

# PADDC Module 2: Patient and Caregiver Community Supports and Resources

## Module 2: Patient and Caregiver Community Supports and Resources

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 Module 2 Conclusion

# Introduction

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This project is funded by the Pennsylvania Developmental Disabilities Council (PADDC). 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**. Please contact Rosemary Corcoran ([rosemary.corcoran@jefferson.edu](mailto:rosemary.corcoran@jefferson.edu)) with any questions about this project.



Thomas Jefferson University

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Pennsylvania Developmental Disabilities Council

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**This is Module 2 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](#).

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This module serves to provide information about resources needed for patients and their caregivers as they transition into adulthood. Interactive knowledge checks are included throughout the module to allow for reflection, understanding of materials, and provide opportunity for self-assessment. Further discussion related to course topics can be found on an interactive discussion board on the

project website, and at the conclusion of this module.

### [Discussion board](#)

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

- Identify transitions throughout the lifespan for people with intellectual and developmental disabilities (IDD), physical disabilities, and their supporters
- Better understand the unique medical and social needs of this complex population
- Identify the various systems of care for people with disabilities and how they interact
- Access tangible resources which can be used in the clinic setting



**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 1: Early childhood services

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**Reflect before beginning:** Think about all the changes a family experiences when they have a new child. Now, think about the additional changes and transitions when a child is identified to have a disability or developmental delay.

A child who is born with a disability, or has a developmental delay identified shortly after birth is often referred to the Birth to Three program. The Birth to Three program is part of Early Intervention (EI) services.

Children can be referred for an EI evaluation if someone has a concern about their development in any domain. Referrals can come from medical providers, social workers, parents, caregivers, or daycare providers.

How does a child qualify for services at an evaluation? One of the following paths must be true: <sup>1</sup>

1

A child must demonstrate at least a 50% delay in one domain of development, or at least a 33% delay in two or more areas of typical development for their age (physical, cognitive, communication, social/emotional, adaptive development)



2

A specialist's determination that there is a delay even if it does not show up on a formal assessment (known as informed clinical opinion)

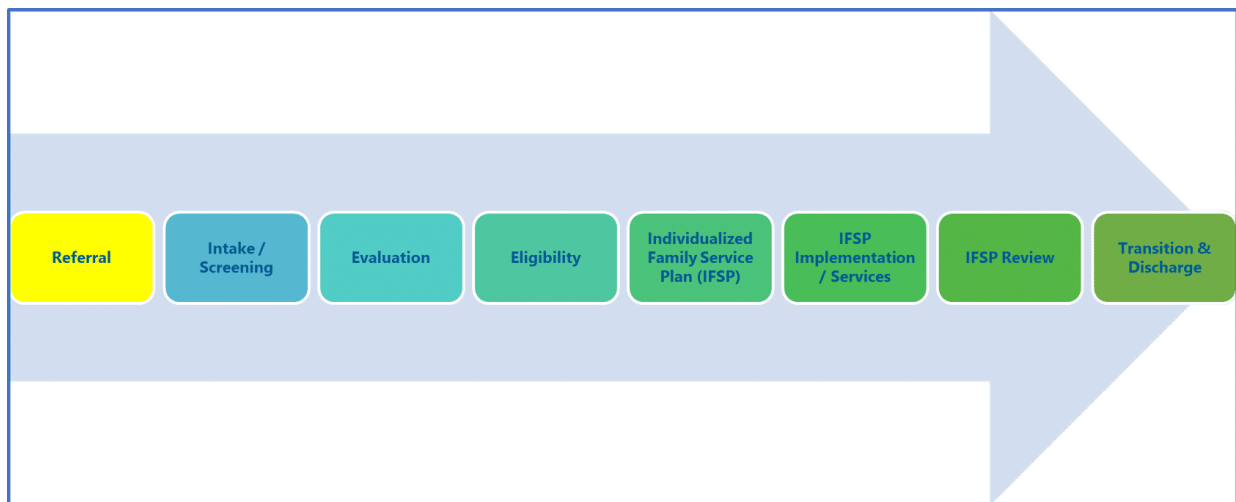
3

The child has a known condition which has a high probability for developmental delay (ex. Down syndrome)

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After the evaluation, an eligible child receives services in their home, at childcare services, or in the community. Their goals and services are documented in an **Individualized Family Service Plan (IFSP)**. In Pennsylvania, EI services use a caregiver coaching model, where the service provider empowers the family and caregivers to support their child's development in a natural environment.

- Services may include speech, occupational, or physical therapy, special instruction, and social work. All families have a service coordinator who provides additional access to resources in the family's community and answers questions as needed.
- As young children change and develop quickly, the service team tracks progress toward goals quarterly. This allows the family and team to collaborate on progress, new areas of concern, and continuously assess the child's development.
- EI services are funded by the state and are provided at no cost to families.



The Early Intervention process <sup>2</sup>

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## A child's third birthday

When birth to three services end on the day before the child's third birthday, the child and their family will transition to the Three to Five program if services are still needed. At this time, their IFSP transitions to an **Individualized Service Plan (ISP)**.

- Services no longer take place in the home, which is the **first big transition for parents and caregivers.**
- These services take place in educational settings of preschools, pre-K, and specialized programs for children with disabilities.

## Turning five

The next transition occurs when a child turns five. Typically, this indicates a transition to kindergarten.

- If a child is receiving services in the Three to Five program, the parent or caregiver can sign an “Intent to Register”.
  - The Intent to Register allows the child an extra year in the EI system before transitioning to the K-12 system.
- When a child enters the K-12 system, their ISP transitions again into an **Individualized Education Plan (IEP)**, which provides them access to special education and related services in the school system.

CONTINUE

## Lesson 2: School age services

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**All children are entitled to a Free Appropriate Public Education (FAPE), in the least restrictive environment for them to be successful. <sup>3</sup>**

Test your knowledge. Review the image, then complete the activity below.



# Free and appropriate public education (FAPE)

Here's what this important legal right means for students who need help in school.



## **is for free.**

Free means the government pays for the education of students with disabilities. There's no cost to families. However, families do have to pay the same extra school fees — for example, sports and club fees — that all students pay.



## **is for appropriate.**

Appropriate means that kids who qualify get an Individualized Education Program (IEP) with services to meet their unique needs. Others may get a 504 plan that gives equal access to learning.



## **is for public.**

Public means supervised by the public school. An IEP team — teachers, parents, and others — decides what services and support the student gets. In a few cases, the government may pay for kids with disabilities to attend private school.



## **is for education.**

Education can include special education. It can also include related services, like speech therapy, counseling, or even transportation. The goal is for kids to make progress in school and be prepared for the future.

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**Drag and drop** items into the correct category that **are** and **are not** true by FAPE.  
*Use your mouse to drag and drop the tile to the correct pile.*

FAPE

Families do not pay for special  
education services

A child who uses a mobility  
device may transition between  
classes early

Speech therapy during the  
school day to make progress  
toward IEP goal

A multisensory reading  
program is used to support  
word identification skills

Not FAPE

A child is guaranteed a spot on  
the varsity football team

Parents request a PhD level  
educator in the child's special  
education room

A 12-year-old child is placed in  
a first-grade math classroom

The diagram consists of three rectangular boxes. Two boxes are positioned at the top, side-by-side. A third box is positioned below them, centered. A horizontal line is drawn above the bottom box. The text 'A 12-year-old child is placed in a first-grade math classroom' is centered within the bottom box.

