



Thomas Jefferson

University

The Impact of Self-Advocate Storytelling on Education Resources for Healthcare Providers

Karin Roseman, LCSW- Co-Director, Jefferson FAB Center for Complex
Care

Suzanne Gladstone - Community Advisory Board Member, Jefferson
FAB Center for Complex Care

This project is funded by the Pennsylvania Developmental Disabilities Council.

Dr. Mary Stephens and Karin Roseman from the Jefferson FAB (For Adolescents and Beyond) Center for Complex Care were recipients of a grant from PADDCC to fund their project:

Increasing Access to Quality Healthcare for People with Disabilities: A Co-Designed Educational Curriculum for Family Medicine Residents

The Pennsylvania Developmental Disabilities Council is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$3,025,222.00 with 100 percent funding by ACL/HHS. Council efforts are those of the grantee and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

We'd like to thank our community advisory board!

To help in the planning and design of this project and our curriculum, we have hired individuals with lived experience with disabilities, as well as some caretakers, as advisors.

We would like to thank Aronya Waller, Cheryl Trexler, Christina Grubelic, Corey and Marie Beattie, Dan Lauria, George Lees, Jackie Shapiro Fishbein, Janine Blythe, Joan and John Thomas, John Griffith, Kirah Burgess-Goard, Kristan Scofield, Linda Turner, Mary Griffith, Mia Andrilla, Namiyah and Nicole Ruley-Minus, Rachel Fishbein, Rebecca Bradbeer, Roc and Donna, Shannon Taylor Ward, Stephanie Andrilla, Steven Seibert, Suzy Gladstone, Thomas Butts, Trish Lauria, Victoria Patterson, Victori Silvestri, Zach Scofield, and Zachary Trexler for their contributions.

Learning Objectives

- Explore creative ways to amplify the voices of self-advocates in academic work.
- Recognize the benefits of creating space in education and research for self-advocates to share their experiences.
- Understand the impacts of self-advocate stories on the knowledge and attitudes of healthcare providers.
- Discuss key points to implementing a community advisory board.

Outline

Our Organization

PADDC Grant

Self-Advocate Storytelling

The Impact

The Jefferson Enterprise

Thomas Jefferson
University

Jefferson Health

Jefferson Health
Plans

Department of Family
and Community
Medicine

Jefferson FAB Center
for Complex Care

The Jefferson FAB (For Adolescents and Beyond) Center for Complex Care

A primary care medical home for adolescents and adults with childhood-onset complex conditions

Established in 2018 and became a formal center in early 2023

Now, there are over 800 patients!



Co-Directors: Dr. Mary Stephens, MD, MPH and Karin Roseman, MSW, LCSW

Grant Activity Overview

Quality Healthcare Access Grant

Year 1

- Design a curriculum for family medicine residents about caring for patients with IDD
- Community Advisory Board (CAB) of people with lived experience of disabilities co-design curriculum
- CAB creates videos to share their experiences

Year 2

- Present 4-part classroom lecture for family medicine residents at Jefferson
- CAB members join presentations and Q+A panels with learners

Year 3

- Adapt in-person lectures to online learning modules anyone can access
- Broader scope for all healthcare professionals
- CAB reviews and adds content to each module

Year 4

- We are creating a video series of simulated healthcare visits with people with disabilities and healthcare providers
- CAB members brainstorm topics, film content, add feedback, and support education materials surrounding the videos

Online Learning Module Content

Module	Theme	Highlights
Module 1	Communication, Common Sense, and Nuance: Care of Patients with IDD	<ul style="list-style-type: none"> • Background on disability and IDD • Barriers to care and health disparities • Ableism and diagnostic overshadowing • Strategies to support patients during office visits
Module 2	Patient and Caregiver Community Supports and Resources	<ul style="list-style-type: none"> • Transitions through the lifespan • The wavier system • Accessing community resources in adulthood
Module 3	Mental and Behavioral Health	<ul style="list-style-type: none"> • Mental health care • Case studies and medication use • Mental health of caregivers • Emerging trends in IDD
Module 4	Working with Interdisciplinary Teams	<ul style="list-style-type: none"> • The role of interdisciplinary providers • Augmentative and alternative communication • Collaboration in care for people with IDD
Module 5 "bonus"	Disability Education: Taking a Physical History	<ul style="list-style-type: none"> • Practical tips for completing a physical exam for an individual with IDD or physical disability

Year 4: Videos and simulated exams

We are developing content across the course of this year highlighting simulated patient encounters in different settings to teach healthcare providers and trainees about best practices.

Stay tuned later this year for this new content!

