SIDNEY KIMMEL MEDICAL COLLEGE

Patient and Caregiver Community Supports and Resources

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

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We'd Like to Thank Our People With Lived Experience!

- To support the planning and design of the following modules and learning opportunities, we have hired individuals with lived experience with disabilities and caregivers as consultants.
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Objectives

- Identify transitions throughout the life span for people with IDD and physical disabilities and their families/caregivers
- 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 you can use in clinic

Transitions Throughout the Life Span

Office of Child Development and Early Learning Waiver (OCDEL): Birth to Three

- Children with an identified disability at or shortly after birth is often referred to the Birth to Three program. The Birth to Three program is part of Early Intervention (EI) services.
  - can include speech, occupational and physical therapies, and social work
  - referrals can come from medical providers, social workers or a parent or caregiver
- When Birth to Three services end, the child and family will then transition to the Three to Five system (if services are still needed).
  - Benefits of the 3-5 system can include specialized Pre-K programs and support with transition to Kindergarten.

Office of Child Development and Early Learning Waiver (OCDEL): From Early Intervention to Kindergarten

- Typically once the child turns 5 they will need to transition to Kindergarten. HOWEVER...
  - if a child is receiving services in the 3-5 system, the parent can sign an "Intent to Register".
  - The Intent to Register allowing the child one more year in the EI system before starting Kindergarten.
- An important part of these services is the Individualized Service Plan (ISP) which will follow the child to kindergarten, ensuring they are receiving the specialized services they need.
  - Supports with transition to an appropriate public education program.

Office of Child Development and Early Learning Waiver (OCDEL): From School to the Community

- During the school age years children with intellectual and developmental disabilities (IDD) may need to transition schools.
- All children are entitled to a Free Appropriate Public Education (FAPE), in the least restrictive environment.
- If a child is in a school environment that cannot meet their needs, the school district is required to find an appropriate placement which can include a public or approved private school.
- Children with IDD are typically eligible to stay in school until the end of the school year of their 22nd birthday.
  - This law recently changed! Until 2023, the age limit was 21.
  - They will sometimes still walk at graduation at age 18 and then participate in a life skills and/or vocational curriculum for the next three to four years.

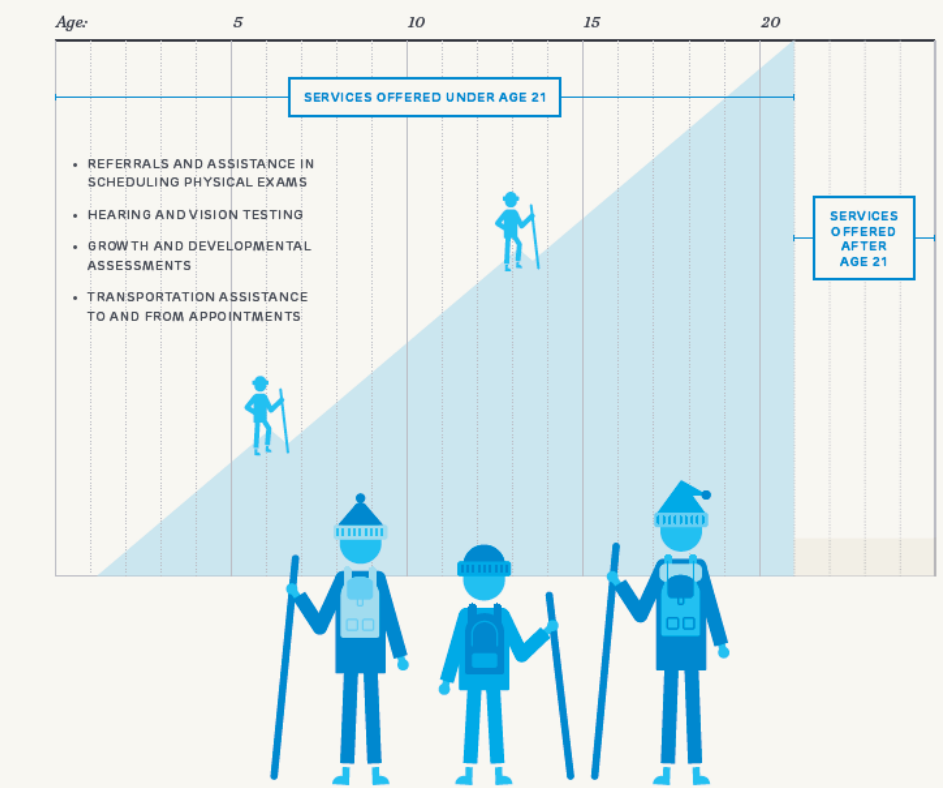
Challenges

The Cliff

Once a person turns 22, they face many changes:

- No more school = no more structured days
- Changes to Medicaid benefits
- Change in financial supports

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



Acquired Disabilities

- We talk a lot about IDD and physical disabilities that happen at birth, but our people with lived experiences (PwLE) reminded us that acquired disabilities should not be left out!
- Two of our PwLE 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
- Schools and community programs are not tailored to meet the needs of these families and patients and families need a lot of support to navigate the system
- Caregiver burn out is real, and it is important that we support the whole family unit, not just our patient

The Waiver System

The Waiver System - What is it?

Waiver services pick up where pediatric Medicaid and the school system leave off.

Waivers can cover:

- Day programs
- Home and community habilitation
- Transportation
- Home health services
- Many more services and supports…

The Waiver System - What is it?

- There are seven active Medicaid waivers in Pennsylvania:
  - Office of Developmental Programs
    - These waivers are the Intellectual Disability and/or Autism waivers
  - Office of Long Term Living
    - These waivers include the Community HealthChoices and OBRA waivers
  - Office of Child Development and Early Learning
    - Provides special instruction to individuals with intellectual disabilities or developmental disabilities ages 0-2 years who meet an Intermediate Care Facility / Intellectual disability (ICF/ID) level of care.

Office of Developmental Programs Waivers

In order to be eligible for a waiver through the Office of Developmental Programs (ODP), a person must be registered with their local county office of IDD.