## What if FAPE cannot be met?

During their school years, a child with IDD may be asked to transition schools if the school does not believe their needs can be met at their local public school. Here are some examples:

- A student with autism spectrum disorder (ASD) is at a school that does not have a comprehensive autism support classroom.
  - **How can this need be met at the student's school?** Parents and students have the right to say what services they need and where they want to attend school.
- A student who uses a wheelchair for mobility is in a school with three floors, and the elevator is not functional so they cannot access their classrooms.
  - **How can this need be met at the student's school?** Schools are required to modify buildings and have functional elevators.
- A student who requires significant behavior support for safety of themselves and others requiring highly specialized staff.
  - **How can this need be met at the student's school?** Schools can contract with neighboring schools or agencies to find and hire supplemental staff.

If the family agrees with the school that the student's needs cannot be met, then **the school district is required to find an appropriate placement and pay for the cost.**

This could be at a different public school, or an approved private school.

Since a student's needs change over time, a student could attend a different school for a number of years, then return to their home district if the change in setting is appropriate for them to access their **least restrictive environment.**

**Each year a child's IEP is updated** based on their goals and needs.

**Every third year, a triennial re-evaluation is completed** which includes updated psychological testing and re-assessment for related services such as speech or occupational therapy to see if the student still qualifies for an IEP. Goals are updated and placements are adjusted, if needed. <sup>5</sup>

A parent or guardian is able to call an IEP meeting for any reason, at any time.

#### What is and isn't covered under FAPE <sup>4</sup>

Review and learn more about FAPE.

[LEARN MORE](#)

[CONTINUE](#)



## Lesson 3: Transitioning from school age services

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Children with IDD are typically eligible to stay in school past the age of 18, until the day before their 22<sup>nd</sup> birthday in Pennsylvania. This change is new as of 2023 - prior to then, a student could stay in school until the end of the school year where they turned 21. <sup>6</sup>



Recall from Module 1: Transition services typically start at age 14 in a child's IEP. These conversations can begin as early as age 12.

Some students and their families choose to participate in the graduation ceremony with their peers at age 18, then continue to receive a life skills or vocational based curriculum for the next three to four years. Note: If a student officially graduates at 18 with a diploma or certificate, they are unable to continue receiving school services.

For some students, this may look like attending immersive life skills at their local school a few days a week and participating in job site training and work experiences on the other days of the week.

These resources focus on the transition process out of high school and supporting individuals with IDD and their families.

### **PA Secondary Transition <sup>7</sup>**

Supports individuals and their families in navigating the transition process, bringing together departments across the state.

[LEARN MORE](#)

### **PA Inclusive <sup>8</sup>**

This organization provides support for individuals with disabilities for living, working, and transitioning in Eastern PA counties.

[LEARN MORE](#)

### **Employment First <sup>9</sup>**

A resource page for individuals and families to assist with education and employment after high school.

[LEARN MORE](#)

### **PEAL Center <sup>10</sup>**

A statewide resource center that supports inclusion and access in education and healthcare for families and young adults.

[LEARN MORE](#)

## **A challenging transition**

The transitional period can be difficult for some students socially and emotionally. They see their friends and peers graduating from high school and moving on to other pursuits while they continue to attend school.

Turning 22 and no longer being eligible for services paid for by the public school district can cause individuals with IDD and their families to face significant challenges.

- No more school = no more structured days
- Changes to Medicaid benefits and insurance coverage
- Changes in financial support
- Changes in daily social routines



Recall from Module 1: "The Cliff" - when a child transitions from pediatric to adult care and loses many of the services and programs offered to them during childhood.

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**Where does my child go when the school bus stops showing up?**

**CONTINUE**

## Lesson 4: Acquired disabilities

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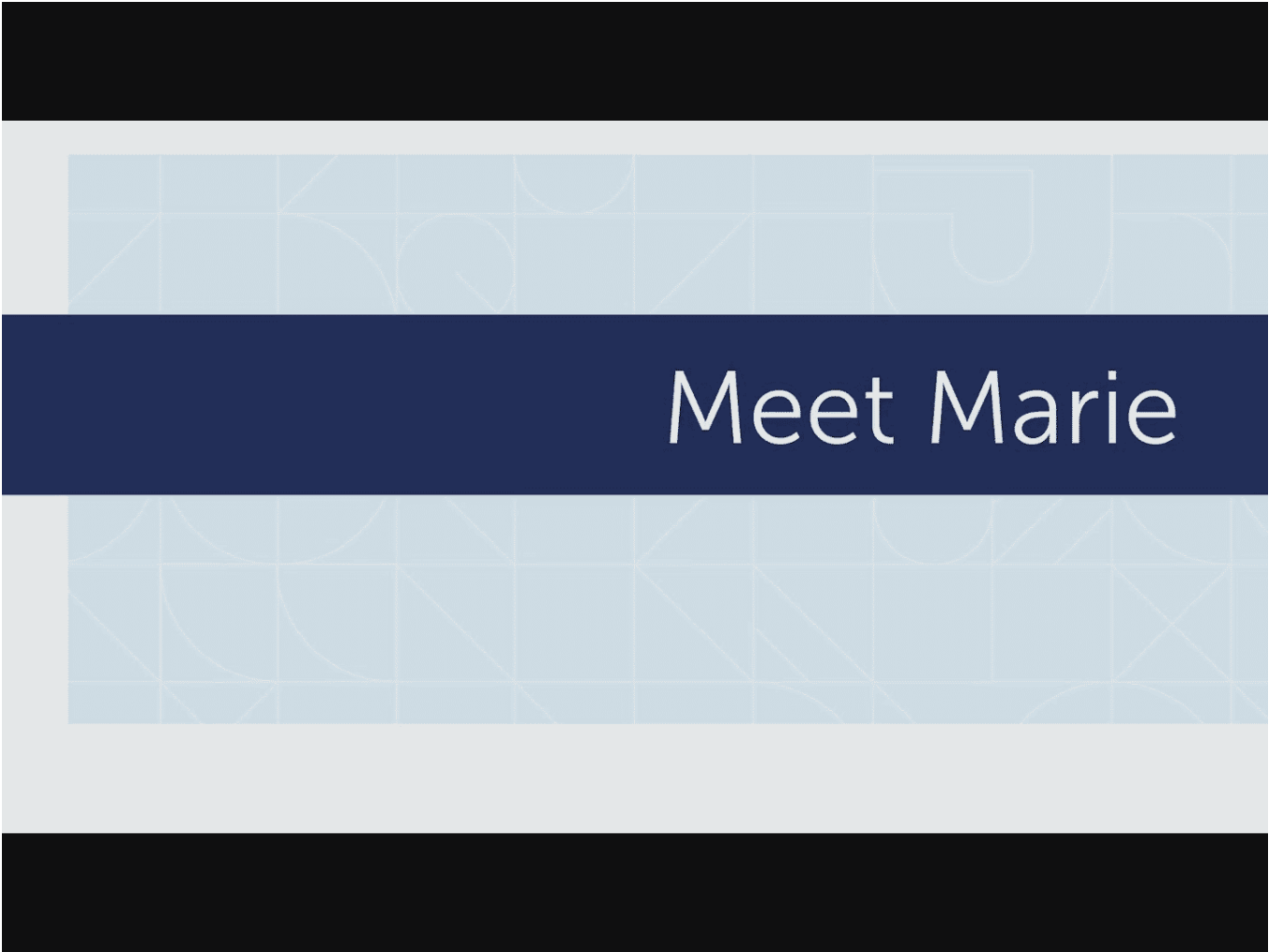
Often, conversations about special education services and school-based support are focused on IDD and physical disabilities present at birth or in early childhood. However, it is important to remember that some disabilities are acquired.

