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PADDC Module 4: Working with Interdisciplinary Teams

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Introduction

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Pennsylvania Developmental Disabilities Council

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This is Module 4 of a 4-part learning series. Additionally, a Disability Education Module for physicians, trainees, and students is provided in the Mini-Modules and Resources section of our project website. The additional learning materials, resources, and a discussion board can be accessed here:
Increasing Access to Quality Healthcare for People with Disabilities.

This module serves to provide information about other disciplines working with people with intellectual and developmental disabilities (IDD) and information for a primary provider to collaborate with these supportive disciplines. Interactive knowledge checks are included throughout the module to allow for reflection, understanding of materials, and provide opportunities for self-assessment. Further discussion related to course topics can be found on an interactive discussion board linked here, and at the conclusion of this module.

At the end of this module, learners should be able to:

- Discuss alternative forms of communication
- Identify the role therapy plays in supporting people with IDD
- Explore different ways professionals can work together to support people with IDD
- Identify the ways in which various disciplines support patients and interact with each other

Note: If you do not complete all of the learning material at one time and would like to pause and return at a later time, you may do so. The system will not save your progress. Make a note of where you stopped and you may return at any point.

CONTINUE

Lesson 2 of 14

Lesson 1: Who is on an interdisciplinary team for individuals with IDD?

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Recall from Module 1: Individuals with IDD face a variety of health disparities and inequalities when accessing healthcare. Primary care providers are well-suited to support individuals with IDD.

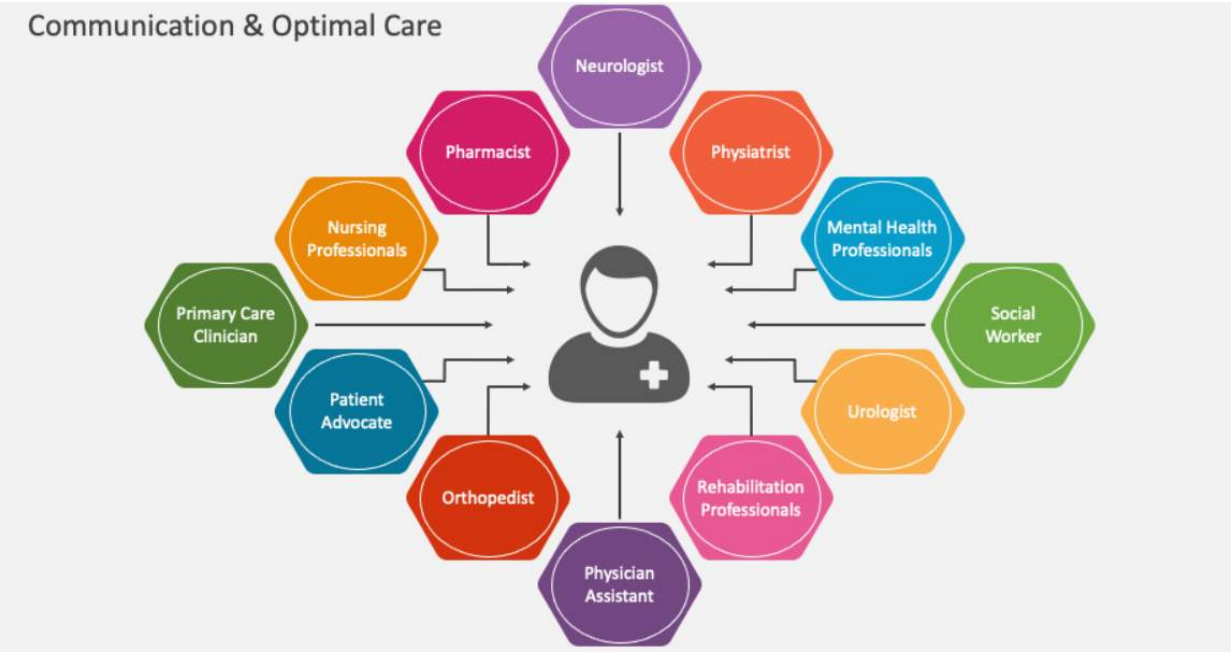
An interdisciplinary team involves professionals from multiple disciplines to improve coordinated and comprehensive care for patients [1]. For individuals with intellectual and developmental disabilities (IDD) and complex care needs, there are many team members who can help a patient reach their health goals and manage their health.

Some members who may be on a patient's interdisciplinary team:

- Primary care physician
- Psychiatry
- Social work
- Dentistry
- Dietician
- Mental health provider
- Physical, occupational, speech therapists
- Case manager
- Direct support professional
- Day program staff

- Nurses
- Orthotist
- Nurse practitioner
- Cardiology
- Rheumatology
- Caregivers and family members
- Home health support
- Pulmonology and respiratory staff

The patient is always the central member of an interdisciplinary team!



Interdisciplinary care team

When a comprehensive interdisciplinary care team is in place for a medically complex patient, there is the potential for improved quality of care, increased patient and caregiver satisfaction, decreased hospitalizations, reduced emergency department use, earlier detection, and overall better outcomes. [1]

Read more about interprofessional teams supporting people with IDD:

Adults with intellectual and developmental disabilities and interprofessional, team-based primary health care: A scoping review. [1]

READ MORE

Interprofessional collaboration in complex patient care transition: A qualitative multi-perspective analysis. [2]

READ MORE

Oral Health Care for Individuals with Intellectual and Developmental Disabilities: A Statewide Model [3]

READ MORE

CONTINUE

Therapy professionals supporting individuals with IDD

Therapists provide valuable support to the everyday lives of individuals with disabilities.

PHYSICAL THERAPY | OCCUPATIONAL THERAPY | SPEECH AND LANGUAGE THERAPY

Physical therapy (PT) helps people improve their movement and physical function, manage pain and other chronic conditions, and recover from and prevent injury and chronic disease. PT promotes wellness through therapeutic exercise, modalities, and assistive devices.[4]

Impairment-related needs within the scope of PT:

- Pain management
- Functional mobility or activity training
    - ex. Wheelchair fitting and mobility training
- Postural and respiratory support
- Secondary impairment prevention / compensatory strengthening
- Spasticity management
- Assistive technology provision

PHYSICAL THERAPY | OCCUPATIONAL THERAPY | SPEECH AND LANGUAGE THERAPY

Occupational therapy (OT) focuses on the use of everyday life activities (occupations) to promote health, well-being, and participation. OT can address a variety of domains including activities of daily living, adaptive equipment, caregiver training, sensory processing, work and leisure, safety, and accessibility. [5]

Impairment-related needs within the scope of OT:

- Activities of daily living / self-care skills

    - Dressing, bathing, toileting, eating, sleeping
- Environmental adaptations and home modifications
- Adaptive equipment including assistive technology provision
- Work readiness and pre-employment skills
- Sensory processing
- Fine motor strength and coordination
- Caregiver training and safe body mechanics

PHYSICAL THERAPY | OCCUPATIONAL THERAPY | SPEECH AND LANGUAGE THERAPY

Speech and language therapy (ST / SLP) works to prevent, assess, diagnose, and treat speech sounds, social communication, cognitive communication, and swallowing disorders across the lifespan. [6]

Impairment-related needs within the scope of SLP:

- Alternative and augmentative communication (AAC) evaluation and training
- Dysphagia and feeding
- Aphasia
- Verbal and nonverbal communication techniques
- Stuttering
- Social interactions

Therapists (PT/OT/SLP) are often defined as rehabilitation professionals. When working with individuals with IDD, the difference between rehabilitation and habilitation are important to recall. [7]

- **Rehabilitation**: Focus on returning to a prior skill level, restoring skills that have been lost of impaired.
    - Ex. Working with an individual who has an acquired disability, like a brain or spinal cord injury on increasing function.

