Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services
We dedicate this manual to those who advocate for the rights of people with disabilities and especially to those who wait.
The community Mental Retardation system in Pennsylvania was established to provide services for individuals and their families. It is a system that may, at times, seem complicated and difficult to navigate. People using the system have continually pressed the need for current and accurate information. Recognizing this, I am pleased to endorse the book *Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services*.

This book is compiled by the same people who were keenly aware of this need and undertook the challenge of writing it—individuals and families. This has truly been a collaborative effort by people using and working in the system who contributed to making this book a readable, understandable and useful tool. I wish to acknowledge Disability Rights Network of Pennsylvania, Vision for Equality, Inc., the Pennsylvania Waiting List Campaign and the Pennsylvania Training Partnership for People with Disabilities and Families for their vision, tenacity and labor that made this document a reality for all Pennsylvanians.

In the following pages, you will find information to help guide you through the Mental Retardation system in the Commonwealth of Pennsylvania.

Sincerely,

Kevin T. Casey
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Information for this manual has been gathered from many sources and compiled in a readable and progressive format. You will find an introduction to the Mental Retardation system, describing how the system works and is funded. The following chapters will help you understand details about the system, including how to register, the waivers, different service models and what to do if you have a problem. We have also added two new chapters, one on Autism Services and another on transition from school to adult life. The Appendices include commonly needed forms, resources, contact information, a listing of advocacy organizations and a glossary.
ADVOCA C TIPS

• Keep a separate file just for copies of letters, reports, or other materials you give or receive from the Administrative Entity (AE)/County Program, your Supports Coordinator or provider(s).

• Keep a notebook and take notes of any conversations you have regarding any of your concerns, including the date you spoke with the person, their phone number, the person’s name, title and outcome of the discussion. You will need to verify information and always keep a paper trail.

• If the Administrative Entity (AE)/County Program or a provider promises to do something for you, make a note of the person’s name with whom you spoke or communicated, the date, what is to be done, and the date by which it is supposed to be completed.

• If you attend a meeting with your Supports Coordinator, provider or representative from your Mental Retardation office and you are unsure of being able to discuss the issue alone, take a friend, neighbor or advocate along.

• If you need to speak to someone about a dispute or problem, contact an advocacy organization in your county. There is an appeals process in place if you disagree with what is offered under the Waiver. For Base funding (which can be referred to as county or state funding), there is a local (county) process for disputes. Remember you have the right to apply for Waiver services at any time; no one can deny you that right.

• Focus on the issue. Gather and prepare your information.

• You can be assertive without being aggressive. You can be straightforward and still maintain your focus and composure on the issue. It is important to remember that you might have to return and speak with the very people you are talking with today. Choose your words carefully.

• Despite all your best efforts, please note the state must limit the number of waiver opportunities based on funds available, and there is limited state funding available to counties, so you could be placed on the Waiting List.

People have benefited and continue to benefit from advocacy and assistance of those in past generations who worked to achieve changes in the MR system. Today, new leaders must emerge to assure that supports and services will be available in the future, that they are of the highest quality and that they continue to improve. We urge you to stand up to lend your support and talents by becoming active in your county advocacy organizations. If you can’t find a group or organization to join, we will help you find or organize one.
INTRODUCTION:
OVERVIEW OF THE OFFICE OF DEVELOPMENTAL PROGRAMS – THE MENTAL RETARDATION SYSTEM

This manual was developed to help you better understand the Office of Developmental Programs’ system in Pennsylvania. Throughout this document the term “you” signifies the person receiving services or the person(s) representing him/her. As things change in your life, so do your needs and the needs of your family. You are advised to remember and work on the principle that regardless of what the system brings or advises you, you do know what is best for yourself and your own life.

Although various sources of funding are available, the major funding source for community services is through the two Waivers available to those with mental retardation age three and over. This manual guides you through the waiver process. Remember that Waivers are always subject to amendments and there is a limited amount of Waiver funding available.

The Mental Retardation system has experienced tremendous growth and change over the past several years, and we write this with the knowledge that change will be constant and should be expected. There are many documents that bring the idea of change from the Pennsylvania Office of Developmental Programs to consumers, beginning with Everyday Lives, The Multi-Year Plan, the Pennsylvania Long Term Plan to Address the Waiting List, How Can I Have the Life I Want, and Everyday Lives – Making it Happen. These documents form the basis for new ideas and offer many opportunities for people to live productive lives. As we write this manual, the Pennsylvania Department of Public Welfare, Office of Developmental Programs is in the process of transforming and streamlining practices on state and local levels which will provide a uniform and consistent method of “doing business” in the Commonwealth. While business practices are being set in place, people will continue to need information to obtain services and supports to better their lives. Contact the Pennsylvania Office of Developmental Programs for the latest updates and information regarding systems change and activities. Visit their website: www.dpw.state.pa.us.
What does the Mental Retardation System look like?