Two people with lived experience (PWLE) of disability who act as project consultants sustained traumatic brain injuries as teenagers in motor vehicle accidents.

Parents and family members mourn the loss of the child they knew and are getting to know the new normal for their child.

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**Hear from Marie, a project consultant, on adjusting to life as a caregiver after her daughter, Cory, sustained a traumatic brain injury.**



# Meet Marie

Schools and community programs are largely not tailored to meet the needs of these families. These patients and families need support to navigate this system which is new to them.

Often systems are not designed for long-term care and support for individuals with acquired disabilities. These families face difficulty in adjusting to their new normal, and access to services which largely are designed for individuals in the first 2 years after their injury.

Caregiver burnout is an important factor to remember for these families and supporters, and it is important to support the whole family unit, not just our patients.

Social work is a helpful discipline to involve in the care of individuals with acquired disability, as they can help to navigate and access resources with a family.

**BrainSTEPS (Strategies Teaching Educators, Parents, & Students) to support individuals in school <sup>10</sup>**

BrainSTEPS is an organization who works with all PA public schools to assist students and their families in communication and accommodations in school after an acquired brain injury. They offer consultations and training to school staff, students, and parents, and support families in IEP meetings and receiving appropriate support after injury. This resource is FREE and you can refer a student.

[LEARN MORE](#)

**BrainLine provides a variety of resources to caregivers, people with traumatic brain injury, veterans, and healthcare providers.**

[READ MORE](#)

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**Michael's family shares their experiences after Michael sustained a traumatic brain injury at age 4, including how his injury shaped his education.**

 **YOUTUBE**

Michael Wight and Elementary S...



## Michael Wight and Elementary School After TBI

After a severe TBI at age 4, Michael Wight is now in fourth grade at Switlik Elementary, where they call him "the mayor." He attends class with other fourth graders and also gets help from a special education teacher, speech therapist, and physical therapist.

**VIEW ON YOUTUBE >**

**CONTINUE**

## Section 1: Knowledge Check

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Please answer the following questions related to the content in Section 1: Transitions and service delivery through the lifespan.

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Question

01/04

Which of these is an appropriate referral for an Early Intervention evaluation? Select all that apply.

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- ☐ A child is meeting all of their developmental milestones.
- ☐ A child is two years old, and at their pediatrician appointment, the caregiver shares the child is not yet standing, making verbal noises, and is not eating solid food.
- ☐ A child is born very prematurely, which has a high probability of developmental delay in childhood.

Question

02/04

What does FAPE stand for?

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- ☐ Free Appropriate Public Education
- ☐ Fair and Public Education
- ☐ Funded Areas Producing Education

*Question*

**03/04**

Until what age are students with disabilities eligible for public education in Pennsylvania?

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- ☐ End of grade 12
- ☐ At the end of the year the student turns 18
- ☐ At the end of the year the student turns 21
- ☐ The day before the student's 22nd birthday

*Question*

**04/04**

True/False. An individual with disabilities maintains their health insurance and additional service eligibility automatically when they turn 18.

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☐ True

☐ False

# Lesson 1: What is the waiver system?

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Waiver services pick up where pediatric Medicaid and the school system's services leave off after an individual transitions out. While traditional Medicaid services cover hospital stays, physician visits, and medications, individuals with IDD typically need additional home and community-based services to stay healthy in their community. Waiver programs make these services possible. <sup>1</sup>

**These are some of the services covered by waiver funding <sup>2</sup>:**

- Community participation support
- Companion
- Consultative Nutritional Services
- Education support
- Family and caregiver training and support
- Home accessibility assistance
- Music, art, and equine assisted therapy
- Residential habilitation
- Respite services
- Shift nursing
- Specialized supplies
- Supported living or employment
- Support coordination
- Therapy: Physical, speech/language, occupational, orientation mobility and vision
- Transportation and vehicle accessibility

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## Where does the term "waiver" come from?

The federal government “waives” Medical Assistance/Medicaid rules for institutional care in order for Pennsylvania to use the same funds to provide supports and services for people closer to home in their own communities. In PA, the Department of Human Services administers multiple Medical Assistance/Medicaid waivers. Each waiver has its own set of eligibility requirements and services. <sup>3</sup>

Learn more about the types of Medicaid waivers offered in Pennsylvania and their eligibility <sup>3, 4, 5</sup>:

### Office of Developmental Programs (ODP) —

ODP runs the Person/Family Directed Support (P/FDS) Waiver, Community Living Waiver, Adult Autism Waiver, and the Consolidated Waiver.

P/FDS waivers offers \$47,000 per year in 2025. Community Living Waiver offers \$97,000 per year, and the Consolidated Waiver has no maximum amount of funding per year. The amount offered under each waiver may vary by year.

To qualify for a waiver through ODP, a person must be registered with their local county office of IDD. **Waiver applications and services are not automatic.**

ODP waivers are intended for individuals with a primary diagnosis of ID or ASD.

Criteria for eligibility:

- A psychological evaluation showing a diagnosed ID (IQ of 70 or below)
  - For students aging out of the school system, this is typically completed by a school psychologist and evaluation team for a triennial IEP
- Deficits in at least 3 areas of daily living as defined through adaptive scales assessment (such as the Vineland)
  - Areas of daily living include self-care, understanding and use of language, learning, mobility, self-direction, and capacity of independent living
- A person with ASD who does not have ID **can qualify** if they show deficits in at least 3 areas of daily living in addition to their ASD diagnosis
- A person must be recommended to an intermediate care facility (ICF) level of care based on a medical evaluation
  - This **does not** mean the individual is or will be living in a care facility. This indicates an individual, without any support, would require this level of care.
- The person must also be eligible for (or already receiving) Medicaid, and other demographic information must be provided

Some waiver funds may cover an individual to live in a group home with other individuals with IDD or attend a "dayhab" or day recreation/care program. Services can also be focused on employment or recreation or provide additional support services like therapy, respite, or personal care support.

Individuals who wait too long to apply risk a long and expensive process to catch up on service provisions. If the student has Medical Assistance/Medicaid, the county IDD/MH office can assist with finding providers to complete the waiver evaluation process.

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## Office of Long Term Living (OLTL) —

OLTL runs the Community HealthChoices and Omnibus Budget Reconciliation Act (OBRA) waiver programs.

OLTL waivers do not have a maximum funding limit per year, as services are provided to those who need long-term care.

OLTL waivers are intended for individuals who have a physical disability, who **do not** have a primary diagnosis of ID or ASD.

Criteria for eligibility:

- 18 years or older with a physical disability – these waivers are primarily designed for people with physical disabilities and those age 65 and older
- Primary diagnosis should **not** be ID or ASD
- Clinical assessment using Functional Eligibility Determination (FED) tool and determines a Nursing Facility Clinically Eligible (NFCE) level of care
  - NFCE level of care is for individuals who do not have ASD or ID as their primary diagnosis and require a high level of nursing or home health support
- Physician Certification form confirming an individual's medical needs
- Demonstrated financial need with the person eligible for or already receiving Medicaid

Services can be provided in the community, or in a nursing facility based on the individual, their level of care, and their living factors. Registration is facilitated by the PA Independent Enrollment Broker.