- **Habilitation**: Learning and mastering new skills which have not been previously learned.
    - Ex. Teaching dressing skills to an individual with autism and decreased fine motor skills.

Promoting positive outcomes

- Therapy can support an individual's independence as they age.
    - Physical therapy for individuals with IDD is shown to improve cardiovascular parameters, functional activity performance, cognitive performance, strength, and dynamic balance. [9]
    - Often, adults with IDD have had many, many years of therapy by the time they transition to adulthood. While the scope of therapy remains the same into adulthood for individuals with IDD, the focus of quality care shifts to consider ways to modify and adapt the environment for an individual to access the things important to them.
        - Power mobility, adaptive clothing, and the provision and training with technology are some areas that a therapist can help find a good fit and keeps the patient and their motivation in the forefront of goal and treatment planning.

- Caregiver and staff involvement can help an individual access their home and community in a way that is safe and meaningful for them.
- There are psychosocial benefits of therapy interventions for individuals with IDD. [9]

- One research study on physical therapy for adults with IDD noted significant positive changes in life satisfaction, self-efficacy, positive attitudes toward exercise, and decreased risk factors of depression.

CONTINUE

Lesson 2: Therapy settings & interdisciplinary collaboration

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Therapy can occur in a variety of settings to best suit an individual's needs.

Educational settings

Therapy occurring in the public-school setting in PA is considered a "related service". Services are part of an IEP (or through a 504 plan in some instances) where a student is receiving special education. **Students must qualify for services based on educational impact, and goals must be related to educational needs.** Services are administered during the school day, in the school setting, either in the student's classroom or a private space depending on their needs.

Additional supports like counseling, social work, and orientation and mobility services can be implemented in a student's IEP, too.

For students with IDD, sometimes goals set in school therapy can feel less transferrable to the "real world" because of the need for their goals to be directly related to educational impact.

However, there are **so many skills** from an educational perspective for students with IDD and complex needs, especially into high school and beyond that can be considered from a 'life skills' or 'pre-employment' perspective to support their transition out of the school system.

Recall from Module 2: An IEP is a student's Individualized Education Plan, which qualifies them for special education services.

Medical outpatient

Outpatient therapy services typically take place at standalone centers or as part of a hospital system. Individuals need a prescription from their physician to be evaluated and receive services.

The scope of practice in an outpatient setting is wider, where an individual can qualify for services based on a delay in skill development or a loss of skills secondary to an injury or event (habilitative or rehabilitative services).

There can be limits in insurance approval in a medical outpatient setting. Limitations in access will be addressed later in this module.

Hospital

Therapy services can be provided in a hospital setting to support an individual's return to their baseline function and determine where the next safe place for them to return after discharge. Early mobilization and patient education are central foci in this setting, along with collaboration with social work and other professionals to support an individual in obtaining new equipment or adjusting to any changes after a hospital stay.

Inpatient rehabilitation

After a hospital stay, if a patient is not at a baseline level of function or needs skilled intervention to adjust to new equipment, self-care, or mobility needs, an inpatient rehabilitation setting is recommended. Here, patients receive a set amount of therapy each day before returning to their home.

Goals are determined based on an individual's baseline function, their injury or impairment, and what level of care they will return to after their inpatient rehabilitation stay.

In the home

Home based therapy can be approved for individuals who are unable to leave their homes to come to an outpatient therapy center due to safety or mobility concerns. Services are provided in the home setting using materials and equipment the patient has in their home.

Recall from Module 2: In home therapy can also be provided to individuals receiving Early Intervention services from age 0-3.

In the community

Depending on funding sources, individuals can receive therapy in community settings. This is valuable for individuals with IDD to generalize their skills to the community for work, leisure, and activities like grocery shopping or eating at a restaurant.

Some individuals may be able to receive therapy services through wavier funding, and these services could be administered during a day program or other community location.

Therapy in practice for individuals with complex needs

First, hear from a PT working in the school setting. She collaborated with the district's carpentry department to work with students with disabilities to support their independence in their daily environment. *Note that this is a school-aged child, however, the creative solution and collaboration could be applied to an adult client.*

Then, hear from an OT working in inpatient rehabilitation with adults after a traumatic brain injury. Notice the way this therapist uses something the patient enjoyed prior to his accident (racecar driving) to support his rehabilitation of physical skills.

Finally, hear from an SLP working with individuals with IDD after they transition out of the school system. Hear about how presuming competence and the addition of a robust communication system helped a young man with IDD expand his engagement into the community in a meaningful way.

COLLABORATION IN SCHOOL-BASED PHYSICAL THERAP...

What OT Can Do For You: Traum...

CONTINUE

Lesson 3: Insurance and other limitations

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While therapy services provide clear benefits to individuals with IDD across the lifespan, accessing quality services as an adult can be difficult.

1

1. What is needed versus what is provided - Insurance limitations

- Most commercial insurances, Medicare, and Medicaid have a cap or maximum number of therapy visits which can be administered in a year. Sometimes, these visits are combined (ex. 60 visits of OT and PT for the year).
    - Professionals must be in contact with each other to manage the service delivery plan for maximum benefit for the patient. This requires an additional layer of care coordination.

- This is **not** a lot of service for an individual with complex needs.
    - These insurance caps are designed for acute injuries such as a hip replacement, or visits for general aches, pains, or strains. The general

insurance cap model on therapy is not built with an individual with lifelong, complex needs in mind.

    - Sometimes, people choose private pay to receive more services once their insurance runs out - this is very expensive.
    - Other times, individuals may choose to advocate for more services to their insurer. This takes a lot of time and energy that many people cannot afford.

- When someone has a lifelong disability or an acquired disability like a traumatic brain injury, the need for services is lifelong as an individual changes and ages.

2

2. Funding

- Best practices in therapy for adults with IDD focuses on technology acquisition and training, environmental modifications, and staff and caregiver training. [8, 9]
    - Insurance is not guaranteed to pay for technology and modifications to the home if it is not considered to be "medically necessary".
    - Private programs can help fill the gap; however, equipment and technology can be expensive.
    - **Recall from Module 2**: Organizations like TechOWL and the Pennsylvania Assistive Technology Foundation (PATF) can help acquire funds and equipment for low or no cost to the user.