- Certain criteria must be met:
  - A psychological evaluation completed within the last ten years that shows a diagnosed Intellectual Disability (IQ of 70 or below)
  - The evaluation must also include adaptive scales (such as the Vineland) showing deficits in at least 3 areas of daily living.
  - A person with Autism Spectrum Disorder who does not have an Intellectual Disability can also qualify so long as they also show deficits in 3 or more areas along with their ASD diagnosis.
  - In addition to the psychological information demographic information must also be provided and the person must be eligible for and/or receiving Medicaid.
  - **A person can register with their county office as a child, they do not need to wait – *and in fact shouldn't wait* – until they are 18 or 21.**

Office of Long Term Living Waivers

- These waivers are primarily designed for people with physical disabilities and people aged 65 or older.
- Primary diagnosis to qualify should not be an ID or ASD diagnosis.
- These waivers are attached to Medicaid plans in PA.
- These waivers are provided through the Office of Long Term Living.
- A physician certification form is sent to the medical provider to certify the person's medical needs.
- A person must also have financial need and be receiving or eligible for Medicaid.

Supports/ Service Coordination

- Whether you are registered with the Office of Developmental Programs or the Office of Long Term Living, you will be assigned to a supports coordinator.
  - The role of the supports coordinator is to work with the individual and their family to:
    - Locate and help apply for waiver services
    - Create an individualized service plan (ISP) to coordinate services
    - Monitor to ensure the person is receiving the services they need to be as independent as possible in their home and community
  - Please note that depending on the entity the terms Supports Coordinator and Service Coordinator are both used. They both refer to the “case worker” and serve the same purpose. This can also be seen with the type of plan – Individualized Support Plan or Individualized Service Plan.

Terms and Acronyms to Familiarize Yourself With

- **ICF/ID** – "Intermediate Care Facility/Intellectual Disability" Provides health-related care to individuals with Intellectual Disability. More care than custodial care but less than in a nursing facility.
- **ICF/ORC** – "Intermediate Care Facility/Other Related Condition" Provides health-related care to ORC individuals. More care than custodial care but less than in a nursing facility. Other related conditions include Autism Spectrum Disorder.
- **NFCE** – "Nursing Facility Clinically Eligible" Requires health-related care and services because the physical condition necessitates care and services that can be provided in the community with Home and Community Based Services or in a Nursing Facility. This is for people with physical disabilities who do not have ASD or ID as their primary diagnosis, and who require a high level of nursing or home health support.

Terms, continued

- **ODP** – Office of Developmental Programs
- **OLTL** – Office of Long Term Living
- **Medicaid Waiver** - Waivers offer an array of services and benefits such as choice of qualified providers, due process, and health and safety assurances. The name waiver comes from the fact that 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 Pennsylvania, the Department of Human Services administers multiple Medical Assistance/Medicaid waivers. Each waiver has its own unique set of eligibility requirements and services.

Wait Lists

- Office of Developmental Programs Waivers (2025):
  - Person Family Directed Service Waiver (PFDS) - $47,000.00 per year
  - Community Living Waiver - $97,000.00 per year
  - Consolidated Waiver – No maximum amount of funds per year
  - There are waiting lists for these waivers
  - People are placed on the waitlist based on need
    - **P**rioritization of **U**rgency of **N**eed for **S**ervices

      "Prioritization of Urgency of Need for Services (PUNS) provides a uniform instrument that is used by County Intellectual Disabilities Programs, on an on-going basis, to collect a standard set of data on individuals who are waiting for intellectual disabilities services and supports. It is a significant management tool for County Intellectual Disabilities Programs. PUNS has been formally adopted by the Office of Developmental Programs as a requirement for annual County Plans and for use in program budgeting. The County Plan and Budget Process is the annual planning and budgeting process in place across Pennsylvania to address the needs of individuals." (PA Department of Human Services)
  - As of January 2025, there are 11,837 individuals on the waiting list for services.

OLTL waivers

- There are no waiting lists for these waivers
  - Some families will opt to apply for these waivers, even if they do not meet all of their needs, so that they do not have to wait for services
- These waivers are not appropriate for young people with IDD or Autism who are looking for day programs or supported employment
- These waivers are appropriate for people who have a high level of need for nursing or home health aide care

How Can I Help My Patients Access These Services?

- If you find that a patient should be registered with the county office of IDD/A and they are not, you should direct them to contact their local office:
  - Philadelphia - 215-685-4677
  - Montgomery - 610-278-3642
  - Delaware - 610-713-2330
  - Bucks - 215-444-2847
  - Chester - 610-344-6265

  - To access services through the Office of Long Term Living call the Pennsylvania Independent Enrollment Broker
    - Helpline: 1-877-550-4227
  - Find your local county IDD/MH office here
    - https://www.pa.gov/agencies/dhs/contact/county-mh-id-offices.html

Office of Vocational Rehabilitation – OVR

- OVR provides a wide range of services to eligible applicants. Some services can help you overcome or lessen your disability; others can directly help you prepare for a career. The services you receive will be arranged to meet your individual needs. Not everyone will need every service. OVR services include:
- **Diagnostic Services:** Medical, psychological, and audiological examinations and tests used to better understand your disability and your needs for specific types of services.
- **Vocational Evaluation:** Aptitude, interest, general ability, academic exams, work tolerance and "hands-on" job experience used to understand your vocational potential.
- **Counseling:** Vocational counseling will help you to better understand your potential, to rely on your abilities, to set realistic vocational goals, to change them when necessary, to develop successful work habits and to begin a satisfying career. Counseling is available throughout your rehabilitation program.
- **Training:** Education to prepare you for a job, including, but not limited to, basic academic, vocational/technical, college, on-the-job, independent living skills, and personal and work adjustment training.
- **Restoration Services:** Medical services and equipment, such as physical and occupational therapy, wheelchairs and automobile hand controls can be provided to enable you to pursue and achieve employment.

OVR (cont.)

- **Placement Assistance:** Counseling, job-seeking programs, job clubs, and job development used to increase your ability to get a job. You will receive ideas, practice and advise on finding job leads, filling out applications, getting interviews for a job and on how to interview. Your counselor may also give you job leads or contact employers about available tax credits and hiring incentives. The more contacts with employers you make, the better your chances are of finding a job.
- **Assistive Technology:** Assistive technology includes a wide range of devices and services that can empower persons with disabilities to maximize employment, independence and integration into society. OVR can assist an individual with a disability in effectively selecting and acquiring appropriate assistive technology. OVR can arrange for a consultant to evaluate your situation and to make appropriate recommendations. OVR also operates and maintains the Center for Assistive and Rehabilitation Technology (CART) at the Hiram G. Andrews Center. There is no charge for evaluation and vocational counseling services through OVR. Based upon your financial needs, you may have to contribute to the cost of assistive technology devices and services.