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## Office of Child Development and Early Learning (OCDEL) —

OCDEL waivers provide special instruction to individuals with IDD age 0–3 who meet an ICF level of care

Criteria for eligibility:

- An OCDEL waiver is appropriate for a child who qualifies for EI services **AND** demonstrates additional needs based on a separate evaluation process
- A family must also demonstrate financial need, where the child is eligible for Medical Assistance
- If a child does not qualify for an OCDEL waiver, their EI service provision and IFSP is not impacted



Registration occurs through the County Office of ID/MH.

CONTINUE

## Lesson 2: Support and service coordination

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To prepare for applying for a waiver in PA, an individual registers with their county office of ID. Once they are registered, they are assigned a support coordinator.



**Note:** In your practice, you will see support coordinator, service coordinator, and case worker all used as interchangeable terms.

Individualized Support Plan and Individualized Service Plan can be interchangeable, too.

### **What does a support coordinator do?**

The support coordinator works with the individual and their family to create an individualized service plan (ISP), help apply for waiver services, and ensuring the individual has access to the services they need to be as independent as possible in their home and community <sup>6</sup>.

Support coordinators provide assistance for individuals and families through their adult lifespan.

It is difficult to navigate through "the system" and figure out what services and supports are available for an adult with complex needs. A support coordinator or case worker is a helpful tool to aide with finding resources and explaining what is available in an accessible way to families.

Let's hear from some support coordinators about their services with individuals and families.

How a Case Manager Can Help



CONTINUE

## Lesson 3: Review of important acronyms and terms in service coordination

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There are many terms, departments, and acronyms which are important in the service delivery process for adults with disabilities as they age out of pediatric care.

Let's review these terms before moving on through a mix and match activity.

Match the following terms to the proper definitions. *Drag with your mouse or select the matching number on the definition card to its correct match.*

|                                                  |                                                                     |
|--------------------------------------------------|---------------------------------------------------------------------|
| ⋮ Office of Developmental Programs (ODP)         | Provides waiver types for intellectual disability and autism.       |
| ⋮ Office of Long-Term Living (OLTL)              | Provides Community Health Choice and OBRA waivers.                  |
| ⋮ Office of Child Development and Early Learning | Provides waivers to children 0-3 who qualify for ICF level of care. |

SUBMIT

Match the following terms to the proper definitions. *Drag with your mouse or select the matching number on the definition card to its correct match.*

|                                               |                                                                                                                                                                                                  |
|-----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ⋮ Medicaid Waiver                             | Provides health related care to individuals with ID or other related conditions. More than custodial care, but less than a nursing facility.                                                     |
| ⋮ Nursing Facility Clinically Eligible (NFCE) | A program that offers varied additional community support and care to qualifying individuals to stay in their homes and communities rather than residing in institutional care.                  |
| ⋮ Intermediate Care Facility (ICF)            | Care for individuals who do not have a primary diagnosis of ID or ASD, who require health-related care due to a physical condition. Care can be provided in the community or a nursing facility. |

SUBMIT

### Pennsylvania Home and Community Based Services <sup>7</sup>

For more information on Medicaid waivers and eligibility, review more information from Pennsylvania's Department of Human Services.

LEARN MORE

CONTINUE

## Lesson 4: Wait lists and service availability

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**Waiting lists can be a major barrier to an individual's ability to receive services.**

### **How does an individual eligible for waiver funding receive services?**

When an individual with IDD qualifies for waiver services, they are placed on a waitlist based on need, though a system called **Prioritization of Urgency of Need for Services** (PUNS).

### **What is PUNS <sup>8</sup>?**

A uniform instrument used by County Intellectual Disabilities Programs, on an ongoing basis, to collect a standard set of data on individuals who are waiting for ID services and supports. It is a significant management tool for County Intellectual Disabilities Programs. PUNS has been formally adopted by ODP as a requirement for annual County Plans and for use in program budgeting. The County Plan and Budget Process is an annual planning and budgeting process in place across PA to address the needs of individuals.

**People are waitlisted by need, not by number.**

Individuals are encouraged to reach out to their service coordinator if their family situation or needs change, as this can influence their place on the list for access to services.

The PUNS list is updated every 6 months or yearly for an individual. It shows their need and their category.

### **Here are some ways an individual's needs can change their place on the PUNS list:**

- An individual is living with their grandparent, who is their primary caregiver. The grandparent has a health event and now is unable to provide the same level of care to the individual.
- A person loses their main source of transportation or moves from an urban area with access to public transportation to a more rural area where they cannot access what they need in the community.
- Someone experiences a change in health status and now requires around-the-clock nursing care.



Guess how many individuals are on the waiting list in PA as of January 2025 <sup>9</sup>

*Click to turn the card over.*

11,837

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## OLTL Waivers

Since OLTL waivers provide services through a managed care model, which is designed to provide medical services in the community and keep recipients out of the hospital, the OLTL waiver does not have a waiting list.

Some individuals and their families will apply even if this waiver does not meet all of their needs so they do not need to wait.

**Note: These OLTL waivers are typically not appropriate for young people with IDD or ASD who are interested in a day program or supported employment. They are meant for people who have a high level of need for nursing or home health aide care.**

CONTINUE

## Lesson 5: Office of vocational rehabilitation

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### **What is The Office of Vocational Rehabilitation (OVR)?**

OVR provides support to access meaningful work and the access to work for individuals with disabilities. Services are arranged to meet an individual's needs, and are highly individualized.

Review the following areas OVR can support <sup>10</sup>.

## Step 1

### **Diagnostic Services**

Medical, psychological, and audiological examinations and tests can be used to better understand an individual's disability and their needs for specific types of services or equipment.

## Step 2

### Vocational Evaluation

Aptitude, interest, general ability, academic exams, work tolerance, and “hands on” job experience used to understand an individual’s vocational potential.

### Step 3

## Counseling

Vocational counseling can be used to help better understand an individual's potential, rely on their own abilities, to set realistic vocational goals, to change goals when necessary, to develop successful working habits, and begin a satisfying career. Counseling is available throughout an individual's involvement in the program.

OVR also offers benefits counseling to help someone understand how their social security and healthcare benefits may be impacted by work.

## Training

Education to prepare for a specific job, including, but not limited to, basic academic, vocational/technical, college, on-the-job, independent living, and personal work adjustment training skills. Job coaching is also offered through OVR, which provides fading support for an individual to do their job as independently as possible.

## Step 5

### Restoration Services

Medical services and equipment, such as physical and occupational therapy, wheelchairs, and automobile hand controls may be provided to support an individual's success in their chosen area of employment.



## Step 6

### Placement Assistance

Counseling, job seeking-programs, job clubs, and job development helps support an individual in finding a job. They can receive ideas, practice, and support to fill out applications and practice interviews.

## **Assistive Technology**

This includes a wide range of devices and services that can empower individuals with disabilities to maximize employment, independence, and integration into society. OVR can support in selecting and acquiring specific technology. This could include consulting with professionals to evaluate and recommend items for an individual's specific situation.

## Step 8

### Support Services

Other services can be provided for eligible persons if they are necessary to start and maintain employment. This can include room and board during an evaluation or rehabilitation program, licenses or equipment for work, home modifications, personal care assistance to allow an individual to participate in a work program, and job site modifications.

Often, people with disabilities begin working with OVR during their transitional age period (18-22). Their services can be very helpful and support individuals who wish to work.

**Hear from individuals in Pennsylvania about their experiences with OVR.**

Listen to the ways OVR is supportive beyond just helping an individual access work itself - OVR supported adaptive technology and modifications to support daily life and accessing education and transportation.