- What about waiver funds? (**Recall from Module 2: Waiver funds are allocated by the state for people with disabilities to access services in their home and community.**)

    - In 2015, only 20 states and DC covered PT services through waiver funds. [9]
    - Reimbursement rates for providers who are qualified and approved to provide waiver-funded services are typically lower than commercial insurers' rates.
- One means of service delivery to account for these limits through insurance is the use of **episodic care**, more commonly seen in pediatric therapy.
    - A plan of care is created for 8-14 weeks, with 1-3 visits per week working on a specific skill or set of skills.
    - Then, the individual takes a break from therapy for the duration of a plan of care for 8-14 weeks to generalize these skills into an individual's daily life and supplemented by natural opportunities.
    - This requires increased support from caregivers to help in following a home exercise program or other continuation of intervention strategies at home to continue carryover and prevent loss of skills.

3

3. Limited specialized providers

- Adults with IDD are underserved across therapy disciplines, with a lack of specialist providers. [8]
- There is a notion that individuals with IDD no longer benefit from therapy after adolescence.
    - Related to speech therapy and speech production, this idea may come from a lack of diagnostic assessments and a lack of validated treatment methods for people with IDD. [10]

    - Research is ongoing and expanding, highlighting that individuals **do** have the potential to continue learning through adulthood and beyond.
        - One study highlights an episodic care model where 3 months of weekly, 30-minute speech sessions were provided to adults with mild-moderate IDD, who then took a 3-month break. Improvements in their speech production and clarity were observed. [10]

- For those who have access to therapies, it can be difficult to find an adult provider who has a good understanding of working with people with IDD.
    - Sometimes a provider is just not a good fit - our project consultants remind us, don't listen to anyone who says "never". One consultant shared an experience where a speech therapist said their son would never be able to eat by mouth. Now, he eats by mouth every day. **No one has a crystal ball.**

- Access to telehealth may increase an individual with IDD's ability to find a provider. However, there are limitations here including funding and technology requirements.

Recall from Modules 1, 2, and 3: It is difficult across disciplines to find an adult provider to provide high quality care to individuals with IDD.

Evidence to inform occupational therapy intervention with adults with intellectual disability: A scoping review. [8]

READ MORE

Physical therapy services for people with intellectual and developmental disabilities: The role of Medicaid home- and community-based service waivers. [9]

READ MORE

Effectiveness of speech therapy in adults with intellectual disabilities. [10]

READ MORE

CONTINUE

Section 1: Knowledge check

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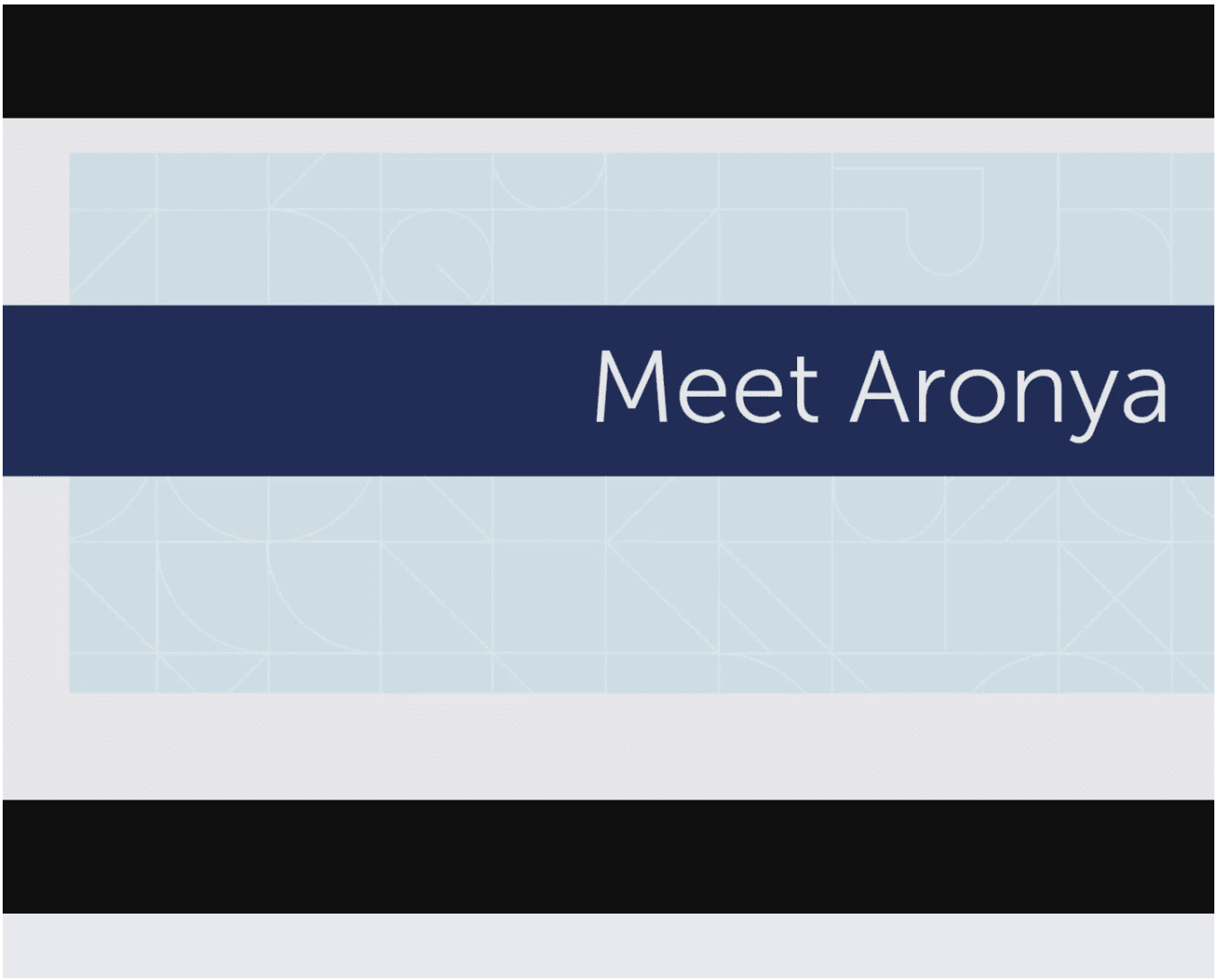
Knowledge check - members of an interdisciplinary team

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.



Add reflection question: Who are some team members who might work with Aronya? What is a modification that Aronya shared that surprised you, or you hadn't thought about before?

Think about your own specialty and scope of practice. What are questions you could ask a patient during an appointment to start a conversation about home safety, or referring to a team member?

Further reading: A seizure safe home environment

PDF

Seizure Safe Environment.pdf

107.1 KB

CONTINUE

Lesson 1: What is AAC?

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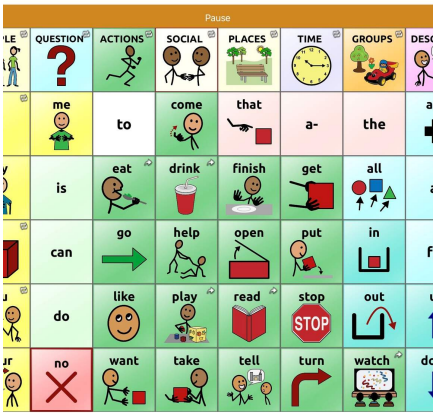
About AAC

- There are an estimated 5 million people in the United States with complex communication needs. [12]
- Augmentative and alternative communication (AAC) refers to enhancing, adding to, or replacing speech with another form of communication.
- There are different types of AAC for different users and their needs:
    - **High technology**: Speech generating devices, eye gaze devices. Most commonly seen as an iPad or tablet which can be handheld or mounted.
    - **Mid technology**: Battery operated devices such as a switch with a pre-programmed message, or a preprogrammed message board.
    - **Low technology**: Picture exchange communication systems (PECS).
    - **No technology**: Using what is on your body to communicate. Sign language, gestures, body language, or hand leading all fall under this category.