OVR (cont.)

- **Support Services:** Other services are provided for eligible persons if they are necessary for you to start and maintain employment. Such services may include:
  - Room, board and transportation costs during an evaluation or while completing a rehabilitation program.
  - Occupational tools, licenses or equipment.
  - Home modifications, adaptive or special household equipment in order to help you get ready to go to and be on time for your job. Van or car modifications, including special driving devices or lifting devices to enable you to travel to your job.
  - Personal care assistance provided to help you with your daily needs in order to enable you to participate in a vocational rehabilitation program.
  - Job site modifications that will enable you to get and keep a job. Independent living training to provide the means for you to become more self-sufficient and thereby make it possible for you to participate in employment.
  - Text Telephone (TTY), signaling devices, hearing aids, and interpreter services may be provided to help you communicate.
  - Specialized services such as Rehabilitation Teaching, and Orientation and Mobility Training for persons who are blind or visually impaired.

Additional Supports

Additional Resources for Assistive Technology

- Pennsylvania Assistive Technology Foundation
  - Pennsylvania Assistive Technology Foundation (PATF) is a statewide, non-profit organization 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 Commonwealth'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.us)
  - PATF offers 0% and low interest loans to purchase a wide variety of assistive technology, including smart home technology.

- TechOWL
  - Pennsylvania Assistive Technology Foundation (PATF) is a statewide, non-profit organization 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 Commonwealth'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. (techowlpa.org)

Medical Transitions

- Pediatric Medicaid Benefits in PA last until age 21
- These cover shift care services, including home nursing and home health aides as well as a wide variety of Durable Medical Equipment (DME)
- Pediatric providers and children's hospitals will often see patients until age 21, however there are certain exceptions:
  - Specialized programs that do not exist elsewhere may keep adult patients (Congenital heart programs, PKU clinics)
  - Some pediatric offices will require patients to transition at age 18
  - This transition often means:
    - Loss of nursing supports
    - Loss of care coordination
    - Loss of social work support

Behavioral Health

- Finding Behavioral Health Services for people with IDD over the age of 21 is incredibly difficult

- Barriers include:
  - Lack of available providers
  - Insurance/funding
  - Lack of providers willing to provide care for this complex population

- Available services also change:
  - No IBHS or “wrap around” services
  - No comprehensive developmental clinics (Trisomy 21, 22Qdel)

Financial Supports

- **SSI** provides benefits to those who meet social security's definition of disability with limited to no income or assets. If you are married, the SSA will consider your spouse's income as your own. Generally, this program is for individuals who have assets that are less than $2,000 in value or married couples living together who have assets that are less than $3,000 in value.
- **SSDI** provides benefits for those who meet social security's definition of "disability" and have at least 40 work credits, 20 of which were acquired in the last 10 years. Each year of employment can earn up to 4 work credits. If you have had consistent work up until you became disabled, you will likely qualify.

Childhood Disability Benefit

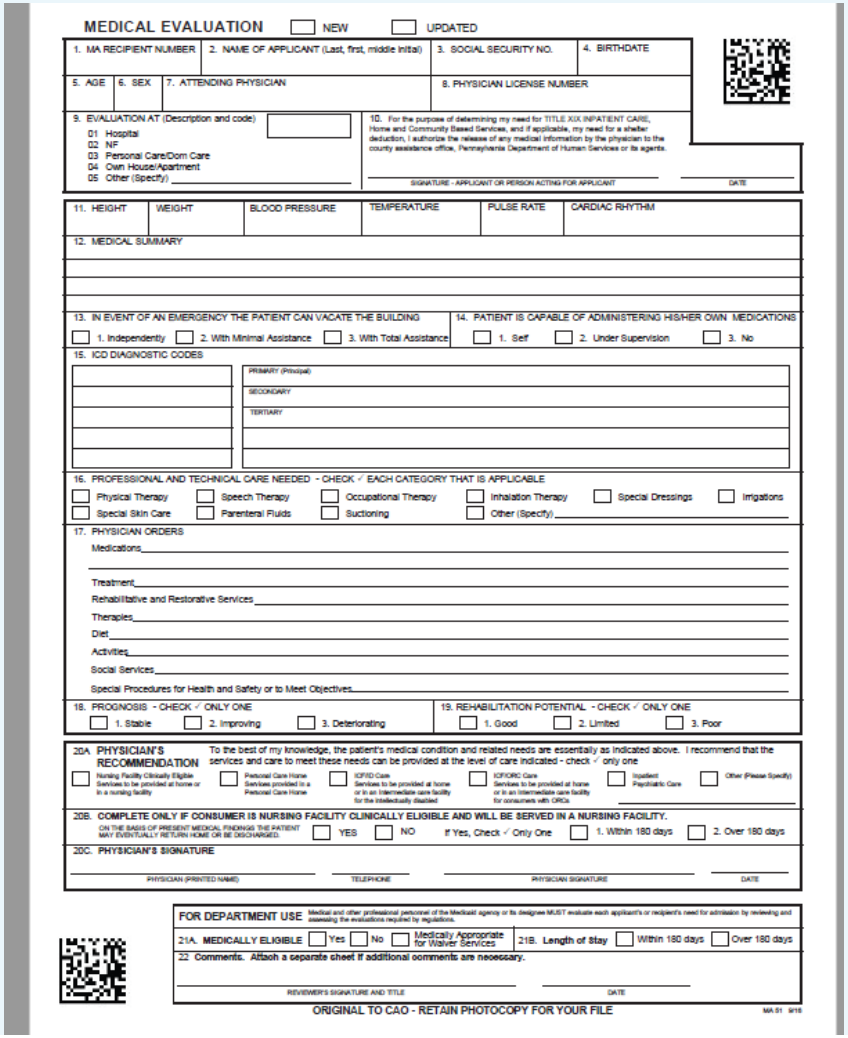
- The Childhood Disability Benefit allows a disabled adult child to receive disability insurance benefits based on the earnings record of a retired, disabled, or deceased parent.
- While the parent must have received taxable wages or self-employment income, no similar requirement applies to the disabled adult child. Rather, disabled adult children may qualify if:
  - their parent is currently collecting a Social Security benefit based on their own work record (or is deceased),
  - Their disability began prior to age 22 and prevents them from participating in "substantial gainful activity," and
  - they are 18 years or older
- Importantly, the CDB payment amount equals half of their parent's full retirement benefit, regardless of whether the parent begins collecting benefits at age 62 or delays claiming until full retirement age.
- In addition, the adult child may become eligible for Medicare 24 months after Childhood Disability Benefit payments begin.