 **YOUTUBE**

## Jason Tweed's Story



## Jason Tweed's Story

Description

**VIEW ON YOUTUBE >**

 **YOUTUBE**

## Leigh Ann Patterson's Story



## Leigh Ann Patterson's Story

Description

**VIEW ON YOUTUBE >**

 **YOUTUBE**

Aidan Todd's Story



## Aidan Todd's Story

Description

**VIEW ON YOUTUBE >**

**CONTINUE**

## Lesson 6: Additional supports

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Medicaid waivers and OVR offer many services to adults with disabilities in their communities. Learn more about how assistive technology needs can be supported in Pennsylvania, as well as federal financial supports.

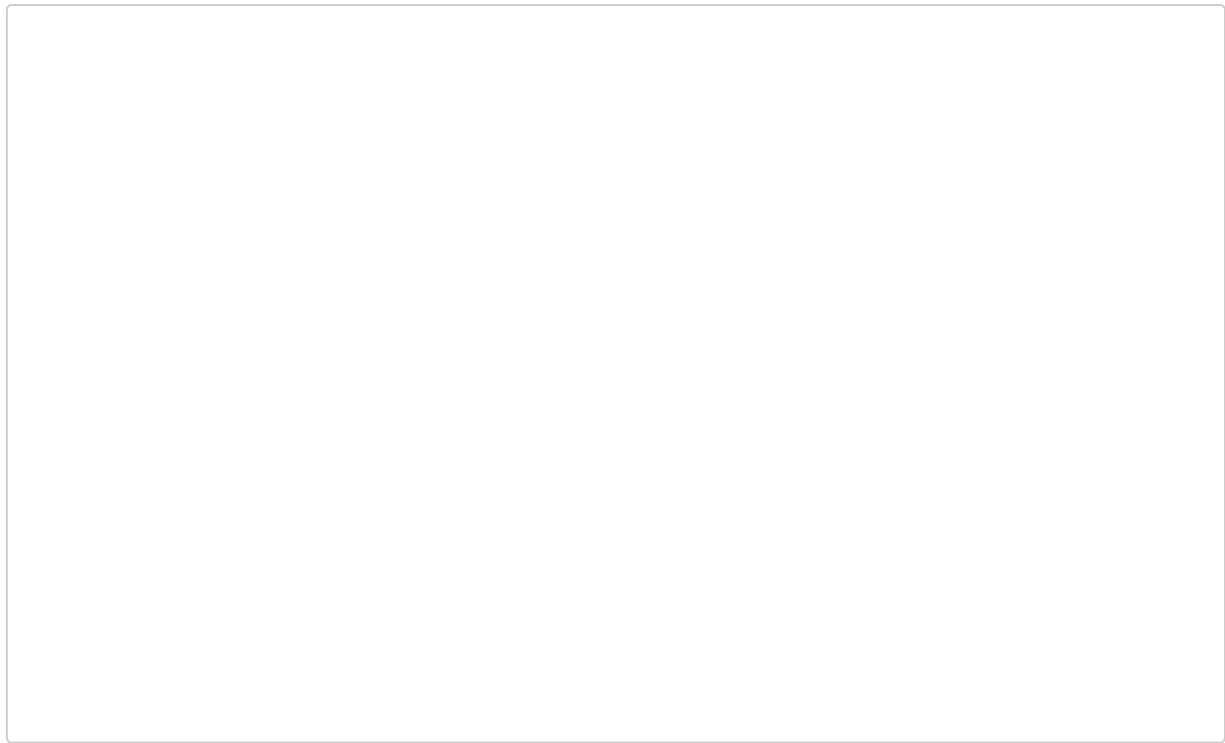
### Assistive Technology <sup>11, 12</sup>

#### Pennsylvania Assistive Technology Foundation (PATF) —

A statewide nonprofit that helps individuals with disabilities and older Pennsylvanians acquire the assistive technology devices and services they want. PATF is a state and federally certified Community Development Financial Institution (CDFI) and is the state's designated alternative financing program (AFP) under the federal Assistive Technology Act. PATF is one of 42 AFPs and state financing entities in the U.S. and territories.

PATF has a low interest loan program, too. People can work with them for something like a wheelchair van or some of the larger things they may need.

Learn more from PATF:



## TechOWL —

TechOWL stands for Technology for Our Whole Lives and is hosted through Temple University's Institute on Disabilities. They offer a variety of opportunities for individuals to learn about, explore, and get assistive technology for their needs.

TechOWL has a statewide lending library of over 1,500 devices. Anyone can check out devices for a trial, and staff is supportive in providing consultation and supplying technology for individuals who choose to purchase a device.

## Tools help people.

TechOWL finds tools and technology for people across Pennsylvania.



|  |                                                                                                                                                      |  |                                                                                                                                          |
|--|------------------------------------------------------------------------------------------------------------------------------------------------------|--|------------------------------------------------------------------------------------------------------------------------------------------|
|  | <ul style="list-style-type: none"><li>• <b>Lending Library</b><br/>see what items will work best for you</li></ul>                                   |  | <ul style="list-style-type: none"><li>• <b>Affordable AT</b><br/>help in paying for what you need</li></ul>                              |
|  | <ul style="list-style-type: none"><li>• <b>Free Special Phones</b><br/>if you have difficulty hearing, talking, seeing, thinking or moving</li></ul> |  | <ul style="list-style-type: none"><li>• <b>iCanConnectPA</b><br/>communication access if you have both hearing and vision loss</li></ul> |
|  | <ul style="list-style-type: none"><li>• <b>Used Equipment Exchange</b><br/>buy, sell or donate</li></ul>                                             |  | <ul style="list-style-type: none"><li>• <b>Testing and Recommendations</b><br/>to match your needs with tools and technology</li></ul>   |
|  | <ul style="list-style-type: none"><li>• <b>Information and Assistance</b><br/>call, email or chat online</li></ul>                                   |  | <ul style="list-style-type: none"><li>• <b>Training</b><br/>wide range of topics for your class or organization</li></ul>                |
|  | <ul style="list-style-type: none"><li>• <b>Emergency Plans</b><br/>in case of a disaster</li></ul>                                                   |  | <ul style="list-style-type: none"><li>• <b>Get Something Made</b><br/>if you can't find it at a store</li></ul>                          |
|  | <ul style="list-style-type: none"><li>• <b>Get a Demonstration</b><br/>try a variety of different devices</li></ul>                                  |  | <ul style="list-style-type: none"><li>• <b>Plus more!</b></li></ul>                                                                      |

VISIT OUR WEBSITE TO GET WHAT YOU NEED  
**TechOWLpa.org**

Pennsylvania's Initiative on Assistive Technology (PIAT) is part of TechOWL.

tel 800-204-7428  
email [ATinfo@temple.edu](mailto:ATinfo@temple.edu)

 **TEMPLE**  
UNIVERSITY®  
Institute on Disabilities



## Financial Supports

### Social Security Income (SSI) —

Social Security Income (SSI) provides benefits to those who meet social security's definition of disability with limited or no income or assets. If someone is married, the SSA will consider spouse's income as your own.

Generally, this program is for individuals who have assets of less than \$2,000 in value, or married couples living together with assets of less than \$3,000 in value. Individuals must apply on their own at age 18.

### Social Security Disability Insurance (SSDI) —

Social Security Disability Insurance (SSDI) provides benefits for those who meet social security's definition of disability **and** have at least 40 work credits, with at least 20 credits in the last 10 years. Each year of employment can earn up to 4 work credits.

If an individual has had consistent work up until they acquired a disability, they will likely qualify.

