Thomas Jefferson University

JEFFERSON 200

Working With Interdisciplinary Teams

Mary Stephens, MD, MPH and Karin Roseman, MSW, LCSW
Co-Directors, 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 PADDC 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% 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 People With Lived Experience!

To help in the planning and design of these didactic sessions, 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.

Objectives

1. Discuss alternative forms of communication
2. Identify the ways in which various disciplines interact
3. Identify barriers and successes in co-treatment

Alternative Forms of Communication

The importance of communication

Developed and refined throughout a person's lifetime, communication requires making many assertions of need and want daily, both consciously and subconsciously.

It requires a sender and receiver- each need to understand the message and the method used to communicate.

Remember- Accessible communication is a human right.

It is your role to set that standard of care.

Universal Declaration of Human Rights. *Rev Enferm Nov Dimens*. Published online 1948.

Augmentative & Alternative Communication

Augmentative communication refers to enhancing or adding onto speech, while alternative communication refers to replacing speech with another form of communication.

- High technology
- Low Technology
- No Technology

It may seem difficult to feel comfortable in silence while your patient answers questions, but it gets easier with practice.

Elsahar Y, Hu S, Bouazza-Marouf K, Kerr D, Mansor A. Augmentative and Alternative Communication (AAC) Advances: A Review of Configurations for Individuals with a Speech Disability. *Sensors (Basel)*. 2019;19(8):1911. Published 2019 Apr 22. doi:10.3390/s19081911

AAC-Smartphone and Tablet Apps

Nondedicated AAC

- While tablets and smartphones are not built with the intention of accessible communication, apps can create accessible communication:
  - **LetMeTalk:** An app to create sentences from a set of photos
  - **SymboTalk:** An app that uses symbols and text-to-speech
  - **CommBoards:** A speech assistance app that can personalize communication boards
  - **Spoken – Tap to Talk AAC:** An app that uses icons and voice output

American Sign Language (ASL)

American Sign Language Overview

American Sign Language is not just English using your hands. It is its own language and does not follow the same grammar rules as English.

- Just as the English language has many dialects and accents, so does ASL.
  - Hand placements and motions may differ slightly depending on what region the individual is from or who they learned ASL from.

ASL Accommodations

Someone who learned ASL before they learned English might make spelling errors when writing or typing English.

By federal law, you must provide ASL as requested. You should arrange for this service so your office can provide it.

Be sure you and your staff get training on learning and providing ASL services.

Interdisciplinary Coordination: PT/OT

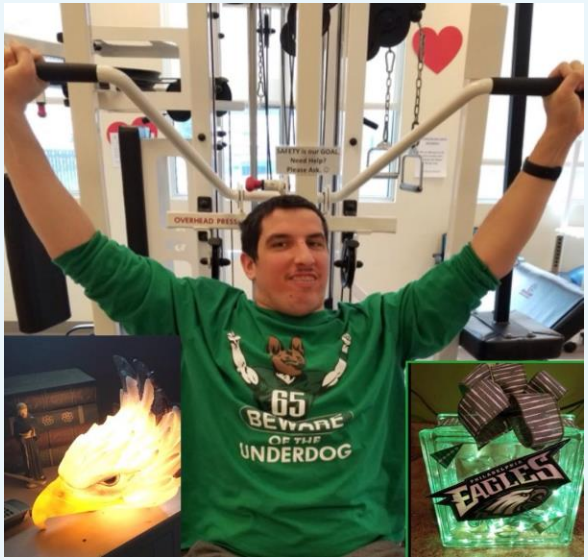
Physical and Occupational Therapy

- Physical therapy (PT) aims to promote, maintain, or restore health through patient education, physical intervention, disease prevention, and health promotion.

- Occupational therapy (OT) utilizes assessment and intervention to develop, recover, or maintain the meaningful activities, or occupations, of individuals, groups, or communities.

PT and OT to support individuals with IDD

- Occupational therapy practitioners use a range of habilitative and compensatory approaches to teach new skills or modify tasks and environments to address occupational performance among adults with intellectual disability (ID)*



*Blaskowitz MG, Johnson KR, Bergfelt T, Mahoney WJ. Evidence to Inform Occupational Therapy Intervention With Adults With Intellectual Disability: A Scoping Review. Am J Occup Ther. 2021 May 1;75(3):7503180010. doi: 10.5014/ajot.2021.043562. PMID: 34781356.