AAC devices

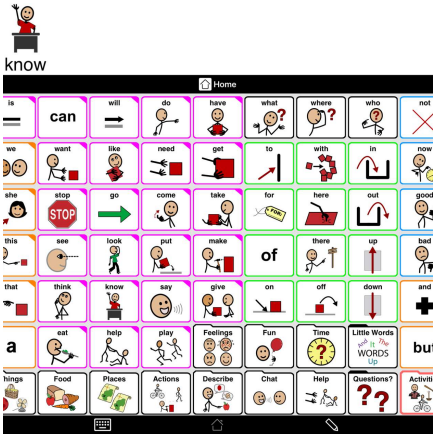
- While tablets and smartphones are not built with the primary function of accessible communication, apps can turn them into a communication device.
    - A device can be a **dedicated AAC device**, where all other tools and functionalities are locked, or a **nondedicated AAC device**, where a user can utilize the communication app in addition to all the functionalities of a tablet.

- Review some common communication applications below:
  (Click on the image to expand it)

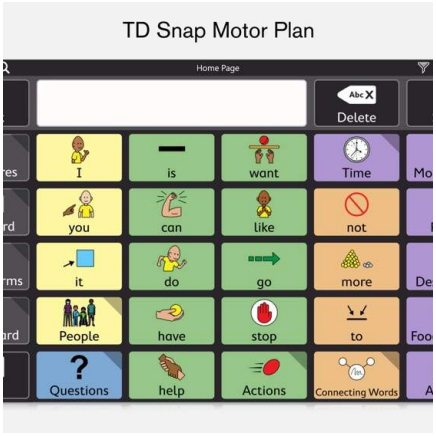


TouchChat

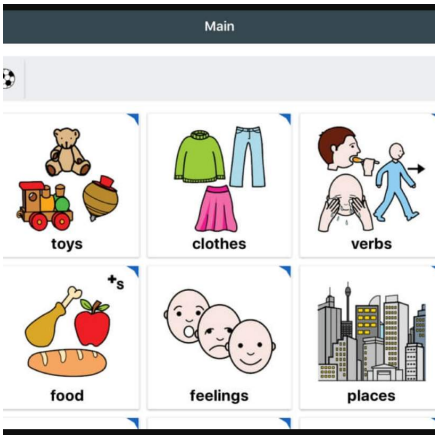
GoTalkNow



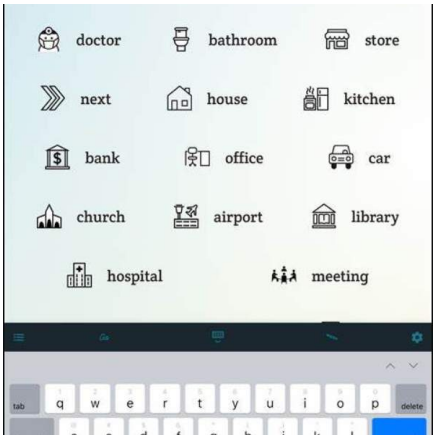
Proloquo2Go



TD Snap



SymboTalk



Spoken

CONTINUE

Supporting positive communication with an AAC user

- When working with individuals who communicate via AAC, it may seem difficult at first to feel comfortable in silence.
    - This is something that gets easier with practice.

- It is important to allow for an individual to process the verbal information presented to them and formulate a response.
    - Wait about 10 seconds (count in your head!) before asking or repeating a question to allow for processing time.
    - **Become used to the silence and wait time.**

- Just because an individual does not respond right away does not mean they do not understand.

AssistiveWare, an AAC research, provisions, and advocacy organization, interviewed AAC users about what makes a respectful communication partner. Here's what they said: [13]

A respectful communication partner...

1. Respects the effort AAC takes
2. Is patient and waits
3. Helps to manage background noise
4. Helps to manage physical space around the AAC device
5. Watches the person, not the device
6. Pays attention to the message and body language cues
7. Does not dominate the conversation
8. Respects an AAC user's voice
9. Asks before looking at, touching, or using a person's AAC device
10. Accepts that communication is on the AAC user's terms

Learn more from AAC users about respectful communication. [13]

LEARN MORE

Assistive Technology Internet Modules [14]

Free continuing education courses on supporting individuals who use technology to communicate.

LEARN MORE

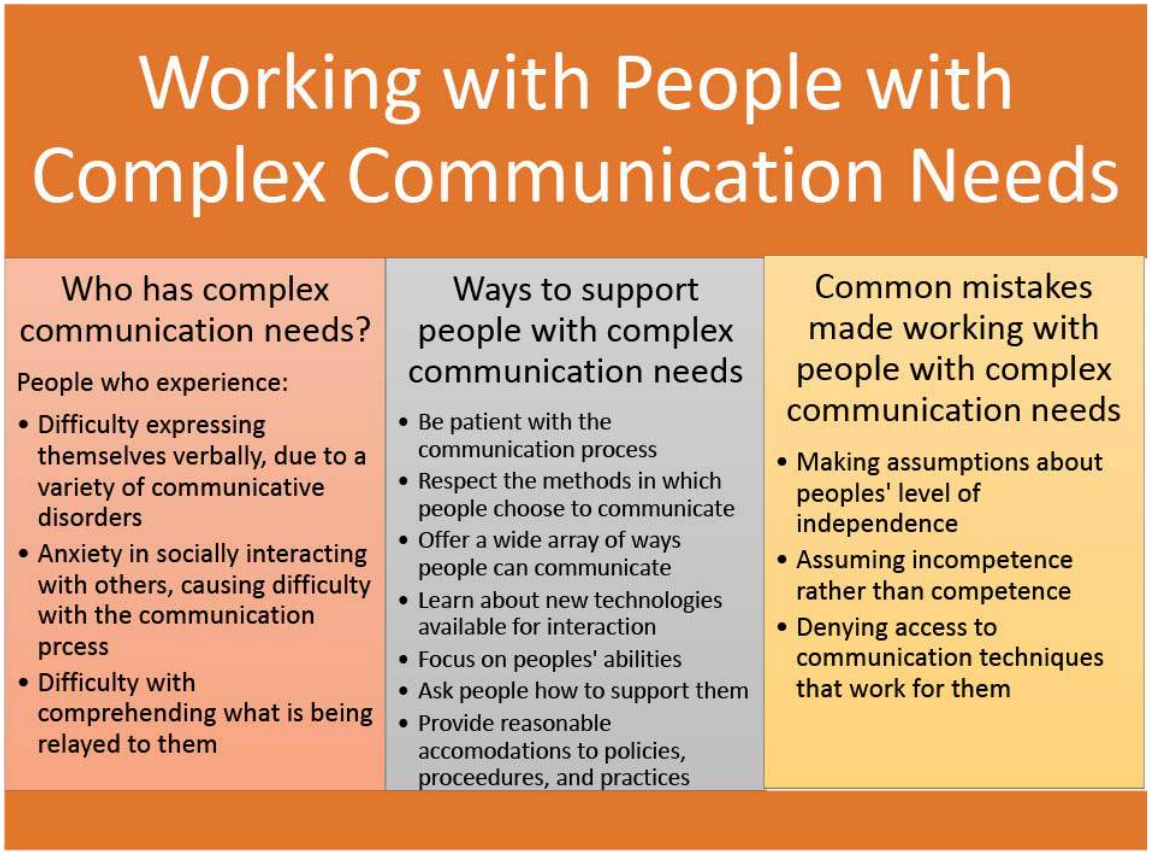
Hear from Sara, a project consultant who uses eye-gaze AAC to communicate. Listen to a Q+A about how she uses her device, then see Sara at a doctor's visit.