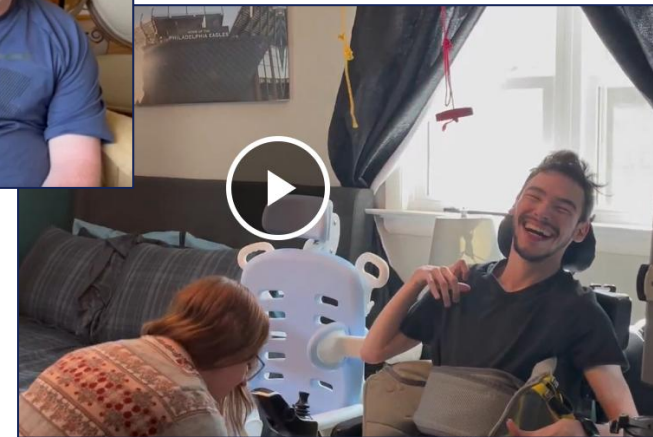
Video	Theme
Video 1	Physical examination in primary care
Video 2	Labs and imaging
Video 3	Cerebral palsy (CP) in adulthood
Video 4	Down syndrome and aging

The Role of Self Advocates

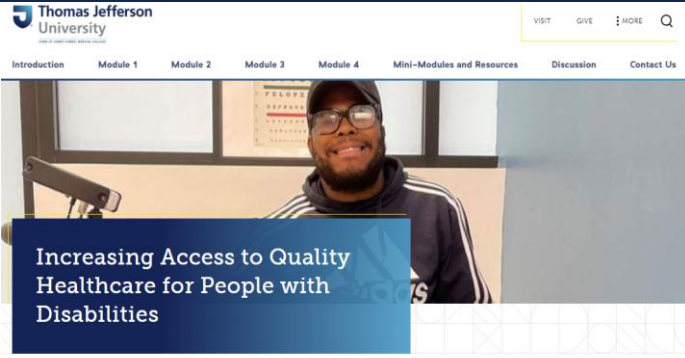
Curricular Design and Review

- Development of Community Advisory Board (CAB) - Spring 2023
 - What is important in our curriculum?
 - What do you think future healthcare professionals need to hear?
- Quarterly meetings to review upcoming presentations - 2023 and 2024
 - Review content
 - Is this information accurate and representative of your experience?
 - Is there anything we should emphasize or share?
- Creating online modules - 2025
 - As each module is created, a peer review meeting is held with CAB
 - Review sections of content for additions
 - What else can we add from your perspective?
- Filming videos & sharing our work - 2026
 - Creating new content - what is a healthcare experience or topic we should focus on?
 - Collaborating as partners in patient panels and conference presentations about experiences and the project

Videos



Online Modules



Module 1: Communication, Common Sense, and Nuance: Care of Patients with Intellectual and Developmental Disabilities (IDD)

These resources are designed to support your continued eng

- [Module 1 References](#) (pdf)
- [Module 1 Additional Resources](#) (pdf)
- [Module 1](#) (pdf offline version)

Medications to consider from a primary care provider's perspective 5, 6, 7, 8

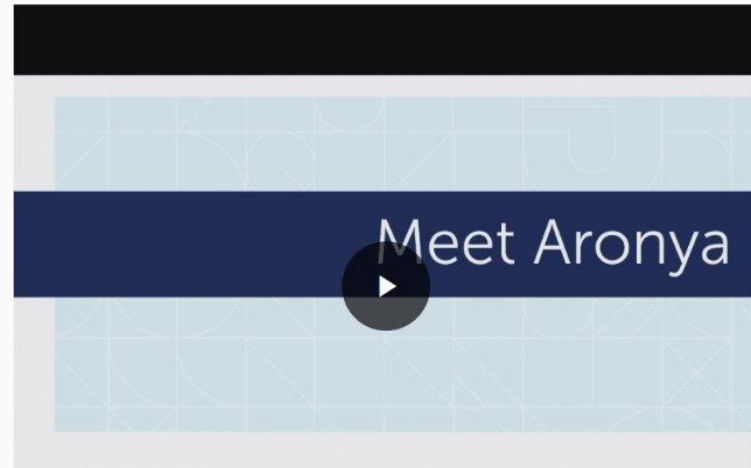
Note: This is not a comprehensive guide for all medications to consider. It can be used as a quick reference and learning guide. For additional information on best practices in prescribing medications for co-occurring conditions in individuals with ASD, read more in the references highlighted at the end of this page.

SLEEP	DEPRESSION, ANXIETY, AND OCD	IRRITABILITY AND AGGRESSION
<ul style="list-style-type: none">• Melatonin, 3-6 mg - Higher doses may contribute to anxiety.<ul style="list-style-type: none">◦ Remember that melatonin is for falling asleep, not for staying asleep• Mirtazapine - May help with sleep, depression, anxiety, and irritability.<ul style="list-style-type: none">◦ May cause weight gain• Trazadone - Less popular but benefits some patients.		
<p>A general note about sleep: If the patient is not sleeping, that means other household members are not sleeping either.</p>		

Knowledge check - members of an interdisciplinary team

Aronya is a person with lived experience of disability and a project consultant. She allows us into her home to see the ways she has made modifications in her home environment to support her safety and independence, and how she moves through her neighborhood.