The Mental Retardation (MR) system is part of the Office of Developmental Programs in the Pennsylvania Department of Public Welfare. The State Office utilizes a Regional and County Office system to administer programs. There are 4 regions and 48 County Offices. You can find your County Office in the Blue pages of your phone book or in Appendix B of this manual. You will need to register in the county where you live in order to request services and supports. The MR system serves individuals in their communities who meet the qualifications outlined in Chapter 1 of this book.

The Office of Developmental Programs (ODP) sets policy and guidelines for the County and Regional Offices to administer and implement the MR programs. These policies are published and distributed through Bulletins issued by the State Office. You can access the Bulletins through the ODP website, http://www.dpw.state.pa.us/About/ODP/, The Partnership Website, www.TheTrainingPartnership.org, or by contacting ODP.

The Office of Developmental Programs is funded through your tax dollars. The Waiver program, which is most of the funding available in the system, is a combination of federal Medicaid monies and state monies. Base money, which can be used for Family Driven Services, is a small amount of money the County Office can spend at its discretion. It is state monies only. The chart on the next page shows how funding moves from the government to the individuals who need services. Read Chapter 6 to learn more about Autism Services, as it is not part of the county based MR system.
How does Waiver funding flow from the Federal and State Governments to the Individual?

Federal funds from the Centers for Medicare and Medicaid Services (CMS)—also known as Medical Assistance, Access, Waiver Funding, Targeted Service Management. CMS provides funding for health care including long term services and supports for people with disabilities.

Pennsylvania Department of Public Welfare (DPW) and Pennsylvania Office of Developmental Programs (ODP). Pennsylvania allocates funding through the annual legislative budgeting process. The amount of state funding appropriated is matched by the federal government through CMS.

Administrative Entities (AE)/County Programs, County Mental Health/Mental Retardation (MH/MR) Offices, AE/County Administrators. AE/Counties enroll individuals into the Waiver program and authorize services outlined in Individual Support Plans (ISPs).

Individuals – Services and Supports for Individuals and Families. Individual Support Plans (ISPs) are developed to outline services needed. An individual chooses who will provide the services and a budget is created. Once the plan is authorized by the AE/County, the providers of waiver services bill the State Treasury for payment of provided services.
How does Base funding flow from the State Government to the Individual?

Pennsylvania Department of Public Welfare (DPW) and Pennsylvania Office of Developmental Programs (ODP). Pennsylvania allocates funding through the annual legislative budgeting process.

Administrative Entities (AEs)/County Programs, County Mental Health/Mental Retardation (MH/MR) Offices, AE/County Administrators. AE/Counties enroll individuals into the Mental Retardation program, determine who will receive Base funding and authorize services outlined in Individual Support Plans (ISPs).

Individuals – Services and Supports for Individuals and Families. Individual Support Plans (ISPs) are developed to outline services needed. An individual chooses who will provide the services. Providers of Base services are paid through the County Offices. This is sometimes called Family Driven Support Services (FDSS).
Various Funding Sources

People with disabilities who need supports to live in their community can access a variety of funding streams to pay for the services they need. What funding will be available to you? How will you be able to implement your plan? There are several funding streams available in addition to what is offered by the Office of Developmental Programs.

• **Office of Vocational Rehabilitation (OVR)** – OVR provides job training and coaching which is generally time-limited. Contact your local OVR. The number can be found in the Blue pages of the phone book. Call and ask for an assessment.

• **Supplemental Security Income (SSI)** – When you reach the age of 18 you can apply as an adult and not have your parents’ income included in your application; you cannot have countable assets of more than $2,000 to be eligible. Contact your local Social Security office.

• **Medical Assistance for Workers with Disabilities (MAWD)** – MAWD is a state Medical Assistance program which encourages people to work. It allows the person to maintain a much higher income and resource level than they would have under the current program. See the DPW web site for information on MAWD (http://www.dpw.state.pa.us).

• **State Family Driven Support Service Funding (FDSS)** – This is generally a small, set amount of Base funding that allows consumers and families to choose the services or supports they need within a loosely defined menu. Request information from your Supports Coordinator.

• **State Base Funding** – This is state funding from the PA Office of Developmental Programs that is given to the counties. The funding is generally placed into “categoricals” such as: residential, day programs, group homes, Lifesharing, etc. This funding is becoming more limited as states turn to federal dollars to support community programs. Request information from your Supports Coordinator about what funds are available.

• **Person/ Family Directed Supports Waiver** – See section on P/FDS Waiver.

