Surrey Centre
- The Golisano Foundation
- The IDD Community
- The Jefferson Center for Autism and Neurodiversity and Jefferson Continuing Care Program



THANK YOU

References

- Cullen, L., Hanrahan, K., Edmonds, S. W., Reisinger, H. S., & Wagner, M. (2022). Iowa Implementation for Sustainability Framework. *Implementation Science*, 17(1), 1-20.
- Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States. *NEJM Catalyst Innovations in Care Delivery*, 2(2).
- Iezzoni, L. I., Rao, S. R., Ressler, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., ... & Campbell, E. G. (2021). Physicians' Perceptions of People with Disability and Their Health Care: Study reports the results of a survey of physicians' perceptions of people with disability. *Health Affairs*, 40(2), 297-306.



Jefferson
Thomas Jefferson University