### Childhood Disability Benefit —

This benefit allows an adult with a disability to receive disability insurance benefits based on the earnings record of a retired, disabled, or deceased parent. The parent must have received income, the child does not. The adult child with a disability may qualify if their parent is currently collecting a Social Security benefit based on their own work record (or is deceased), if their disability began prior to age 22 and prevents them from participating in "substantial gainful activity" and if they are 18 or older.

The CDB payment equals half of parent's full retirement benefit. The child may become eligible for Medicare 24 months after CDB payments begin.

CONTINUE

## Section 2: Knowledge Check

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**This knowledge check will give you the opportunity to learn more about a topic from this lesson.**

1. Choose which program you would like to learn more about: ODP waivers, OVR programs, or assistive technology.
2. Visit their website using the buttons below.
3. Find 1 services or supports offered by the program.
4. Learn more about what the service or support is.
  - a. (ex. A support offered through ODP is Consultative Nutritional Services. Search this service to learn about what it is)
5. Share in the box below how this service might be helpful for an individual with IDD in their community.

ODP Waiver Information and Services, PA.

ODP

Learn about assistive technology through TechOWL, or browse their lending library to see what is offered.

TECHOWL

Learn about the services offered through OVR.

OVR

Learn more about Pennsylvania Assistive Technology Foundation (PATF) and their resources.

PATF



What service or program did you learn about?  
How might this service be used for an individual  
with a disability in their community?

CONTINUE

## Lesson 1: The intersection of medical and social needs

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Recall from Module 1: Transitioning from pediatric to adult providers for individuals with IDD is challenging. Barriers including a lack of available providers, and difficulty finding providers who are willing to provide care for complex patients. These factors impact the quality of care for individuals with IDD.



As a provider, why do you think it is important to understand the services your patients are receiving or are eligible to receive?

**Think about each area and ways a provider can support a patient's medical and social needs, together.**  
***Click the card to turn it over.***

Access

There are many medical forms providers need to complete to allow for access to services.

Advocate

Providers can be informants of services available, and can push for services via medical appeals if they are denied.

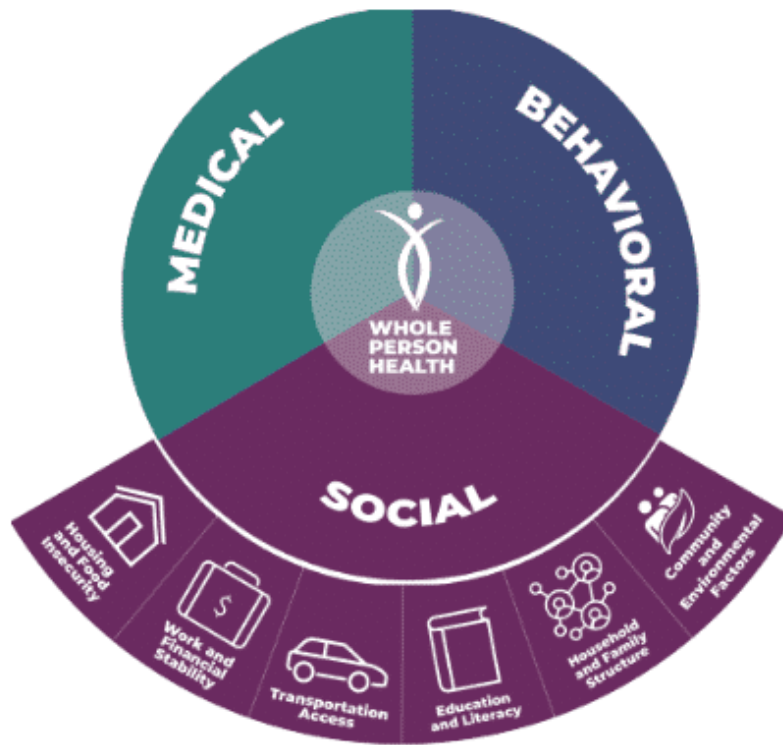
Prevention

There are countless negative effects if an individual is unable to access their environment and community in a meaningful way.

**Learn more:** Review some forms you as a healthcare provider might fill out for an individual with IDD. [Example forms.](#)

A provider may complete these forms for an individual with IDD to access resources and support for medical and community needs.





[Image source](#)

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Recall the Social Determinants of Health and their impact on overall-well being.

CONTINUE

## Lesson 2: Review decision making



Recall this content from Module 1. Review your knowledge, then review the additional resources for more information.

Match the proper definitions for types of decision making. *Drag and drop with your mouse or choose the corresponding number from the term to the definition.*



Power of Attorney

A court-appointed person is responsible for all decision making. An individual is considered unable to make care decisions for themselves.



Guardianship

An individual appoints someone to act as an equal decision maker in their presence or on their behalf.



Supported Decision Making

Individuals make their own choices with support from a team of people they know and trust.

SUBMIT



Need help to recall, or want to learn more? Refer back to Module 1, or review the websites below.

### **Power of Attorney vs. Guardianship <sup>1</sup>**

Learn more about each of these options. Recall that guardianship is the most restrictive option.

[READ MORE](#)

### **Supported Decision Making <sup>2</sup>**

The national resource center for supported decision making offers a variety of resources and support in establishing and maintaining this process.

[READ MORE](#)

# Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.



This form has 3 parts. It lets you:



## **Part 1: Choose a medical decision maker.**

A medical decision maker is a person who can make health care decisions for you if you are too sick to make them yourself.



## **Part 2: Make your own health care choices.**

This form lets you choose the kind of health care you want.

This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.



## **Part 3: Sign the form.**

It must be signed before it can be used.

Health care directive

Using plain language to explain decision making can be supportive for individuals with IDD to participate in their own care.

CONTINUE

## Lesson 3: Support recreation

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**Overall health is determined beyond the walls of a provider visit. A person's access to leisure, recreation, and social opportunities are positive and protective factors that support a healthy lifestyle.**

Encourage participation in local recreation programs – Special Olympics is a great opportunity for many individuals with IDD. A provider can complete a physical form for Special Olympics at a physical that can reduce barriers to an individual getting started.

*\*All organizations below are linked in the Additional Resources at the end of this module.*

### **Physical Activity** 3, 4, 5, 6, 7, 8

#### **Special Olympics** —

Special Olympics serves over 15,000 athletes in Pennsylvania through a variety of sports and recreation during the year. Individual and team sports are offered to athletes by season, and individuals with disabilities are supported by volunteer coaches.

Competitions occur throughout the year, including a yearly Fall Festival at Villanova University. Beyond sports, Special Olympics offers its athletes a variety of health screenings and opportunities to improve their overall well being through their Healthy Athletes initiative.

 **YOUTUBE**

### This is Special Olympics Pennsylvania



### This is Special Olympics Pennsylvania

Join the movement. Visit [www.specialolympicspa.org](http://www.specialolympicspa.org) to become an athlete or volunteer today!

**VIEW ON YOUTUBE >**

## Fitness Center Membership Benefits

Most Medicaid plans have fitness center community membership benefits. You can support an individual in identifying their local center and accessing these benefits.

 **YMCA**



## Find Your Y

Find your local YMCA! Search for a location closest to you to best suit you and your family's needs. Get involved in your local community through the YMCA!

**READ MORE YMCA >**

## iCan Shine

This organization provides one-week programs to help participants with IDD learn to ride a conventional two-wheel bicycle. Their programming also includes opportunities for learning to swim, and some dance programs.

 **ICAN SHINE**



## Bike, Swim & Dance Camps - Everyone Can Shine - iCan Shine

iCan Shine is an international charitable nonprofit organization which teaches those with disabilities how to ride a bike independently, swim, and dance.