The Role of Providers

Intersection of Medical and Social Needs

- Why is it important for doctors to understand these services?
  - In order to access services as an adult, there are many medical forms the providers need to complete.
  - We are often advocating for our patients to get supports and services in the community.
  - We see what can happen to the mental and physical health of an individual, and their family/caregivers, when appropriate services are not in place.

Sample Forms – MA 51



MEDICAL EVALUATION ☐ NEW ☐ UPDATED

1. MA RECIPIENT NUMBER	2. NAME OF APPLICANT (Last, first, middle initial)	3. SOCIAL SECURITY NO.	4. BIRTHDATE
5. AGE / 6. SEX	7. ATTENDING PHYSICIAN	8. PHYSICIAN LICENSE NUMBER	

9. EVALUATION AT (Description and code)
01 Hospital
02 NF
03 Personal Care/Dom Care
04 Own House/Apartment
05 Other (Specify) _____

10. For the purpose of determining my need for TITLE XIX INPATIENT CARE, Home and Community Based Services, and if applicable, my need for a shelter deduction, I authorize the release of any medical information by the physician to the county assistance office, Pennsylvania Department of Human Services or its agents.

SIGNATURE - APPLICANT OR PERSON ACTING FOR APPLICANT _____ DATE _____

11. HEIGHT	WEIGHT	BLOOD PRESSURE	TEMPERATURE	PULSE RATE	CARDIAC RHYTHM

12. MEDICAL SUMMARY

13. IN EVENT OF AN EMERGENCY THE PATIENT CAN VACATE THE BUILDING
☐ 1. Independently ☐ 2. With Minimal Assistance ☐ 3. With Total Assistance

14. PATIENT IS CAPABLE OF ADMINISTERING HIS/HER OWN MEDICATIONS
☐ 1. Self ☐ 2. Under Supervision ☐ 3. No

15. ICD DIAGNOSTIC CODES

	PRIMARY (Principal)
	SECONDARY
	TERTIARY

16. PROFESSIONAL AND TECHNICAL CARE NEEDED - CHECK ✓ EACH CATEGORY THAT IS APPLICABLE
☐ Physical Therapy ☐ Speech Therapy ☐ Occupational Therapy ☐ Inhalation Therapy ☐ Special Dressings ☐ Irrigations
☐ Special Skin Care ☐ Parenteral Fluids ☐ Suctioning ☐ Other (Specify) _____

17. PHYSICIAN ORDERS
Medications _____
Treatment _____
Rehabilitative and Restorative Services _____
Therapies _____
Diet _____
Activities _____
Social Services _____
Special Procedures for Health and Safety or to Meet Objectives _____

18. PROGNOSIS - CHECK ✓ ONLY ONE
☐ 1. Stable ☐ 2. Improving ☐ 3. Deteriorating

19. REHABILITATION POTENTIAL - CHECK ✓ ONLY ONE
☐ 1. Good ☐ 2. Limited ☐ 3. Poor

20A. PHYSICIAN'S RECOMMENDATION
To the best of my knowledge, the patient's medical condition and related needs are essentially as indicated above. I recommend that the services and care to meet these needs can be provided at the level of care indicated - check ✓ only one
☐ Nursing Facility Clinically Eligible Services to be provided at home or in a nursing facility
☐ Personal Care Home Services provided in a Personal Care Home
☐ ICF/ID Care Services to be provided at home or in an intermediate care facility for the intellectually disabled
☐ ICF/ORC Care Services to be provided at home or in an intermediate care facility for consumers with ORDs
☐ Inpatient Psychiatric Care
☐ Other (Please Specify) _____

20B. COMPLETE ONLY IF CONSUMER IS NURSING FACILITY CLINICALLY ELIGIBLE AND WILL BE SERVED IN A NURSING FACILITY.
ON THE BASIS OF PRESENT MEDICAL FINDINGS THE PATIENT MAY EVENTUALLY RETURN HOME OR BE DISCHARGED. ☐ YES ☐ NO If Yes, Check ✓ Only One ☐ 1. Within 180 days ☐ 2. Over 180 days

20C. PHYSICIAN'S SIGNATURE
PHYSICIAN (PRINTED NAME) _____ TELEPHONE _____ PHYSICIAN SIGNATURE _____ DATE _____

FOR DEPARTMENT USE Medical and other professional personnel of the Medicaid agency or its designee MUST evaluate each applicant's or recipient's need for admission by reviewing and assessing the evaluations required by regulations.

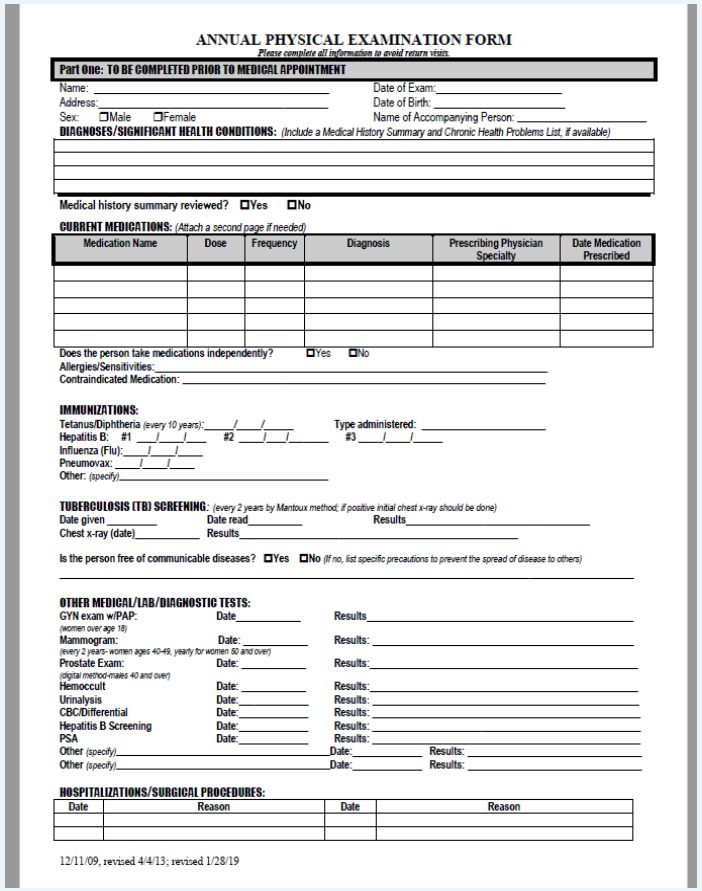
21A. MEDICALLY ELIGIBLE ☐ Yes ☐ No ☐ Medically Appropriate for Waiver Services 21B. Length of Stay ☐ Within 180 days ☐ Over 180 days

22 Comments. Attach a separate sheet if additional comments are necessary.

REVIEWER'S SIGNATURE AND TITLE _____ DATE _____

ORIGINAL TO CAO - RETAIN PHOTOCOPY FOR YOUR FILE MA 51 M16

Sample Forms – Annual Physical



ANNUAL PHYSICAL EXAMINATION FORM

Please complete all information to avoid return visits.