PT to support individuals with IDD

Impairment-related needs that fall within the scope of physical therapy practice:

- pain management
- functional mobility or activity training
- postural and respiratory support
- secondary impairment prevention
- assistive technology provision
- environmental modification

Along with PT, people with intellectual and developmental disabilities (IDD) have also increasingly sought out lay recreation and fitness opportunities to improve their health, wellness, and participation.*

*Carli, Friedman, Heather A Feldner, Physical Therapy Services for People With Intellectual and Developmental Disabilities: The Role of Medicaid Home- and Community-Based Service Waivers, *Physical Therapy*, Volume 98, Issue 10, October 2018, Pages 844–854, https://doi.org/10.1093/ptj/pzy082

OT to support individuals with IDD

- As a part of the Individualized Education Plan (IEP), PT and OT can assist with supporting activities in the school setting.
  - Not always transferable to life outside of school.
  - Parents and people with IDD express that they do not help with learning skills that will increase independence (ex. using a can opener).
  - Families will sometimes request PT and OT scripts for their child when school is on break so that there is no loss of skills.

Speech Therapy

- Speech and language pathologists enhance adaptive communication functioning, as many of the adaptive skill areas rely on communication abilities.
  - Dysphagia
  - Augmentative and Alternative Communication (AAC)
  - Aphasia
  - Verbal and non-verbal communication techniques
  - Social Interaction

What's Needed v. What's Provided

- Most commercial, Medicare and Medicaid plans have a cap on how many sessions of PT and OT are covered
- There is a huge disconnect for many people between what's needed and what's provided.
- Some patients opt to private pay for therapies.

Finding therapists who “get it”

- It is difficult to find adult providers who have a good understanding of working with people with IDD as many of these providers are often working in pediatrics.

- Our consultants shared some negative experiences:
  - “We had a speech therapist tell us that our son would never be able to eat for nutrition”.
  - This patient eats by mouth every day now!

Don’t listen to anyone who says “never”!

Interdisciplinary Coordination: PM+R

Physical Medicine and Rehabilitation

- We consult and co-treat with PM&R often
- Patients can be referred to PM&R for everything from leg length discrepancy to cerebral palsy
- Often PM&R will have recommendations for specific equipment that our office can assist the patient in obtaining through their insurance.

Independence for Roc!

Hear from Roc to hear about the importance of a power chair for his physical and mental health and how physical therapy helped him get comfortable using it!

Creating Inclusive Environments

- People with lived experience shared that positive experiences in provider offices were the outlier and not the norm.
- There are many touch points in care
  - Phone room
  - Main building lobby staff and security
  - Front desk
  - Medical assistant
  - Nurse
  - Doctor
  - Social Worker
- It’s is important that patients feel welcome at every point of care
- Share communication tips with staff
- Don’t forget, language is important!

Forms

- Please remember that completing forms efficiently helps our patients access services, equipment, activities, and so much more!
- For AAC, the company's want the doctor's signature on the forms, even though it is typically a Speech Therapist who does the evaluation.
- When asking patients to complete forms - take the time to read through and explain forms to people with IDD, be open to questions.

Resource sharing

Patients/families don't always know what to ask for. Primary care team should know what to offer

- Magee Riverfront + wellness program
  - Outpatient rehab
  - Wellness program which includes a gym, music, dance and art therapies, and much more
- Recreational sports
  - Special Olympics
  - Wheelchair sports
- Inglis House/Inglis Foundation
  - Offer AAC consults to people in the community who are wheelchair users
  - Supported and independent accessible living
- IM Able Foundation
  - Provides athletic opportunities for people with disabilities
  - Life Rolls On
    - Adaptive Sports

Discussion / Q+A

Contact Information

Mary Stephens, MD, MPH
Mary.Stephens@Jefferson.edu
215 503-3300
Karin Roseman, LCSW
Karin.Roseman@Jefferson.edu
215-890-0168

Thomas Jefferson University

JEFFERSON 200

Jefferson.edu

HOME OF SIDNEY KIMMEL MEDICAL COLLEGE