**READ MORE ICAN SHINE >**

### Pennsylvania Center for Adapted Sports —

Pennsylvania Center for Adapted Sports (PCAS) offers 13 sport and wellness programs year-round in Philadelphia at Boathouse Row. All participants are provided with equipment, venues, instruction, training, a team of peers, and supportive volunteers. These programs are for children, adults, and veterans with disabilities.

 **PA CENTER FOR ADAPTED SPORTS**



**PA Center for Adapted Sports**



Our mission is to improve the health and well-being of people with disabilities through inclusive sport, wellness and recreation programs.

**READ MORE PA CENTER FOR ADAPTED SPORTS >**

## Jefferson Moss-Magee Wheelchair Sports —

Jefferson Moss-Magee Rehabilitation offers opportunities for individuals with qualifying disabilities to take part in free, competitive sports programming. These programs take place in Philadelphia with participants from the tri-state area.



## Rehabilitation Medicine - Wheelchair Sports | Jefferson Health

**READ MORE JEFFERSONHEALTH >**

## U.S. Olympic & Paralympic Sports - Pennsylvania —

The United States Olympic and Paralympic Committee (USOPC) shares a collection of adapted and paralympic sports for individuals with disabilities. These are located across the state and offer a variety of competitive and noncompetitive opportunities.





UNITED STATES  
OLYMPIC & PARALYMPIC  
COMMITTEE

## Find A Club - Pennsylvania

A to E Achilles International Achilles International is a leading adaptive running nonprofit that transforms the lives of youth, adults and veterans with disabilities through athletic programs and social connection. Achilles has 62 chapters hosting week...

**READ MORE USOPC >**

## Camps 9, 10, 11, 12, 13

Camp is not just for children! Many organizations serving individuals with disabilities offer programs for individuals 18+, often as weekend or modified programs. The benefits to a camp setting are innumerable.

Learn more about these options and get a glimpse into each of these camp programs in Pennsylvania.

Camp PALS —

PALS offers inclusive camp experiences where individuals with Down syndrome are paired 1-1 with a volunteer Peer. Camps take place on university campuses and are overnight, one-week long opportunities.

PALS serves individuals 12-30 in traditional one-week settings and offers a modified 21+ program for adult participants looking for more independence.

 **YOUTUBE**

### PALS End of Year Video 2024



### PALS End of Year Video 2024

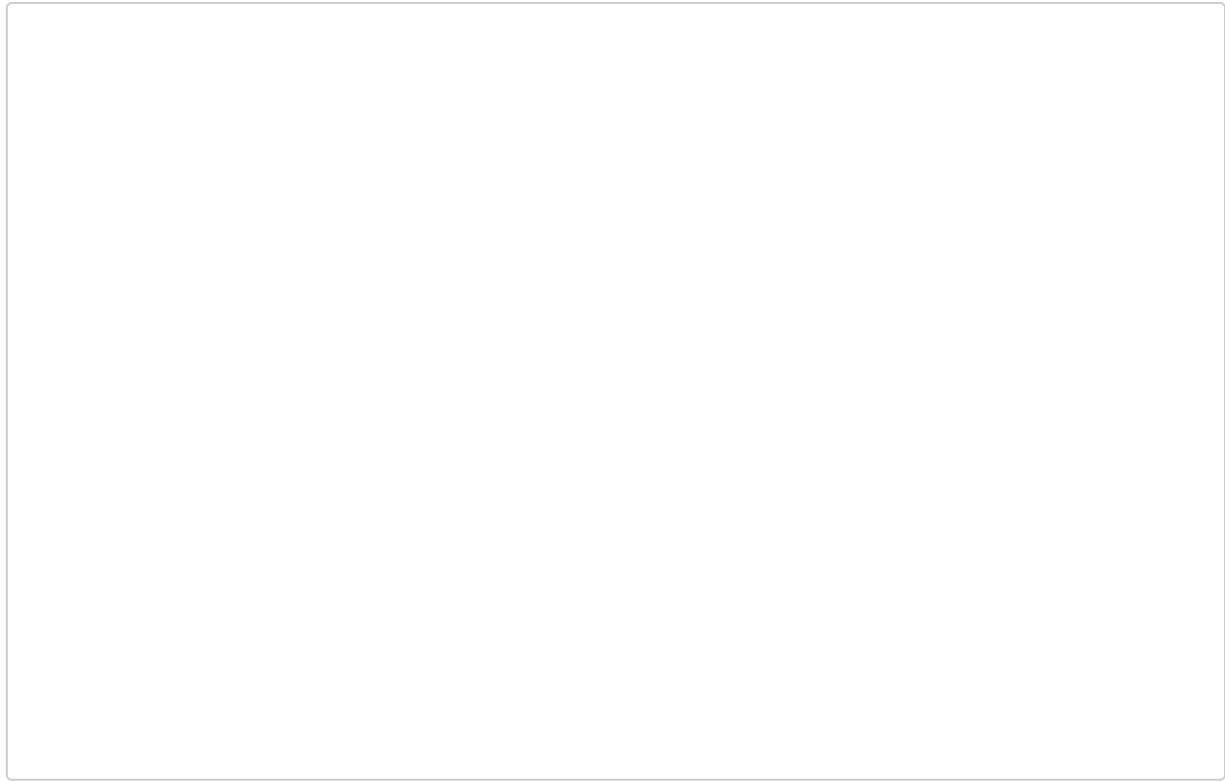
For more details, visit us at [www.palsprograms.org](http://www.palsprograms.org)

**VIEW ON YOUTUBE >**

## Carousel Connections —

Carousel Connections offers a participant centered model for adults with disabilities to collaborate, connect, and engage with the community.

Their programs are focused on job and skill building, independent living skills, and community involvement for individuals after they transition out of high school.



## Easter Seals —

Easter Seals provides a variety of therapeutic and recreational services for individuals with disabilities across the lifespan.

They offer accessible camping and recreation for adults with disabilities, in addition to providing respite programs for caregivers and their families.

 **YOUTUBE**



## Easter Seals Camp Benefits Video



## Easter Seals Camp Benefits Video

<https://www.eastersealscamps.org/>

**VIEW ON YOUTUBE >**

### PA Vent Camp —

PA Vent Camp takes place at a fully accessible campground and provides an overnight camp experience for individuals who rely on mechanical ventilation to breathe. They are a volunteer run program and support the needs of all campers.

Camp participants have the opportunity to engage in activities like zip-lining, rock climbing, crafts, and more camp activities with supportive staff and friendships.

They offer weekend-long opportunities for adults to attend.



PA Vent Camp

PA Vent Camp

03:24

## Variety Club Camps —

Variety offers many opportunities for children and young adults with disabilities age 5-24 in the Delaware Valley area of Pennsylvania. During the summer, they offer day camp, overnight camp, and vocational camps for individuals to nurture independence and self-confidence.

 **YOUTUBE**

## Join the Club: Variety Club Camp and Developmental Center



### Join the Club: Variety Club Camp and Developmental Center

The Variety Club Camp and Developmental Center -- located in Worcester, Montgomery County, PA -- enables children and youth with varying levels of abilities to experience new things, learn new things and make new friends! With your support and participation, the Variety Club Camp can continue providing programs, services and fun to children and youth with disabilities and their families!

**[VIEW ON YOUTUBE >](#)**

**CONTINUE**

## Lesson 4: Advocacy and resources

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**Providers advocate for patients every day, in big and small ways!**

There are many advocacy groups who specifically serve individuals with disabilities and their families. They can provide support on an individual level, or larger on a policy and systems level.