American Sign Language (ASL)

- ASL is **not** just English using your hands. It is recognized as its own language and does not follow the same grammar rules as English.
- Just as English has many dialects and accents, so does ASL. Hand placement and motions may differ slightly depending on what region the individual is from, or where they learned ASL.

    - Some individuals may use approximated signs based on differences in motor control. This can initially be more challenging to understand, and sometimes a caregiver or supporter can help to interpret the meaning if it looks different than a traditional sign.

- By federal law, you must provide an ASL interpreter as requested. This service should be arranged ahead of time. Sometimes, an ASL interpreter needs to be physically present, which is different than a service like Language Line offered in some hospitals.



Working with People with Complex Communication Needs. Rackensperger, 2020. [15]

CONTINUE

Lesson 2: Case study: WK

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This case study highlights the use of AAC supporting an adult with IDD. Case study and information comes from Laura Nagy, an SLP, in their article It's Never Too Late to Communicate: Increasing Communication Access for Adults with Intellectual Disabilities and Autism. [12]

1

Background Information

- WK is a 51-year-old nonspeaking man with severe ID and spastic quadriplegic cerebral palsy.
- He is highly social and has spent the majority of his life relying on no-technology communication like gestures and body language.
    - When unable to effectively express himself, WK demonstrates challenging behaviors such as disruption and aggression to meet his needs.

2

Introducing AAC

- At age 51, WK began using a low-technology AAC option, Picture Exchange Communication Systems (PECS). This is where an individual uses a picture of an object and hands it to a communication partner or points to it to make a request.
- Due to limited mobility, WK was only able to communicate with people in his immediate area.
    - The physical icons became lost and damaged over time, which limited what WK was able to communicate.
    - WK showed an increase in challenging behaviors when he could not request or gain staff attention effectively using PECS.
        - This indicated the need to consider other AAC options.

3

Trialing a high-tech device

- At age 53, WK began trialing a high-tech AAC device. This device provided auditory output so WK could communicate with people at a greater distance.
- He had increased access to vocabulary via the AAC device, and he increased his working vocabulary and expanded his communication skills.
- WK demonstrated consistent interest in using the device and began to independently activate icons on the screen.

- He also demonstrated skills in operating the device, independently adjusting the brightness of the screen and using the arrows and folders to navigate to different pages of vocabulary on his AAC device.

4

1 year later

- WK is demonstrating impressive gains in communication.
    - He is requesting preferred items and across categories including foods, drinks, toys, and locations.
    - He uses functional communication responses to gain the attention of others, leave an area, or express that he's finished with an activity.

- WK has shown significantly fewer challenging behaviors since his communication has improved to have his needs met.
- WK enjoys having access to social language, where he is able to greet others, and is able to identify people he regularly interacts with via icons on his device.
- He uses a walker bag to safely carry his device with him while using the mobility device.
    - To further support WK's access to his device, a custom plastic key guard was placed onto his device to support decreased fine motor skills.

- WK has expressed his love of his communication device; he frequently shows the device off to his friends and family and requests attention from others in the room when he is using his device.

Takeaways

- It is never too late to introduce AAC! We are all lifelong learners.
    - Adults around 40 and older may never have had access to the services necessary for acquiring AAC. **AAC was introduced as a viable treatment option in 1981.** [11]
    - This is a great opportunity for interdisciplinary collaboration to support an individual's access to communication.

- **Always presume competence.** This case reminds us that everyone has a right to communicate, at any age.
    - Accessible communication is a human right. As a provider, it is your responsibility to set the standard of care.
    - Nonspeaking patients can hear and understand. Do not talk about someone when they are in the room like they are not there.

- **An individual's AAC device is their voice**. They should have access to their device at all times, including when receiving medical care.

CONTINUE

Lesson 3: Spelling to communicate

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What is Spelling to Communicate (S2C)? [16, 17]

- S2C is a method created for individuals with complex communication needs who are nonspeaking.
    - The method involves pointing at a stenciled letter board and spell words to communicate with others, using the support of a facilitator to dictate the message.

- S2C is based on the idea that many nonspeaking individuals have difficulty with motor plans and patterns (apraxia), and that these motor plans can be learned over time.
- Some S2C users utilize a communication partner to hold their letter board or have a supporter provide joint stabilization at the shoulder or elbow to encourage and refine motor movements in the hand and wrist.
    - As learners become more confident in their motor plan to spell words, they can transition to a keyboard on a slant board or high tech AAC device to produce written output independently without the need for a facilitator.

Controversy and ongoing discourse [18, 19]

- There are individuals who are now able to communicate using written language because of typing from S2C interventions and have shared positive experiences.
- Facilitator involvement is a major **area of controversy** for this method. **Supporters** argue that due to motor planning difficulties, a facilitator is necessary for the individual to learn new patterns and use their body to communicate. **Adversaries** argue that the facilitator is unknowingly or subconsciously the one providing or influencing the messages rather than the learner.
- It is important to acknowledge a challenging history with current S2C and its predecessors, Facilitated Communication (FC) and Rapid Prompting Method (RPM).
    - These methods have been scrutinized and researched, with a lack of scientific validity of authorship from the individual when messages were produced using this method.
    - The American Academy of Pediatrics, American Psychological Association, American Speech-Language-Hearing Association, American Association on Intellectual and Developmental Disabilities, Association for Science in Autism Treatment, National Council on Severe Autism, and International Society for Augmentative and Alternative Communication **have all ratified position statements against the use of facilitated communication**.
- Though controversial, the International Association for Spelling as Communication (I-ASC) highlights S2C has evolved and is a continued popular method. Lived experiences from nonspeaking individuals support this method, and there are many case examples of those who have used these methods and are now communicating independently through spelling.

Empirical evidence vs. lived experience

- The S2C community and individuals with lived experience with disability highlight the variance in opinions and communication methods.