• **Consolidated Waiver** – See section on Consolidated Waiver.

Other funding sources may be available in various counties. Contact your Supports Coordinator or AE/County for additional information on funding.
What is the difference between Waiver Funding and FDSS?

- Family Driven Support Services are generally a very small and set amount of state funding offered by some counties to allow you to purchase services you need from a select menu on a limited basis.

- Waivers are federal and state funded programs that support larger funding needs such as day, in-home or residential supports. Services available are outlined in the Waiver chapter of this book.

State rules do not prohibit funding from both sources.

Rate Setting

ODP has moved from “program funding” of services to paying for services that are delivered. Rates were developed for all services by the Office of Developmental Programs. The rates were developed using a methodology that ODP created (based on information in provider cost reports). Some rates for services vary by provider and by location. Some rates are on a fee schedule. Other rates are vendor rates. This change increases the opportunity of choice for the individual (to choose another service provider that better meets his/her needs) but it also increases the financial risk of the providers (they can no longer rely on “program funding” to support their costs).

Through the business changes implemented by ODP, individuals continue to have a choice of willing and qualified providers. As long as the provider meets the qualifications established by the state, they can offer services in any county they choose. If the person or family locates a qualified provider who is willing to provide an approved support or service, ODP will assign a rate within the established guidelines. The ISP will then be revised to reflect the new service provider and/or services. The Administrative Entity will follow their standardized process to review and authorize the services in the ISP. The AE cannot refuse to authorize services in an ISP solely based on the individual’s choice of a provider as long as that provider is willing and qualified.

The following principles underlie rate setting:

- People and families have a choice of providers that are state qualified and have state approved rates.

- People and families have information about services, providers, rates, and consumer satisfaction.

- Providers may provide any services in any location as long as the agency is qualified and has state approved rates.
• Provider rates are adequate to enable economically and efficiently managed agencies to provide services that meet individual needs as specified in the ISP and ensure the health, safety, and welfare of the people served.

• The risks presented to providers by fee-for-service reimbursement and consumer choice are balanced by rate setting practices that recognize reasonable and necessary costs. This includes the opportunity for economically and efficiently managed providers to retain earnings or revenue.

• The policies give providers an opportunity to realize retained revenues, but do not guarantee it.

• Reimbursement is adequate and timely to sustain a network of financially stable, economically and efficiently managed providers to ensure that people and families have choices.

Provider rates are all public. You can review all available providers and all approved rates on DPW’s website in the Services and Supports Directory or by asking your Supports Coordinator to supply you with this information.

Services and Supports Directory:

https://www.hcsis.state.pa.us/hcsis-ssd/pgm/asp/prhom.asp
Registering for Mental Retardation Services

WHY DO I NEED TO REGISTER FOR MENTAL RETARDATION SERVICES?
In order for the state to plan and fund services and supports for people across Pennsylvania, it is important that the County and State Offices of Developmental Programs know you exist and that you need some type of support or service. You cannot receive Supports Coordination or funding for services and supports or be placed on the Waiting List for services unless you are registered with the County Mental Retardation system.

HOW DO I REGISTER WITH THE COUNTY MENTAL RETARDATION OFFICE?
There are several simple steps you need to take in order to register with the Mental Retardation system:

1. Begin by looking in the Appendix for the Advocacy and Agency Contacts section of this manual and find your County Program listing and phone number. The Blue Pages of your telephone book also lists your County Program under Human Services or Mental Retardation Services.
2. Call your County Program to register. They will set up an appointment with you to take your information.

WHAT WILL HAPPEN AT REGISTRATION? WHAT DO I NEED TO BRING WITH ME?
You will be asked to bring information and documents with you including:

• Social Security Card (if you have one)
• Birth Certificate

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• Proof of Address
• MA Card (if you have one – also referred to as Medicaid, Access Card, Medical Assistance)
• Psychological evaluation (if you have one)

The County Mental Retardation Program representative will ask you to sign a Release of Information form. This form authorizes the County to obtain medical records and other supporting documents. If you need assistance with finding an evaluator to do the psychological assessment, your County can help you find someone or you may be able to use documentation from your school records. Once you have registered, if you have not received written notice of eligibility in 30 days, call your County Program.

**HOW DO I QUALIFY FOR MENTAL RETARDATION SERVICES?**

The essential feature of mental retardation is significantly sub-average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. The onset must occur before the individual’s 22nd birthday.

1. Except as specified, significantly sub-average general intellectual functioning is determined by a standardized, individually administered, intelligence test in which the overall full-scale IQ score of the test and of the verbal/performance scale IQ scores are at least two standard deviations below the mean taking into consideration the standard error of measurement for the test. The full scale IQ shall be determined by the verbal and performance IQ scores (See Appendix A – DSM IV).