Part One: TO BE COMPLETED PRIOR TO MEDICAL APPOINTMENT

Name: _____ Date of Exam:_____

Address:_____ Date of Birth: _____

Sex: ☐Male ☐Female Name of Accompanying Person: _____

DIAGNOSES/SIGNIFICANT HEALTH CONDITIONS: *(Include a Medical History Summary and Chronic Health Problems List, if available)*

Medical history summary reviewed? ☐Yes ☐No

CURRENT MEDICATIONS: *(Attach a second page if needed)*

Medication Name	Dose	Frequency	Diagnosis	Prescribing Physician Specialty	Date Medication Prescribed

Does the person take medications independently? ☐Yes ☐No

Allergies/Sensitivities:_____

Contraindicated Medication: _____

IMMUNIZATIONS:

Tetanus/Diphtheria *(every 10 years)*:____/____/____ Type administered: _____

Hepatitis B: #1 ____/____/____ #2 ____/____/____ #3 ____/____/____

Influenza (Flu):____/____/____

Pneumovax: ____/____/____

Other: *(specify)*_____

TUBERCULOSIS (TB) SCREENING: *(every 2 years by Mantoux method; if positive initial chest x-ray should be done)*

Date given _____ Date read_____ Results_____

Chest x-ray (date)_____ Results_____

Is the person free of communicable diseases? ☐Yes ☐No *(If no, list specific precautions to prevent the spread of disease to others)*

_____

OTHER MEDICAL/LAB/DIAGNOSTIC TESTS:

GYN exam w/PAP: Date_____ Results_____
(women over age 18)

Mammogram: Date: _____ Results: _____
(every 2 years- women ages 40-49, yearly for women 50 and over)

Prostate Exam: Date: _____ Results: _____
(digital method-males 40 and over)

Hemoccult Date: _____ Results: _____

Urinalysis Date:_____ Results: _____

CBC/Differential Date:_____ Results: _____

Hepatitis B Screening Date:_____ Results: _____

PSA Date:_____ Results: _____

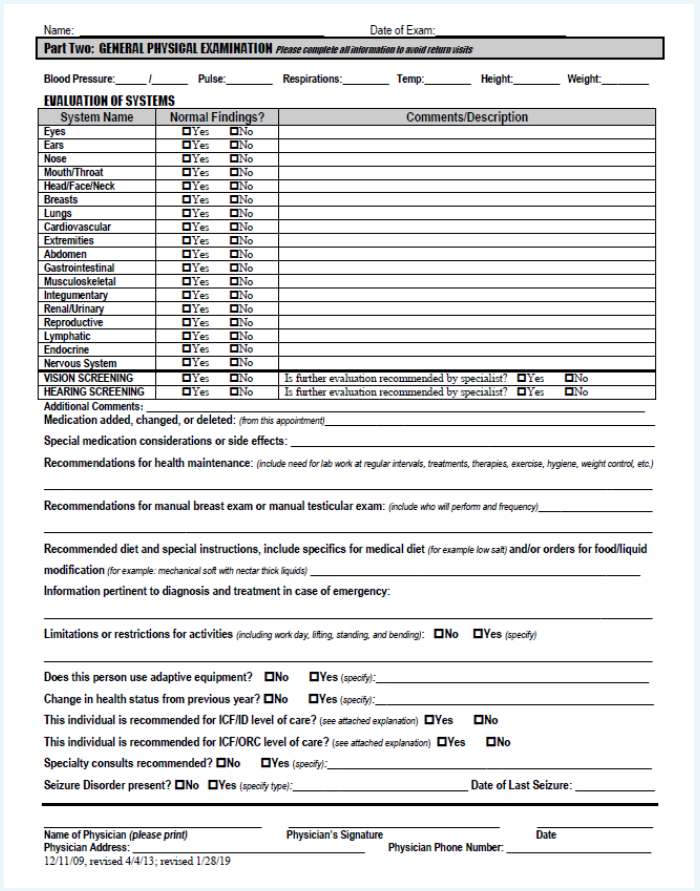
Other *(specify)*_____ Date: _____ Results: _____

Other *(specify)*_____ Date:_____ Results: _____

HOSPITALIZATIONS/SURGICAL PROCEDURES:

Date	Reason	Date	Reason

12/11/09, revised 4/4/13; revised 1/28/19



Name: _____ Date of Exam:_____

Part Two: GENERAL PHYSICAL EXAMINATION *Please complete all information to avoid return visits*

Blood Pressure:_____/_____ Pulse:_____ Respirations:_____ Temp:_____ Height:_____ Weight:_____

EVALUATION OF SYSTEMS

System Name	Normal Findings?	Comments/Description
Eyes	☐Yes ☐No	
Ears	☐Yes ☐No	
Nose	☐Yes ☐No	
Mouth/Throat	☐Yes ☐No	
Head/Face/Neck	☐Yes ☐No	
Breasts	☐Yes ☐No	
Lungs	☐Yes ☐No	
Cardiovascular	☐Yes ☐No	
Extremities	☐Yes ☐No	
Abdomen	☐Yes ☐No	
Gastrointestinal	☐Yes ☐No	
Musculoskeletal	☐Yes ☐No	
Integumentary	☐Yes ☐No	
Renal/Urinary	☐Yes ☐No	
Reproductive	☐Yes ☐No	
Lymphatic	☐Yes ☐No	
Endocrine	☐Yes ☐No	
Nervous System	☐Yes ☐No	
VISION SCREENING	☐Yes ☐No	Is further evaluation recommended by specialist? ☐Yes ☐No
HEARING SCREENING	☐Yes ☐No	Is further evaluation recommended by specialist? ☐Yes ☐No