Learn more about some of these groups in PA:



**Module 2 Additional Resources\_\_.pdf**  
144.3 KB



Additionally, there are some free programs available across regions in Pennsylvania that can be supportive for families. Learn about them below <sup>11</sup>.



| SAFECARE                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | MEDICAL HOME<br>COMMUNITY TEAM | TECHNOLOGY<br>ASSISTED<br>CHILDREN'S HOME<br>PROGRAM | COMMUNITY TO<br>HOME | PA<br>F |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|------------------------------------------------------|----------------------|---------|
| <p><b>SafeCare Augmented for Family Empowerment (SAFE)</b></p> <ul style="list-style-type: none"> <li>• Parent training curriculum for parents of children 0–5 aimed at home safety and the prevention of child neglect and abuse.</li> <li>• SAFE providers work with families in their homes to improve parents’ skills in three areas: <ul style="list-style-type: none"> <li>◦ 1) Parent–infant/child interaction skills</li> <li>◦ 2) Health care skills</li> <li>◦ 3) Home safety</li> </ul> </li> <li>• Visits are conducted at home, weekly for 60–90 minutes and lasts 18–20 weeks for each family.</li> <li>• Philadelphia county residents with children age 0–5 are eligible.</li> </ul> |                                |                                                      |                      |         |

| SAFECARE                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | MEDICAL HOME<br>COMMUNITY TEAM | TECHNOLOGY<br>ASSISTED<br>CHILDREN'S HOME<br>PROGRAM | COMMUNITY TO<br>HOME | PA<br>F |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|------------------------------------------------------|----------------------|---------|
| <p><b>Medical Home Community Team</b> provides care coordination support to families living in Philadelphia with children age 0–21.</p> <ul style="list-style-type: none"> <li>• Offers social work, nursing, and community health worker support.</li> <li>• Supports families in accessing physical and mental health care, education advocacy, and community resources.</li> <li>• Often have bilingual staff support.</li> <li>• Families must consent for referral; referrals come from a family's pediatric medical care facility.</li> </ul> |                                |                                                      |                      |         |

- Currently only accepting referrals for patients with Geisinger or United Medicaid plans.

| SAFECARE                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | MEDICAL HOME<br>COMMUNITY TEAM | TECHNOLOGY<br>ASSISTED<br>CHILDREN'S HOME<br>PROGRAM | COMMUNITY TO<br>HOME | PA<br>F |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|------------------------------------------------------|----------------------|---------|
| <p><b>Technology Assisted Children's Home Program (TACHP)</b></p> <ul style="list-style-type: none"> <li>• Provides patient navigation services throughout Eastern PA to families of children who have special health care needs that require a medical device to compensate for injury or loss of a vital organ (ex. Ventilator use).</li> <li>• TACHP's services include case management, home visits, care coordination, one-on-one education, and training for home health and school nursing professionals.</li> <li>• Serves 31 counties, children 0-22, living and being cared for in their homes who use medical technology to make up for the loss of or diminishment of a bodily function or organ.</li> </ul> |                                |                                                      |                      |         |

| SAFECARE                                                                                                                                                                                                                                                                                                                                                                           | MEDICAL HOME<br>COMMUNITY TEAM | TECHNOLOGY<br>ASSISTED<br>CHILDREN'S HOME<br>PROGRAM | COMMUNITY TO<br>HOME | PA<br>F |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|------------------------------------------------------|----------------------|---------|
| <p><b>Community to Home (C2H)</b></p> <ul style="list-style-type: none"> <li>• Serves families of newly diagnosed children in rural counties and regions of PA.</li> <li>• Focus on strengthening the capacity of caregivers and families to support positive health outcomes for complex medical needs.</li> <li>• Provides care coordination and caregiver education.</li> </ul> |                                |                                                      |                      |         |

|          |                                |                                                      |                      |         |
|----------|--------------------------------|------------------------------------------------------|----------------------|---------|
| SAFECARE | MEDICAL HOME<br>COMMUNITY TEAM | TECHNOLOGY<br>ASSISTED<br>CHILDREN'S HOME<br>PROGRAM | COMMUNITY TO<br>HOME | PA<br>S |
|----------|--------------------------------|------------------------------------------------------|----------------------|---------|

**PA Safe Sleep Program**

- Designed to support families in preventing instances of Sudden Unexpected Infant Deaths (SUIDs).
- Supportive program for families to increase their awareness of safe sleep.
- Increases education and opportunities for both families and healthcare professionals.

| SAFECARE | MEDICAL HOME<br>COMMUNITY TEAM | TECHNOLOGY<br>ASSISTED<br>CHILDREN'S HOME<br>PROGRAM | COMMUNITY TO<br>HOME | PA |
|----------|--------------------------------|------------------------------------------------------|----------------------|----|
|----------|--------------------------------|------------------------------------------------------|----------------------|----|

## Families in Recovery

- Program designed for families with a history of substance use disorder (SUD) to increase child abuse prevention, support, and training.
- The program operates as a community-based, comprehensive experiential and educational program to decrease parental stress.
- Utilizes a Protective Factors Framework (PFF) and strengths-based approach to parenting and parent-child interactions.

**A AMCHP**



## Families in Recovery - AMCHP

Recognizing the significant gap in parenting interventions for parents with SUD, the Pennsylvania Family Support Alliance (PFSA) nonprofit developed the Families in Recovery (FIR) program. PFSA was established in Pennsylvania 40 years ago with a child abuse prevention mission, providing education, support, and training programs to make Pennsylvania safe for children.

UNDEFINED AMCHP >

CONTINUE

## Section 3: Knowledge Check

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Using the information from the lessons in this module, provide your answer to the case study below.

You see a patient, Abe, who is 26 years old. Abe has a primary diagnosis of cerebral palsy and ID. Abe lives at home and is supported by a parent as his primary caregiver, with some supplemental nursing support. He receives these services through waiver funding.

Abe was recently denied a hospital bed for use at home, which was requested for providing care at home and reducing the risk of pressure sores, and decreasing the need for caregiver support through the nighttime.

Abe has demonstrated interest in seeking employment in the community. The vocational experiences he had through his transition program in high school were cut short because of the COVID-19 pandemic, and he did not return to those originally offered. Abe feels isolated and wants to get out of the house. He feels stuck at home and wants to be included in the community and with other people his age. He and his care team aren't sure where to start.



What can you do as a provider to support Abe  
and his caregivers?  
Based on the information and resources shared

CONTINUE

## Module 2 Conclusion

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Thank you for participating in Module 2: Patient and Caregiver Community Supports and Resources. This is part 2 of a 4-part education series funded by PADDC. Additional information related to this project is found on the Introduction page of this website.

[Increasing Access to Quality Healthcare for People with Disabilities](#)

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

Thank you for your support, engagement, and interest in increasing high quality care for patients with IDD. Please review the additional resources below after completing the survey and share this module with your colleagues!

For continued discussion, you may visit our live discussion board page on the Discussion tab of the project website.





This survey will take 2-5 minutes to complete.

For each question, please choose the categories



**References Module 2\_\_.pdf**

167.6 KB



**Module 2 Additional Resources\_\_.pdf**

144.3 KB



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**Thank you for your participation!**

## **Learning Objectives from Module 2**

- Identify transitions throughout the lifespan for people with IDD and physical disabilities and their supporters
  - Better understand the unique medical and social needs of this complex population
  - Identify the various systems of care for people with disabilities and how they interact
  - Access tangible resources which can be used in the clinic setting
-

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