2. Diagnosis of mental retardation is made by using the IQ score, adaptive functioning scores, and clinical judgment when necessary. Clinical judgment is defined as reviewing the person’s test scores, social and medical history, overall functional abilities, and any related factors to make an eligibility determination. Clinical judgment is used when test results alone cannot clearly determine eligibility. The factors considered in making an eligibility determination based on clinical judgment shall be decided and documented by a licensed psychologist, a certified school psychologist, a physician, or a psychiatrist. In cases where individuals display widely disparate skills or achieve an IQ score close to 70, clinical judgment should be exercised to determine eligibility for Mental Retardation services.

3. If eligibility cannot be determined through a review of the individual’s record and social history, any necessary testing (e.g., adaptive functioning) shall be completed by a licensed psychologist, a certified school psychologist, a physician, or a psychiatrist. This includes determining the eligibility for an individual who is 22 years of age or older, has never been served in the Mental Retardation Service system, and has no prior records of testing.
Clinical judgment may be used to determine whether the age of onset of mental retardation occurred prior to the individual’s 22nd birthday.

4. Sub-average intellectual functioning is usually determined through an IQ test with a score of 70 or below. IQ test results can vary depending on the person giving the test and the person taking them. Consider obtaining an independent evaluation by a psychologist of your choice if the IQ number is borderline (70-75). Eligibility determination is appealable (as per MR Bulletin #4210-02-05).

5. You will be notified about your eligibility within 30 days of receipt of needed information. The letter should explain whether or not you are eligible, and if you are not, why not. You can appeal the eligibility decision through the process outlined in Chapter 4: Understanding Your Rights.

### Supports Coordinators: Locate, Coordinate, Monitor

Your Supports Coordinator is someone with whom you should be able to discuss your life and goals freely. When you register for Mental Retardation Services through your County Program/Administrative Entity you will be assigned a Supports Coordinator.

A Supports Coordinator is responsible for making sure all steps leading to applying for and receiving Mental Retardation services are followed. They will seek your input and assist you in developing a comprehensive Individual Support Plan (ISP) which should meet your needs. The ISP should be updated at least annually and/or when your needs change.

Your Supports Coordinator will provide ongoing oversight to make sure the goals of your ISP take place and your ISP is working for you. Your Supports Coordinator will also monitor services and supports to ensure your health and welfare. He or she will reassess your needs and update your ISP and budget as your needs change. He or she is required to assist you with identifying services. You may call your Supports Coordinator to make an appointment to review your personal records at any time.

**CHOOSING YOUR SUPPORTS COORDINATOR**

If the relationship with your Supports Coordinator is not working out, or if you feel the Supports Coordinator is not representing or helping you, or if there is a personality conflict or other issues, you have the right to contact the Supports Coordination Organization and/or Supervisor to request a change in Supports Coordinator at any time.

When you are enrolled in a waiver, you have the right to choose your Supports Coordination Organization (SCO). You can choose any willing qualified Supports Coordination Organization.
Prioritization of Urgency of Need for Services (PUNS) Form

In 1996 the Pennsylvania Office of Mental Retardation (OMR), now the Office of Developmental Programs, commissioned Temple University/Institute on Disabilities, University Center for Excellence in Developmental Disabilities, to conduct a standardized survey of people waiting for services and supports in Pennsylvania. Temple University, in concert with ODP, developed the Prioritization of Urgency of Need for Services (PUNS) process and conducted a statewide study to capture information, which allowed the Counties to report data directly to the State in a consistent manner. These data shows the number of people waiting for services in Emergency, Critical or Planning categories. This information is used by the State in planning future needs for services and informs the County and State annual budget requests to the Governor.

After you are determined eligible for services you will be assigned a Supports Coordinator. It is absolutely necessary for you, along with your Supports Coordinator, to fill out the PUNS form. **PUNS should be considered the “gateway into the system.” If you do not have a PUNS form, you will not receive services, including Waiver services.** The PUNS form is the tool AE/Counties use to determine and document your need for services and supports. Anyone waiting for new or enhanced services should have a PUNS form.

**PUNS DETAILS**

The PUNS is a critical planning tool used for planning and funding your services and supports. You will be placed in one of three categories depending on need:

1. **Emergency** - Person needs services immediately, within the next six (6) months
2. **Critical** - Person needs services more than six (6) months but less than two (2) years from now
3. **Planning** - Person needs services more than two (2) but less than five (5) years from now.

People in the Emergency category should receive priority in services and funding.

The PUNS form further describes the services you receive and need. This includes the services you are receiving, what those services are, and what services you need now or will need in the future.