Additional Comments: _____

Medication added, changed, or deleted: *(from this appointment)*_____

Special medication considerations or side effects: _____

Recommendations for health maintenance: *(include need for lab work at regular intervals, treatments, therapies, exercise, hygiene, weight control, etc.)*

_____

Recommendations for manual breast exam or manual testicular exam: *(include who will perform and frequency)*_____

_____

Recommended diet and special instructions, include specifics for medical diet *(for example low salt)* and/or orders for food/liquid modification *(for example: mechanical soft with nectar thick liquids)* _____

Information pertinent to diagnosis and treatment in case of emergency:

_____

Limitations or restrictions for activities *(including work day, lifting, standing, and bending)*: ☐No ☐Yes *(specify)*

_____

Does this person use adaptive equipment? ☐No ☐Yes *(specify)*:_____

Change in health status from previous year? ☐No ☐Yes *(specify)*:_____

This individual is recommended for ICF/ID level of care? *(see attached explanation)* ☐Yes ☐No

This individual is recommended for ICF/ORC level of care? *(see attached explanation)* ☐Yes ☐No

Specialty consults recommended? ☐No ☐Yes *(specify)*:_____

Seizure Disorder present? ☐No ☐Yes *(specify type)*:_____ Date of Last Seizure: _____

_____ _____ _____

Name of Physician *(please print)* Physician's Signature Date

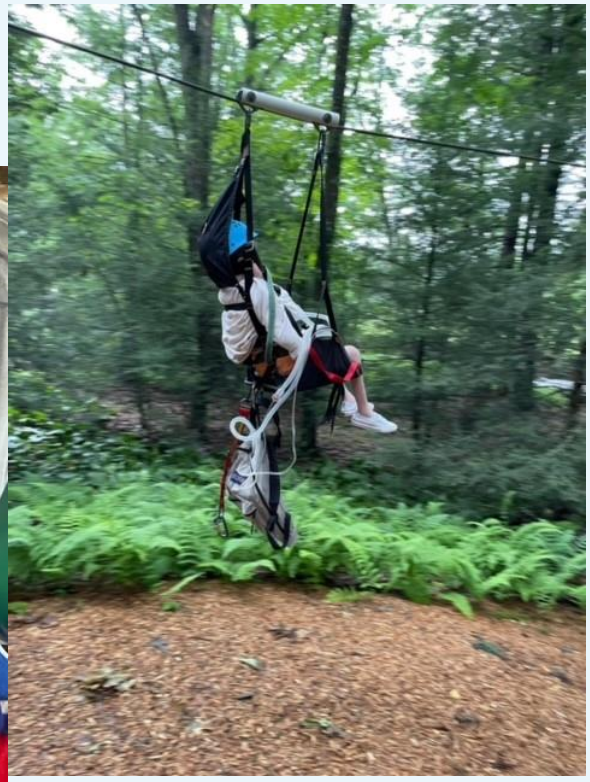
Physician Address: _____ Physician Phone Number: _____

12/11/09, revised 4/4/13; revised 1/28/19

Recreation

- Encourage participation in recreation programs and complete physical forms ASAP. We like to fill out Special Olympics physical forms at the visit, even if the person has not yet signed up. This is one less barrier to participation, since they can walk out with their form!
  - Special Olympics
  - Most Medicaid plans have fitness center membership benefits – support with accessing these
  - Camps are also available!
    - Camp PALS
    - Variety Club Camps
    - Easter Seals
    - Carousel Connections

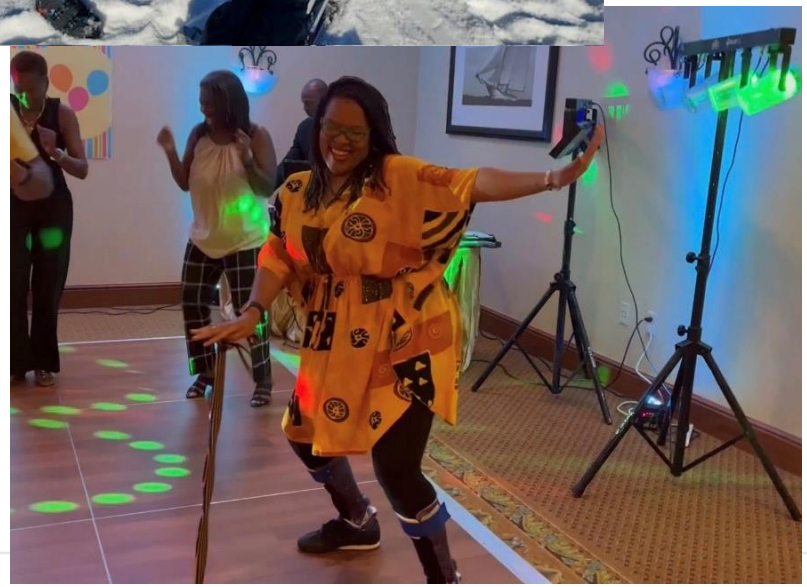
Remember when we said patients may be medically vulnerable but that doesn't mean they're fragile?...



Caroline went zip lining (vent and all) at PA Vent Camp!

https://www.paventcamp.org/

And don’t forget other recreation options, like wheelchair sports and inclusive races!



Supported Decision Making, Guardianship, and Power of Attorney

Supported Decision Making, Guardianship, and Power of Attorney – What's the difference?

- This is an incredibly important discussion during transition!
- When an individual reaches the age of 18, regardless of any functional limitations or disabilities, s/he has the legal right to make decisions on his or her own behalf.
- A great resource to refer individuals are the local Centers for Independent Living.
- The Disability Rights PA website also has printable resources and brochures, and videos to share with patients so they can learn more about their options.

Guardianship

- This is the most restrictive option and only a judge or court can grant guardianship. A Pennsylvania court may appoint a guardian after a hearing that the individual is "**incapacitated.**"
- An incapacitated person is: [A]n adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or to meet essential requirements for his physical health and safety. 20 Pa. Cons. Stat. Ann. § 5501.2

Is Guardianship the best option?