    - There are a lot of variances in S2C methods. Many individuals are using keyboards to type and communicate along with the use of an AAC device. This is a modified version of the approach and helps individuals expressively communicate.
- Families are looking to do the best for their nonspeaking children and adults.
- There are many stories, videos, and media of nonspeakers being successful through the use of these methods.
- Recall the three elements to evidence-based practice: Best available evidence, clinician's knowledge and skills, and the patient's wants and needs.
- **Remember to presume competence and be a supporter of an individual's most successful mean of communication.**

Hear from individuals who use spelling to communicate and their experience learning through this method:

YOUTUBE

Living Our Lives Through Letters

I am a nonspeaking person with autism. My friends and I want to show you how much Spelling To Communicate has changed our lives. I think being autistic is a challenge sometimes, but my life is so much better than I ever thought it could be since I am now able to communicate.

VIEW ON YOUTUBE >

Presume competence when working with any individual with communication differences.

The best practice for developing expressive and receptive communication skills comes from working with a speech language pathologist (SLP).

CONTINUE

Section 2: Knowledge check

DR DFCM Research

AAC in practice

Hear about how Claire uses eye gaze AAC to communicate with the people important to her, and the way independent communication has increased her quality of life.

Have you ever trialed the use of an AAC device?
Cboard is an open access, browser based AAC device. *This open access software has limited options compared to a customized AAC device; however, it can be a useful tool for demonstration.*

Remember that an individual's AAC device is typically more customized for them, and that there are many software options available where a Speech Language Pathologist uses their clinical expertise to match the best software to an individual based on their needs and skills.

Visit the Cboard website and trial the software. Practice answering the following questions:

Cboard [20]

- How are you feeling?
- What would you like to do with your free time?

Consider all of the elements to use AAC. Be a patient communication partner and remember to presume competence.

Reflect on practicing AAC: Was this easier or harder than you may have expected? Did you notice how it takes increased time to respond?

CONTINUE

Lesson 1: PM&R: Who they are and how they can help

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What is Physical Medicine and Rehabilitation (PM&R)? [21]

- Also known as physiatry or sports medicine, PM&R is a medical specialty to enhance or restore functional ability and support quality of life for those with disabilities impacting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons.
    - Do not focus on a "cure", instead use medical interventions and identify supportive equipment to maximize independence and quality of life.

- When serving patients with complex needs and IDD, there is frequent collaboration between primary care and PM&R.
- Patients can be referred to PM&R for a variety of conditions, including but not limited to:

- Brain injury
- Cerebral palsy
- Contractures
- Equipment needs
- Gait impairments
- Leg length discrepancies
- Joint differences or pain
- Multiple sclerosis
- Neurogenic bowel and bladder
- Pain management
- Pressure sore management
- Nerve injury or disability

- Some preventative care
- Spinal cord injury

- PM&R can also help with appropriate recommendations for specific equipment or devices that a primary care office can help a patient obtain through their insurance.

CONTINUE

Collaboration with PM&R: Roc's story

Roc is a project consultant with lived experience of disability. He has cerebral palsy and primarily uses a wheelchair to ambulate. At the time of this case study, Roc only has access to a manual wheelchair. He is experiencing tendonitis from overuse, which is impacting his ability to move through his environment and complete the activities he enjoys doing, including making art.

When consulting with his team, PM&R felt that Roc would be a good candidate to trial power mobility. He was assessed at the seating clinic at Jefferson Magee Rehabilitation, where the team agreed with PM&R's recommendation.

Initially, insurance denied the request for a power mobility chair.

With the support of their PM&R physician and Roc's primary care team at the Jefferson FAB Center for Complex Care, Roc and his grandmother Donna filed an appeal of the insurance company's decision. The initial refusal was overturned, and Roc was able to acquire a power chair!

Below, hear from Roc and Donna about what brought the decision to pursue a power chair, and see Roc practicing with his physical therapist.

Meet Roc


LightYear (First Look)
12.12.2020
By: Abdur-Razzaq
Abdul-Malik
December 27th 2020
Light Year 2022
Next-Gen. Nat 1.30.2021

Some of Roc's artwork

With the use of a power chair, Roc is able to continue engaging in the activities he enjoys, like making art.

Roc and Donna worked with PM&R, primary care, and physical therapy to have his new mobility device approved. Collaboration between disciplines addressed functional concerns (mobility and overuse injuries) while considering Roc's independence and quality of life.

Learn more from PM&R physicians about how they collaborate with others:

The primary care-PM&R collaboration can help keep patients out of the OR [22]

Dr. DJ Kennedy shares his insight about referrals between primary care and PM&R, and ways the disciplines can work together to promote positive patient outcomes.

WATCH HERE

What I wish other doctors knew about PM&R [23]

Hear from Dr. Nicolet Finger on the work she does as a PM&R physician and common misconceptions.

READ MORE

CONTINUE

Lesson 2: Home modifications and interdisciplinary collaboration

DR DFCM Research

What are home modifications? [24, 25]

- Home modifications are an area of collaboration between patients, primary care providers, PM&R, occupational, and physical therapists.
- Home modification - making changes to the physical home environment to maximize an individual's **independence, participation, and quality of life** with changing needs throughout their life. Changes can help adapt the environment to make daily activities easier, reduce safety hazards, support caregiver health and safety, and increase the amount of time someone can stay safely at home.
- Modifications can help an individual move through their environment in a way that is safe and accessible to them.
    - Note: Not all homes are created equal! The Americans with Disabilities Act (ADA) of 1990 does **not apply to private residences**. Individual residences are not required to be accessible by law.
    - There are some requirements for accessibility in shared areas of multi-dwelling units (ex. apartments) which were built after the Fair Housing Act in 1991, however, dwellings built before this time do not have these requirements.
- ***Stop and think***: Consider your current home. How would you rate its **visitability** [26], or how accessible is your home to a person with a disability? Think about steps to

enter, railings, the width of your doorway, the type of floor material, the size of your bathroom, lighting, and more.

Note: "Home" defines any space where an individual lives. This could be a private residence, a family home, a group home, an apartment, a temporary living area, or more. Every person has a right to a safe home environment.

The most 'dangerous' areas of the home are where most modifications are typically needed.
Guess which three areas of the home you think this may be, then click to flip the card.