**PUNS HELP**

- The PUNS should be completed during a face-to-face meeting with your Supports Coordinator.

- After you sign the form at the meeting, you will receive a copy of the Home and Community Services Information System (HCSIS) PUNS form in the mail in approximately 3 weeks, along with a letter describing your rights and what you should do if you disagree with the
information on the PUNS form. This is the information that is entered into the State database.

- All updates require your signature.
- PUNS forms should be updated yearly or whenever you experience a life-changing situation such as a graduation or serious illness of a caregiver.
- Be honest when completing the PUNS form. We often put our best foot forward when talking about our lives and tend to diminish or lessen the problem we might be experiencing. Your honesty in describing your needs can make a difference in which category you are assigned and how soon you might be able to receive services or supports.
- There are waiting lists. Funding and services may not be available even though you fall into the Emergency or Critical category of the PUNS.
- No one who is in the Consolidated Waiver should have a PUNS form listing them in the Emergency category. If you receive the Consolidated Waiver, your assessed needs must be met.
- You need to know the PUNS category you are in. Remember, people in the Emergency category are generally the top priority when funding becomes available.
- Refer to the FORMS section of this book for a sample of the HCSIS PUNS form.
- If you have questions about the PUNS form or process, you can call your Regional Office or the ODP Customer Service Line at 888-565-9435.

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**SIS™ and PA Plus**

The Office of Developmental Programs (ODP), together with stakeholders from across the state, chose the Supports Intensity Scale (SIS) to be the standardized needs assessment for Pennsylvania. The SIS was developed by the American Association on Intellectual and Developmental Disabilities (AAIDD) in 2004 and is used in 10 states and several foreign countries. It was chosen so that you will get the same needs assessment no matter where you live. The SIS focuses on what supports you need to have an everyday life, rather than on what you cannot do. You and your team of respondents, people you choose who know you well and can give good information about your support needs, answer questions about supports needed to help you live independently. Topics covered include home and community living, lifelong learning, and employment, to name a few.

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The PA Plus is an additional set of nine questions designed by stakeholders to gather information about areas that the SIS does not cover. Some areas addressed include vision, hearing, safety and assistive technology. Both the SIS and the PA Plus assessments are administered by a professional assessor during the same meeting.

The SIS and PA Plus assessments are used along with other sources of information to determine support needs and will help you and your team during the Individual Support Plan (ISP) planning process. These assessments do not determine your budget or funding in any way.

**ASCEND**
ODP wanted assessments to be conflict-free so an independent contractor was selected to administer assessments. Ascend Management Innovations (Ascend) from Tennessee has lots of health care experience and administers various assessments in other states. Ascend hired assessors who live in Pennsylvania, and the assessors complete assessments in all areas of the Commonwealth.

Assessors must have a four-year degree and three years of experience of direct work with individuals with intellectual and developmental disabilities. They are required to complete ODP and AAIDD training before they are approved to begin completing assessments. Their training continues after they are approved to maintain their assessor status.

**WHO WILL RECEIVE A SIS ASSESSMENT?**
Everyone aged 16-72 enrolled in the Consolidated or the Person/Family Directed Supports Waivers will receive a SIS and PA Plus assessment. The assessments will also be given to people on the Waiting List identified to receive Waiver funding. The assessments are typically done at least every three years, but can be given more frequently if there is a dramatic change in your support needs.

**WHAT IS THE PROCESS?**
Assessments are scheduled prior to the ISP review date so you and your team have the information gleaned from the SIS and PA Plus to help in your planning. You will be contacted via telephone by a scheduler from Ascend to determine who you would like to be present at the assessment (your respondents) and to discuss possible dates, times, and locations.

The information from the assessment is entered into HCSIS by Ascend staff, and after two weeks it is available to your Supports Coordinator (SC). Your SC will then share the results with you and anyone else that you choose as part of your ISP planning process.
Chapter 1: Accessing the MR System

The Individual Support Plan (ISP)

An Individual Support Plan (ISP) is a planning document that should be developed by you, the people who support you, and members of your planning team. Your ISP should be all about you and written in a way that lets others know what support, if any, you need, at home and in the community.

Your ISP should include outcomes and be written in a way that promotes action by you and by those who support you. Ask those who know you well to help in the planning process which includes developing your plan. They may see your needs differently and it will be helpful for you to know their perspective. You can ask your Supports Coordinator, job coach, friends, relatives, advocate or anyone else who knows and cares about you to help develop your plan. If the ISP is implemented properly, it can help you attain your goals and dreams.

The ISP is extremely important because it allows you to have control and make choices about important activities in your life. Your ISP will include Outcome Statements to outline what you and your team agree to do to make sure you have a safe, healthy and happy life. The services included in your ISP must be related to an identified need. Services included in your authorized ISP must be provided.