- **Why guardianships may not be the best option:**
  - It is often unnecessary (there are usually viable alternatives)
  - It is burdensome and expensive (there are legal fees and detailed annual filing requirements with accompanying filing fees for the guardian)
  - It takes away the rights of the person. (Disability Rights PA)

Alternatives to Guardianship

- Health Care Representatives
- Health Care Advance Directives or Health Care Powers of Attorney
- Supported Decision Making

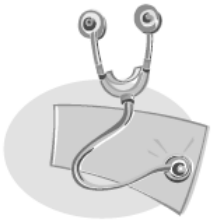
Alternatives to Guardianship Explained

- **Health Care Representatives** – Pennsylvania law (commonly called "Act 169") allows certain family members or friends to make health care decisions, when the person does not have capacity to make those decisions themselves. These decisions can include regular health care decisions (e.g., surgery, medical treatment) and decisions relating to disability services. Health Care Representatives have access to information through HIPAA.
  - Varies from state to state
- **Health Care Advance Directives or Health Care Powers of Attorney** – Those with sufficient capacity to understand documents designating others to make decisions for them can create these documents which would take effect in the event that they lose capacity to make their own decisions.
- **Supported Decision Making** – For some decisions, family and friends of a person with a disability can provide them with the support that they need to be able to make their own decisions.
  - Formally recognized in some states

Sample Forms

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 REPRESENTATIVE DECLARATION

I/we, have authority to serve as the health care representative for with whom I/we have the following relationship:

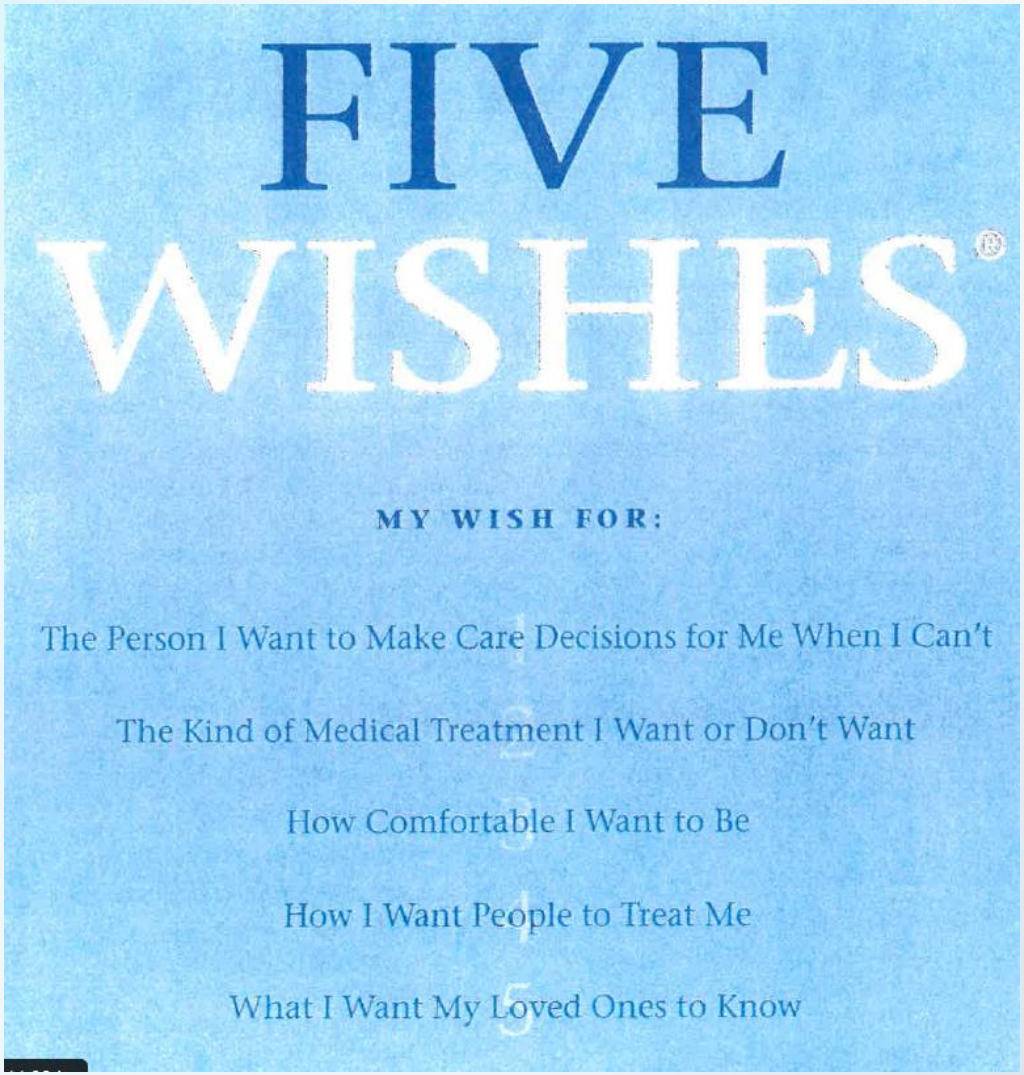
- ☐ Spouse (and there are no adult children with a person other than the spouse)
- ☐ Spouse and adult child(ren) of person other than the spouse
- ☐ Adult child(ren)
- ☐ Parent(s)
- ☐ Adult sibling(s)
- ☐ Adult grandchild(ren)
- ☐ Other adult who has knowledge of the values and preferences of

I/we certify that there are no persons in a higher class (as designated above) who are available and willing to serve as the health care representative.

I/we certify that there either are no other members of the same class or that any other members of the same class do not wish to act as health care representatives.

We certify that we understand that health care decisions can be made by a simple majority of the health care representatives and that in

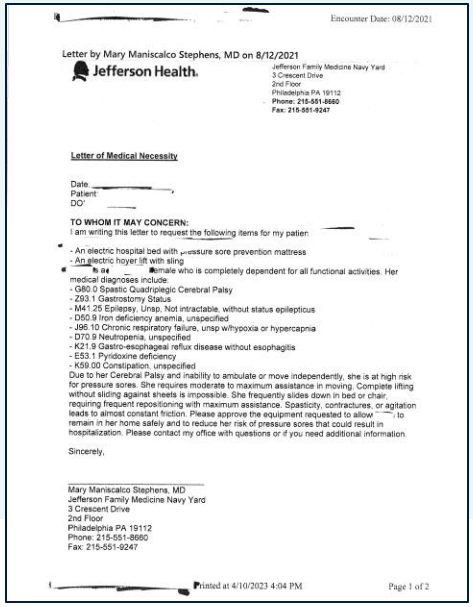
x 11.00 in


FIVE WISHES®
MY WISH FOR:
1 The Person I Want to Make Care Decisions for Me When I Can't
2 The Kind of Medical Treatment I Want or Don't Want
3 How Comfortable I Want to Be
4 How I Want People to Treat Me
5 What I Want My Loved Ones to Know

Advocacy and Resources

Advocacy

- We advocate for our patients in big and small ways every day
- We don't need to be a social worker to advocate!
- Sometimes a letter from a provider can go a long way!
- Encourage families to tap into resources in the community to assist with advocacy:
  - Vision for Equality, PA Family Network, PICC, The ARC of PA, Intermediate Units, Centers for Independent Living, PEAL Center, PA Assistive Technology Foundation, Tech OWL, PA Health Law Project, Disability Rights PA, PA Health Access Network, Education Law Center



[redacted] Encounter Date: 08/12/2021

Letter by Mary Maniscalco Stephens, MD on 8/12/2021

Jefferson Health.