- Bathroom
- Kitchen
- Entryways

1 of 1

CONTINUE

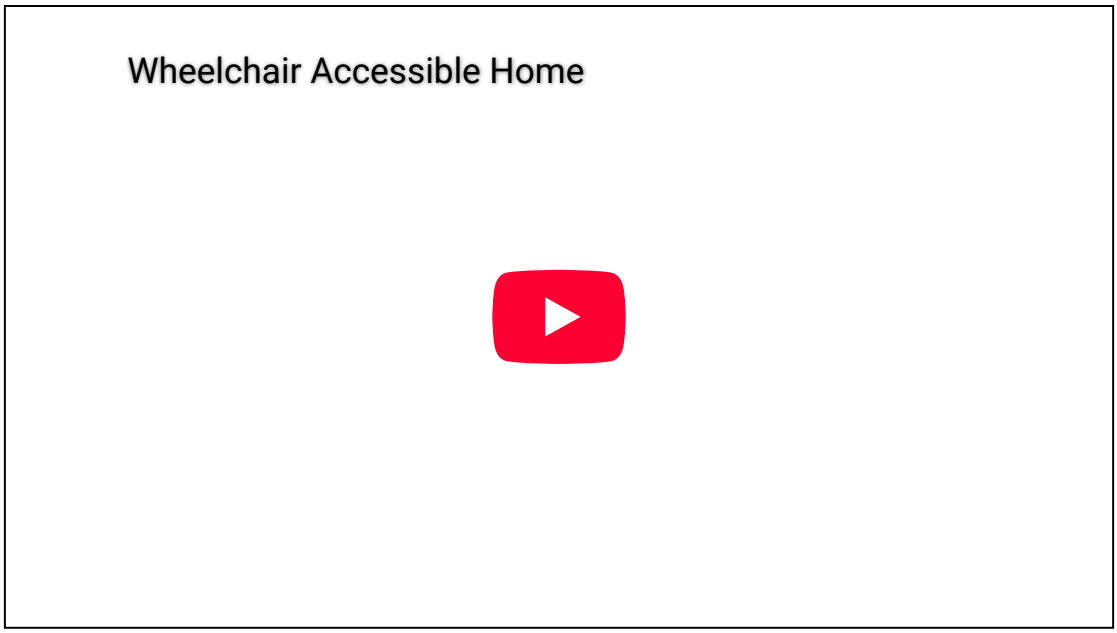
- It is important to check in with patients, especially as they age, about their perception of the safety inside their home. An occupational therapist and PM&R

physician may be helpful to collaborate and make recommendations about the home environment. [24]

- *Did you know?* Under Medicare Part B, a home safety assessment completed by an occupational therapist can be a covered service **with the referral of a medical provider.**
- If an individual has a family caregiver, check in with this individual too. **Recall from module 3: 80% of individuals with IDD have a primary caregiver who is a family member.** Many times, this is a parent or a grandparent who is aging. Home modifications can help reduce the physical toll on a caregiver to increase their quality of life and ability to provide safe care.

- **Recall from earlier in this module**: Aronya shared the changes she made in her home to keep her safe with her epilepsy. These are home modifications, too!
- Hear from Brian Kinney. He has a spinal cord injury, and built a house customized for wheelchair accessibility. This is a large financial undertaking, and not a reality for most individuals. However, the video is a great look at all of the considerations for wheelchair users in each room of the house.

YOUTUBE



Wheelchair Accessible Home

This video shows the modifications made during the construction of my home to make it wheelchair accessible.

VIEW ON YOUTUBE >

CONTINUE

Funding avenues for home modifications

Funding for home modifications can come from varied sources. In some cases, modifications can be approved by insurance, through waiver funds, loans, or private funding sources.

Funding availability is varied based on individual circumstance. Many home modification providers are versed in fund acquisition and options to pay for modifications.

Fall prevention Center of Excellence at USC [24]

Resources for professionals, individuals with disabilities, and caregivers. There is a directory of home modification professionals as well as shareable resources.

LEARN MORE

Liberty Home Solutions [27]

This is a Philadelphia-based organization who can help assess and supply home modifications. They can help with finding funding and payment assistance.

LEARN MORE

Pennsylvania Assistive Tech Foundation (PATF) [28]

PATF helps individuals with disabilities afford assistive technology, which can include low-interest loans for certain home modifications for individuals of all income levels.

LEARN MORE

CONTINUE

Section 3: Knowledge check

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Knowledge check: Interdisciplinary teamwork for equipment at home

Background Information

A primary care provider sees a 23-year-old female patient, JH, with cerebral palsy in the clinic along with her mother who serves as her primary caregiver. JH uses a power wheelchair for mobility. She can complete a sit-to-stand transfer with support, though most often is dependent in transfers for safety.

JH's mother is experiencing arthritis in her hips and knees, and reports that it has been more difficult for her to transfer JH in the bathroom for showering. They have a Hoyer lift in JH's bedroom, however, the shower chair they have now is stationary, and JH can only be transferred into it while in the bathroom.

For now, they have decreased the number of full showers for JH due to this and are opting for the use of washcloths to bathe.

JH explains that she likes to take showers and is worried about developing pressure injuries from transferring out of her chair less frequently.

We are going to explore options for JH and her mother.

Below, review the possible equipment options to recommend for JH. Look at the photo, read the description, and rate how effective you think this solution would be for JH.

Ultima bath chair, Adaptive Solutions

Baseline: Current setup

- JH's bedroom is attached to her bathroom, and there is a door wide enough for JH's wheelchair to go between the two rooms.
- In the bathroom, there is a toilet, vanity sink with storage, and a walk-in shower with a 1" level to enter.
    - There is another bathroom in the house which JH can access if needed. It has a tub/shower combination.

- Currently, JH's mother transfers her into this chair in the shower. They have used this shower chair since JH was around 14 years old.
    - This chair has head and lateral support for safety and a nonslip bottom.
    - It cannot be moved out of the shower.

Option 1: Shower Buddy/Tub Buddy

- Allows for a single transfer to complete toileting and showering in the bathroom.
- The chair is detachable, the chair rolls on the track to transfer into the tub.
    - An option with headrest and tilt is available for a higher cost.
- Can be used for a tub or a shower.
- Note: There is no leg support on this device. An individual would need their legs to be lifted or be able to lift them to clear the tub. This is less of a concern if sliding into a shower, however, if leg support is needed for safety this product does not provide it when moving.

Shower Buddy / Tub Buddy, [Solutionbased.com]

FAWSsit, shop.fawssit.com

Option 2: FAWSsit Portable Shower

- This unique shower option turns any space into a shower.
- The hose is connected to a house faucet, and the drainage is also connected into the sink.
- Users can be rolled in and utilize a handheld shower head with room for caregiver support.
- This can be temporary or permanent, and users do not need to enter a bathroom.
- Chair not included.

Option 3: Rifton Hygiene and Toileting System (HTS)

- Highly customizable wheeled shower/toilet chair. Tilt addition optional.
- Allows for transfer in any area of the home, into the bathroom for use with toilet and shower.
- Chair can be moved with detachable push handles on the back. Can transfer in one area, then move to another.
- Can be wheeled over any standard toilet. Has opening in back for any hygiene support.
- Rolls into shower; large castors allow for navigating levels to entry.

Rifton HTS, Rifton

Based on the options above (and without considering finances), which option do you think would be a better recommendation for JH and her mother?

- ○ Option 1: Shower Buddy / Tub Buddy
- ○ Option 2: FAWSsit
- ○ Option 3: Rifton HTS

SUBMIT

Note: These are not the only products available to consumers. If recommending products, consider the specific needs of the patient, and consult with specialty providers like PM&R and occupational or physical therapists.