The ISP must be updated at least once per year and at any time necessary to reflect changes in your life and priorities. The monitoring requirements followed by your Supports Coordinator ensure that your ISP will be followed as written and also that your interests and priorities remain in the center of your life. If these services are not provided, or if at any time you have a dispute about Waiver services you can request Dispute Resolution and/or Fair Hearing (see Chapter 4).

Helpful Information Needed to Prepare for Your ISP

- Write down the important milestones of your life.
- Don’t be afraid to share this information with your team before the ISP meeting.
- Think ahead about what a productive and fulfilling life means to you and what you need to make it happen. Example: You want to work. Will you need a job coach? Transportation?
- Is your team prepared to help you with the goals listed on the ISP by doing what they said they would do?
- What happens at your ISP Meeting?

At least once a year, your team will come together to review, discuss, add to or change your ISP to reflect what you need in your life, what is important to you and what you hope and dream your life will look like. Most importantly, your team will make commitments so that your plan will actually happen.
WHAT INFORMATION SHOULD GO INTO YOUR COMPREHENSIVE ISP?
The ISP form is made up of six main sections: Individual Profile, Medical, Health and Safety, Functional Information, Financial, and Services and Supports. This form becomes the record of your needs. Your team will also receive a copy of this form to refer to whenever necessary. Your plan should be written so that anyone who reads it will know who you are, what is important to you, what you need, and how to support you in your life.

INDIVIDUAL SUPPORT PLAN (ISP) – QUESTIONS
The following questions will help you and your team begin thinking of important information about your preferences used in developing your ISP. It may be helpful for you and those who support you to make a list of these questions before your annual ISP meeting. Make some time to go over each question and jot down answers to bring with you to the ISP meeting. Everyone should include their first name on their list of questions and answers so the Supports Coordinator can easily identify who provided what information on your behalf. You can also provide information on your behalf by developing your own list or with someone’s help.

What do people like and admire about you?
• Be sure to gather multiple viewpoints. With your family, friends, and people who know you the best discuss your positive traits, characteristics, ways of interacting, accomplishments, strengths, etc.

What makes sense?
• When responding to this question, you and those who support you should write down what works best for you right now in your life, what needs to stay the same, be maintained or enhanced in your life right now.

What does not make sense?
• When responding to this question, you and those who support you should write down what’s not working for you in your life right now, what needs to change, and what must be different.

What does someone need to know to support you?
• Be sure to talk with the people who know you best to outline your traits, habits, coping strategies, preferences for interaction and communication, relationships, types of activities, approaches or reminders that have been helpful to you. This information can assist others in supporting you.

What are the activities you would like to participate in or explore?
• Consider job/work opportunities, community connections/programs, learning new skills or hobbies, and things that you would find enjoyable—connections with other people, helping others (as a community volunteer), etc. What activities are important to you?
• Make a list that describes what needs to stay the same in your life and/or changes that would be important for the team to address. Consider relationships, job situation, living arrangement, health and safety, etc. In the listing decide and prioritize what you absolutely need and strongly desire.

**What makes sense? What works for you?**
• Ask those who know you best. Their opinions will help you and your team reach agreement on the best supports to help you attain an Everyday Life.

**What are your medical needs?**
• A list of your medical history, diagnoses, and needs is required to complete your ISP. Part of the Waiver requirements is an annual medical evaluation. This is not optional.
• Have your prescribing doctors’ and dentist’s names, addresses, and phone numbers; a list of all medications and dosages; a list of any allergies; and the dates of any health evaluations. Examples: eye doctor, hearing test, specialist visits, etc.

**HEALTH AND SAFETY**
Health and safety risks are also part of the ISP. Information gathered during your SIS assessment is valuable and should be incorporated into your ISP. Health and safety questions describe your ability to give yourself medicine, note if you need protection from heat sources (examples: stove, grill), and your needs in the following areas:

**Fire Safety**
• Your ability to react during a fire.
• Have you received fire safety training?
• This information should include the level of supervision and assistance you need to evacuate any place you spend a lot of time.

**Traffic Safety**
• Your traffic safety awareness.
• This information should include the level of supervision required.

**Cooking/Appliance Use**
• Your ability to use cooking and kitchen appliances.
• This information should include the level of supervision required.

**Outdoor Appliances**
• Your ability to use outdoor appliances. (examples: gas grill, lawn mower, weed whacker).
• This information should include the level of supervision required.
Safety Precautions
• Your ability to understand safety precautions and instructions, (such as wearing seat belts, using bike helmets and other safety equipment when necessary), including handling or storage of poisonous substances.