Watch the video below to hear from Aronya. Think about which members of an interdisciplinary team might work with or have worked with Aronya to support her. Then, answer the question below.



Impacts and Implementation of a CAB

Learner Feedback

- It is well accepted that people with lived experience of disability are the best people to teach about disability
- Feedback has been positive, and learners share about gaps in existing knowledge
- Overwhelmingly, residents responded that their favorite parts of the sessions were having CAB members present and having videos to share.

“Understanding lived experiences is so eye opening”

“I really enjoyed the patient panel. It brought a different, more dynamic aspect to the lecture that I enjoyed.”

The most meaningful part of the session was... “Having the guest panelists present to discuss their lived experiences, challenges, and what we can do to improve how we care for them”

How can I create this in my organization?

- Individuals with lived experience are the experts - consider who is in the room when decisions are made, and who we are making decisions for
- Create a specific role description:
 - Time commitment - 1-3 hours per month
 - Meeting expectations and location (virtual)
 - Types of activities
 - Accommodations
 - Compensation
 - Opportunities for personal and professional development
- Added benefits for members:
 - Community with others
 - Building advocacy skills from other's shared experiences
 - New experiences and confidence! Many people do not have experience with academic presentations and conferences - participation in a CAB opens the door for new opportunities

Reflections from Suzy

As a caregiver, advocate, and professional in the IDD community, what has it been like to share your story and input with so many learners?

For someone considering starting a CAB or joining an existing CAB, what advice would you give them?

Why do you think this project and the CAB are important?

Reflections from Suzy

Why do you think this project and CAB are so important?

“I want physicians to learn and understand as much as they can about people with disabilities so they can help families like mine when we walk through the door.”

- Physicians must learn about people with disabilities so they can better support and care for families.
- Families rely on physicians as one of their first and most trusted resources.
- Medical appointments can be vulnerable experiences for families.
- Greater understanding and awareness improves communication, trust, care and health outcomes.
- Experiences of families and people with disabilities are important to physician learning.

Seth



Reflections from Suzy, continued...

THE EARLY YEARS

- Seth was diagnosed with Autism at 4 years old.
- Strong network of friends and family
- Access to high quality Early Intervention providers in our Main Line community.
- Seth attended elementary school in the Lower Merion School District.
- Introduced to IEPs, Autism Support services, and the value of community inclusion.
- A strong relationship developed with Seth's pediatrician, Dr. Madeline Weiser, who introduced the family to the SHOT BLOCKER device.
- The SHOT BLOCKER is a non-invasive, drug-free tool designed to reduce pain during vaccines and procedures by overwhelming sensory nerves.

Reflections from Suzy, continued

CROHN'S DISEASE

- Accepted into a Master's-level Occupational Therapy program at Thomas Jefferson University while Seth was in elementary school
- Occupational Therapy profession with a focus on supporting people in meaningful daily activities and routines resonated with me
- Seth was soon diagnosed with Crohn's Disease
- Received specialized GI care at Children's Hospital of Philadelphia
- Began infusion therapy around age 10
- Treatments were successful until adolescence and puberty-related weight changes created new challenges

Reflections from Suzy, continued

HEALTHCARE CHALLENGES

- Physician recommendations to diet felt overwhelming for the family
- How to support an autistic child with food sensitivities and a limited diet
- Managing healthy nutrition across two households with different routines was difficult
- Physician provider was unable to offer helpful resources
- A friend recommended a Registered Dietician who accepted insurance.
- Practical strategies and ideas: “Snobby Snacks”
- Professional nutrition guidance was invaluable

Reflections from Suzy, continued

PROFESSIONAL ROLES

- OT at Moss Rehab in North Philadelphia working with diverse client populations
- Observed disability intersect with income disparities
- Learned about community resources for insurance, housing, transportation, food, and more
- Collaborated with an interdisciplinary team to enhance patient outcomes
- Easterseals in Media, PA with preschool children with disabilities
- Carousel Connections in Montgomery County
- Support adults with community participation, employment, and independent living
- Use occupational therapy to build skills in self-advocacy, mobility, social interaction, and sexuality education

Learn more about our project!

- Visit our project website to learn more, view our modules and resources
 - <https://academiccommons.jefferson.edu/ext/FAB/>
 - Questions?
 - § rosemary.corcoran@jefferson.edu for more information



Questions? Let's discuss!



Thomas Jefferson
University

Jefferson.edu

HOME OF SIDNEY KIMMEL MEDICAL COLLEGE