Jefferson
HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

Reflection Question: How might you gather information about the needs of a patient in their home? JH and her mother were up front about

See more about the medical equipment shown:

Tub Buddy [29]

SEE MORE

FAWSsit [30]

SEE MORE

Rifton HTS [31]

CONTINUE

Thinking bigger about the interdisciplinary team

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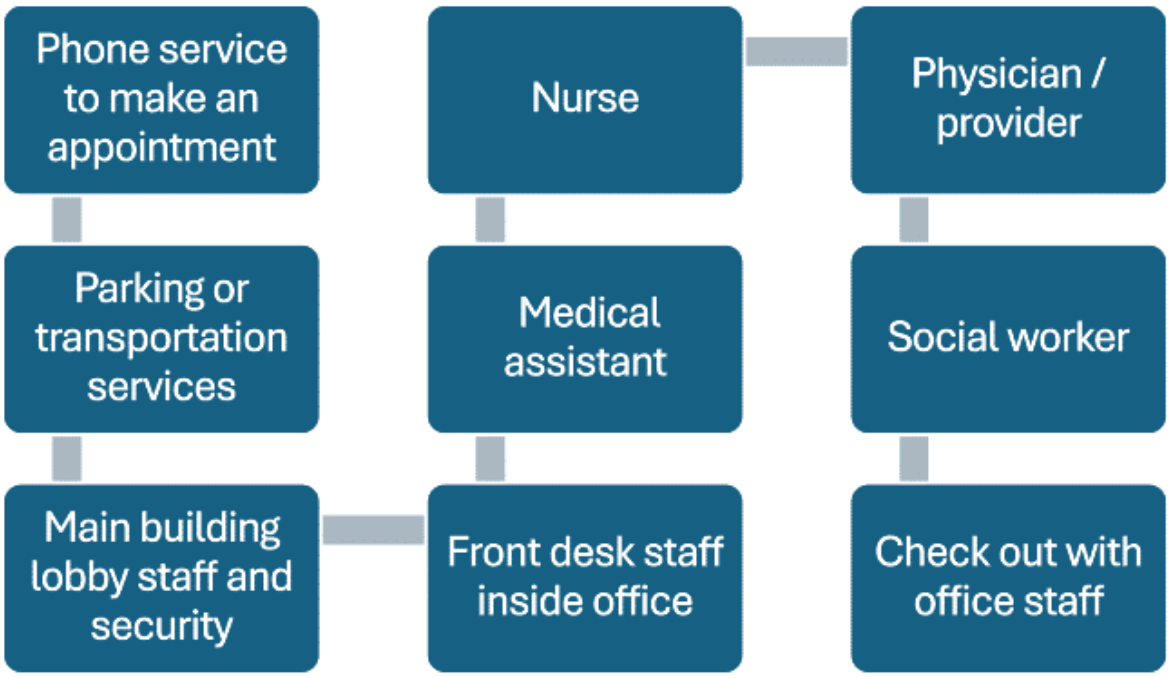
- When considering the interdisciplinary team, think broadly. Consider all of the people a patient interacts with through a provider visit.
    - Our project consultants with lived experience of disability shared that positive experiences in provider offices were the outlier, not the norm.

- There are many touchpoints and individuals who patients will interact with during a visit to a provider:



Patient touchpoints

How can you work with your team to make every step a positive one for patients with IDD and complex needs?

- It is important for **all patients** to feel welcome at **every point of care**
    - Increased comfort will lead to increased trust, and support a strong working relationship to improve outcomes.

- Set the tone!
    - Post flyers about accessibility and disability.
    - Do a walkthrough of your facility - is it accessible as it is right now? What changes would need to be made?

        - Talk to your patients. Do they face any facility-related challenges to come to their appointments? Are there changes you can make?
    - Does your practice have opportunities for online or phone-based feedback?
- Remember that language is important. If you hear someone say something that is not best practice, assume positive intent. Provide correction. It is okay to make mistakes! We can all work together to create a more inclusive environment.

Continued learning with interdisciplinary teams

- Working with complex patients can be difficult! It helps to have a collaborative environment when needs may not be straightforward.
- Consider joining an interprofessional learning group to collaborate with professionals from other disciplines, consult on case studies, and ask questions as needed.
    - These groups may cost a fee to join; however, providers gain valuable opportunities for continuing education, networking, professional collaboration, and education.
    - There are often low and no-cost options for students in training or residency, and early-career professionals.
    - Review a few of these organizations below.

American Academy of Developmental Medicine and Dentistry (AADMD) [32]
Increasing knowledge for providers to provide care to individuals with IDD. Offer journals, forums, and collaboration between healthcare and advocacy.

LEARN MORE

American Association on Intellectual and Developmental Disabilities (AAIDD) [33]

An interdisciplinary organization increasing public policy, education opportunities, journal, and research for people with IDD.

LEARN MORE

Down Syndrome Medical Interest Group (DSMIG). [34]

Interdisciplinary group bringing together providers who care for people with DS across the lifespan. Offer practice guidelines, recommendations, and collaborative spaces for professionals to share cases.

LEARN MORE

CONTINUE

Another note on patient forms

Recall from Module 1: Patients with IDD often require 3x more paperwork from providers.

- Although it is extra work, completing forms efficiently helps our patients access services, equipment, activities, and more.
- Delays in completion or signing off on forms may not make a big impact in your day-to-day as a provider, but can cause major burdens and disruptions to patients.

    - For example, with AAC devices, the company providing the device access often requires a physician's signature on the form, even though a Speech Therapist is completing the evaluation.
    - Some home modifications, if being paid for by an insurer, may also require additional paperwork.
- Review some examples of patient forms for IDD on the project website. Patient Form Examples

CONTINUE

Doing your part: Resource sharing

- People with IDD and their caregivers do not always know what to ask for. Especially after the transition to adult services, patients are left to figure things out on their own.
- Primary care teams can be a 'hub' of sharing resources, opportunities, and community programs that might be of benefit to patients.
- It can be difficult to know about all of the resources in your area! Utilize the resources shared at the end of each of this project's four modules. They can be found on the project website for you to download. Increasing Access to Quality Healthcare for People with Disabilities - Resources
- Listen to your patients. Ask them what they are involved in (and gain valuable information about their social history and daily routines) and try to keep track of these local activities or groups.
- Note: It is not expected for you to know every resource or possible resource. As this project series highlights, there is a lack of high-quality resources and opportunities for adults with IDD. Collaborate with colleagues, support patients as best you can, and use resource sheets like the ones provided in these modules.

- Know a great resource you'd like to share? Join this project's interactive discussion board. Discussion Board

CONTINUE

Conclusion

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Conclusion

Thank you for participating in module 4, Working with Interdisciplinary Teams. This is part 4 of a 4-part education series funded by PADDC. Additional information related to this project can be found on the project website.

Please complete the post-module satisfaction survey below in order to provide information to PADDC for reporting purposes.

If you are a healthcare professional or a student in training to be a healthcare professional, there is a post-assessment to complete for this project's research and reporting. Please complete this post-assessment.

If you are not a healthcare professional or student, please answer the screener question, then you may move scroll down to complete the 7-question satisfaction survey for PADDC.

Are you a healthcare professional or a student in training to become a healthcare professional?

This survey will take 2-5 minutes to complete.

References Sheet Module 4 (1).pdf

184.6 KB

Module 4 Additional Resources (1).pdf

140.8 KB

Thank you for your support, engagement, and interest in increasing high quality care for patients with IDD. Please review the additional resources below and share this project with those in your professional network.

For continued discussion, you may visit our live discussion board page: Discussion board.