Knowledge of Self-Identifying Information
• Your ability to give self-identifying information, such as your name, address, and phone number as well as your ability to responsibly carry this information.

Stranger Awareness
• Your ability to interact with strangers.
• This information should include the level of supervision required.

Meals/Eating
• Your ability to eat during mealtime.
• This information should include the level of supervision required during meals, information from dietary and nutritional appraisals, and any information about adaptive equipment/assistive technology.

Home Supervision
• Can you be left alone at home? How long?
• Describe any plans to increase time alone. Always indicate if intensive supervision is required at home. (Intensive supervision is defined as one-to-one supervision within arms length.)

Day Supervision
• Some examples of day activities are volunteering, working, and attending training centers, etc.
• What is the level of supervision you need during day activities? Can you be left alone during day activities? How long?
• Describe any plans to increase time alone. Always indicate if intensive supervision is required. (Intensive supervision is defined as one-to-one supervision within arms length.)

Community Supervision
• Some examples of community activities are eating in a restaurant, taking public transportation, etc.
• Can you be left alone during community activities? How long? Describe any plans to increase time alone.
• Always indicate if intensive supervision is required. (Intensive supervision is defined as one-to-one supervision within arms length.)

**Behavioral Support Plan**

• Certain licensed settings require a Social, Emotional and Environmental Support Plan.
• Do you have a Behavioral Support Plan in place? Yes or No? If yes, is it restrictive?
• Does it limit your movement, activity or function?
• Does your Behavioral Support Plan interfere with your ability to acquire positive reinforcement, result in the loss of objects or valued activities, or require a particular behavior that you would not normally do if you could choose?

**FUNCTIONAL INFORMATION**

**Physical Development**
Describe your skills and needs that include gross (large muscle) and fine (small muscle) motor, vision and hearing, as well as gait assessment, transfer and positioning needs.

**Adaptive/Self Help**
Describe your skills and needs that include development in areas such as eating, drinking, toileting, bathing, etc. Also include skills and adaptations needed while showering and bathing. Examples: seating, rails, supervision, etc.

**Cognitive Development**
Describe your skills and needs about how you learn and process information, think, remember, reason, problem-solve, make decisions, manage money, etc.

**Communication**
Describe your skills and needs that address expressive/receptive language and assistive technology skills and needs if appropriate.

**Social/Emotional Information**
Describe your skills and needs related to the process of learning to control your emotions, having empathy and respect for others, and having the ability to initiate and maintain social contacts.

**Educational/Vocational Information**
Describe your educational and vocational needs. Are you a student? If yes, what school do you attend? What grade are you in now? Are you in a training program? Are you connected with the Office of Vocational Rehabilitation (OVR)?

**Employment Information**
Do you have a job? Do you want a job? What are your job related goals?
Financial Information
You will need to provide your social security number and information about any Social Security and SSI benefits. You will need to provide other information on benefits you receive such as Veteran’s benefits, railroad retirement fund benefits, civil service annuity benefits, etc. You should also have your personal resource information available. Personal resources include: life insurance, trust/guardianship, burial reserve, burial plot, pre-paid funeral arrangements, checking and savings account information, and information about property you may own.

Other Information: Understanding Communication
Communication can be verbal or nonverbal, overt or subtle actions or gestures that you use to tell others what you need, want, like or dislike, and what is important to you. Communicative actions help others understand you and respond in a helpful way. This is important knowledge of people who know you well, so that those you will meet in the future will understand your communication style. If you use assistive technology, it is important that your skill and needs be described. This is critical information to be included in your Individual Support Plan.

Outcomes Summary: Outcome Action
Outcome statements represent what is currently important to you and also what needs to be changed. The outcome should describe how it will make a difference in your life. Outcomes must build on information gathered during the ISP process and reflect a shared commitment to action.

Outcomes supported by MR funding must be written within the context of your health and safety and/or assuring your continued life within the community. Outcomes that address other priorities should be represented and supported with other community, family or non-traditional supports.

Your team uses the outcomes in your ISP to determine which services or supports are needed and funded. Services and supports are directly tied to one or more of the outcomes and should promote the outcomes.

Developing an ISP and Outcome Statement
• When you and your team develop the outcome statement, use the phrases “in order to” or “so that.” These phrases link the needed service to the outcomes.
  ➢ Example: John will need a job coach to help him on the job “so that” he will be able to maintain his employment, increase his independence, and enhance his social interactions.
• Planning is everything. If we carefully approach planning our life as we do other special events, such as a party or graduation, we will be successful. Think about writing a detailed plan. For life changing events, writing a detailed plan will result in success.
• Your completed plan should be a life story. Should an emergency occur, a person could pick up your plan and after reading it, understand you and your needs.