Jefferson Family Medicine Navy Yard
3 Crescent Drive
2nd Floor
Philadelphia PA 19112
Phone: 215-551-8660
Fax: 215-551-9247

Letter of Medical Necessity

Date:
Patient: [redacted],
DO

TO WHOM IT MAY CONCERN:
I am writing this letter to request the following items for my patient:

- An electric hospital bed with pressure sore prevention mattress
- An electric hoyer lift with sling

[redacted] is a 04 [redacted] female who is completely dependent for all functional activities. Her medical diagnoses include:
- G80.0 Spastic Quadriplegic Cerebral Palsy
- Z93.1 Gastrostomy Status
- M41.25 Epilepsy, Unsp, Not intractable, without status epilepticus
- D50.9 Iron deficiency anemia, unspecified
- J96.10 Chronic respiratory failure, unsp w/hypoxia or hypercapnia
- D70.9 Neutropenia, unspecified
- K21.9 Gastro-esophageal reflux disease without esophagitis
- E53.1 Pyridoxine deficiency
- K59.00 Constipation, unspecified

Due to her Cerebral Palsy and inability to ambulate or move independently, she is at high risk for pressure sores. She requires moderate to maximum assistance in moving. Complete lifting without sliding against sheets is impossible. She frequently slides down in bed or chair, requiring frequent repositioning with maximum assistance. Spasticity, contractures, or agitation leads to almost constant friction. Please approve the equipment requested to allow [redacted], to remain in her home safely and to reduce her risk of pressure sores that could result in hospitalization. Please contact my office with questions or if you need additional information.

Sincerely,

Mary Maniscalco Stephens, MD
Jefferson Family Medicine Navy Yard
3 Crescent Drive
2nd Floor
Philadelphia PA 19112
Phone: 215-551-8660
Fax: 215-551-9247

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Advocating in small ways (at the patient level)

and in big ways (at the government level)!

SafeCare Program

- ***SafeCare Augmented for Family Empowerment (SAFE)***
- SAFE is a program that utilizes the SafeCare parent-training curriculum for parents of children ages 0-5 aimed at home safety and the prevention child neglect or physical abuse.
- SAFE providers work with families in their homes to improve parents' skills in three areas: (1) parent-infant/child interaction skills, (2) health care skills, and (3) home safety.
- The SAFE program is typically conducted in weekly home visits lasting from 60-90 minutes each.
- The program typically lasts 18-20 weeks for each family.
- Eligibility: Phila County resident and children ages 0-5.

Medical Home Community Team

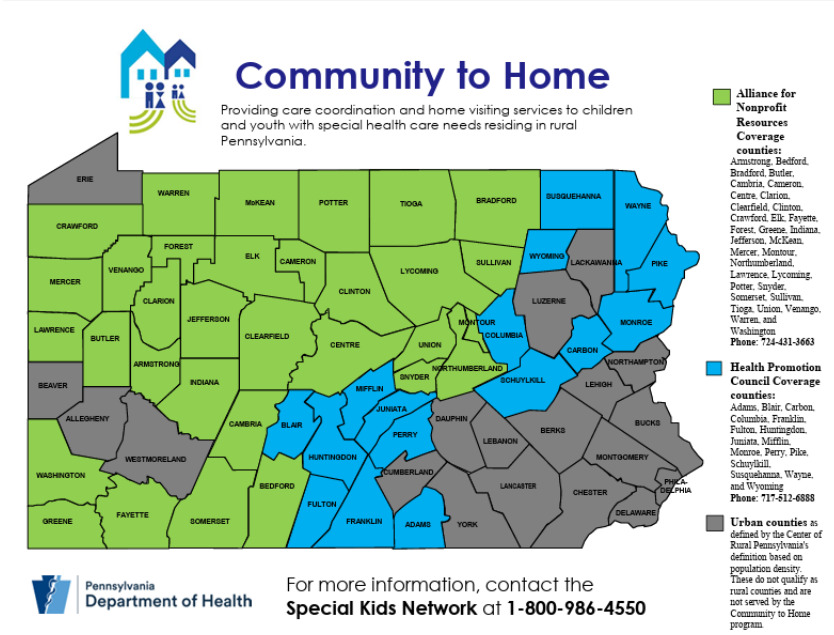
- Provide care coordination support to families living in Philadelphia with children age Birth-21
- Families need to consent for referral
- Offer social work, nursing, and community health worker support
- Often have bi-lingual staff
- Support with accessing physical and mental health care, education advocacy and community resources
- Currently they are only accepting referrals for patients with Geisinger or United Medicaid plans

Technology Assisted Children's Home Program

- Provides patient navigation services throughout Eastern Pennsylvania 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.
- TACHP’s comprehensive services include case management, home visits, care coordination, one-on-one education, and training for home health professionals and school nurses.
- Serving 31 counties, children ages 0–22, living and being cared for within their homes, who use medical technology to make up for the loss or diminishment of a bodily function or organ.

Community to Home (C2)

- **Community to Home (C2H)**
- Serves families of newly-diagnosed children in the the South Central, Northeast Central, Northwest Central, Northwest, Southwest, and Northeast regions of PA
- Focus on strengthening the capacity of caregivers and families to support positive health outcomes for complex medical needs
- Provides care coordination and caregiver education



Pennsylvania Safe Sleep Program

- **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

Families in Recovery

- **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.

Additional Resources

- **Additional resources including organizations and programs throughout the state of Pennsylvania can be found in the 'Additional Resources, Module 2' document on the project website.**

Contact Information

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215-890-0168

Jefferson

Thomas Jefferson University

Jefferson.edu/SKMC