The final and possibly most important step in the ISP process is the ACCEPTANCE and APPROVAL of the plan by you.
“How Do I Get Services” Checklist

Registration Process

_____ I’ve contacted my AE/County and told them I want to register for services and supports.
_____ I’ve agreed on a time and place for the registration meeting.
_____ I’ve gathered the important documents I will need to bring for the registration meeting. (Example: Social Security Card, Birth Certificate, Proof of Address, MA Card (if I have one), Health Insurance Information, Psychological Evaluation).
_____ I will be notified in writing within 30 days.
_____ When I am found eligible for services, I will be assigned a Supports Coordinator.

Prioritization of Urgency of Need for Services (PUNS) Form Process

_____ I have filled out a PUNS form with my Supports Coordinator and I know my category of need (Emergency, Critical or Planning).
_____ My Supports Coordinator explained what services are available. (Example: Waivers, FDSS, EPSDT, OVR)
_____ I have applied for Family Driven Support Services (FDSS or FSS, if available in your county) and / or other funding sources, such as Early Periodic Screening, Diagnosis, and Treatment (EPSDT) or Office of Vocational Rehabilitation (OVR) services. Your Supports Coordinator can assist you to apply.

Waiver Registration Process

_____ I have applied for an MA Card through the County Assistance Office (CAO).
_____ I will be notified in writing within 45 days if I am eligible for MA.
_____ I have filled out the Service Delivery Preference Form (DP457) and chose Home and Community Based Services.
_____ I went over a description of services needed with my Supports Coordinator.
_____ I received a letter from the AE/County that states whether or not I am likely to be eligible for Waiver services.
_____ When waiver capacity and funding becomes available, I will receive a letter stating that I will have a formal assessment to verify eligibility for the Waiver and a list of additional documents I might need to submit (may include: medical evaluation, IQ test, adaptive behavior scale, proof of an MR diagnosis prior to age 22).
_____ I received a copy of the Certification of Need for ICF/MR Level of Care (DP250) form that was filled out by the Qualified Mental Retardation Professional (QMRP) stating that I meet the criteria for Waiver.
_____ I completed an Individual Support Plan (ISP) in conjunction with my Supports Coordinator.
_____ A budget for my Individual Support Plan (ISP) was established/approved and authorized and I received a copy.
How to Choose Home and Community-Based Waiver Services

WHAT IS A WAIVER?

Waiver is the shortened term for Medicaid Home and Community-Based Waiver Programs. Waivers provide the majority of funding for the Pennsylvania mental retardation supports and services which help people live in their homes and communities rather than in institutions. In 1981, Congress amended the Medical Assistance program to permit states to shift their Medical Assistance resources from institutional settings (like Intermediate Care Facilities for Persons with Mental Retardation [ICF/MR] programs) to more integrated community-based settings. Congress gave states flexibility to create programs known as “home and community-based waivers.” Home and Community-Based Waivers (which must be approved by the federal government) allow states to:

- Specify the types of services that may be provided in home and community settings;
- Cap the number of people who may receive services under the waiver;
- Limit the services to people with specific eligibility;
- Cap the amount of spending that any individual’s services may cost.

The name Waiver comes from the fact that the federal government waives Medicaid rules for institutional care so the state can use the same funds to provide supports and services for people in the community. The state must make specific assurances to the federal government when requesting a Medicaid Waiver.

Federal and state funds are combined in Medicaid Waivers. The federal and state shares are not the same in each state and they are adjusted each year. In Pennsylvania, it is generally somewhere around a 54/46 split.

The majority of Mental Retardation services in Pennsylvania are funded by Medical Assistance programs (also called MA or Medicaid), a combined state and federal program for persons who have limited income. Based on criteria of eligibility, there are two types of Medical Assistance funding available to support Mental Retardation services. They are:
• **Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR):** ICF/MR funding supports state-operated institutions and private ICFs/MR. ICF/MR services are an entitlement for eligible persons and cannot be capped or subject to waiting lists.

• **Home and Community-Based Waivers:** Waivers generally support persons in their own homes, in their family home, in a family living home (Lifesharing), or in group living arrangements (Community Homes). Pennsylvania has received federal approval to operate two waivers that serve Pennsylvanians with mental retardation. These two waivers are known as the (1) Consolidated Waiver and (2) Person/Family Directed Supports Waiver.

You will need to sign a Home and Community-Based or ICF/MR Application and Service Delivery Preference form (DP 457) indicating a choice of Home and Community-Based Services or ICF/MR Services. Anyone who is eligible for Mental Retardation services and enrolled in Medical Assistance (MA Card) must be provided with service delivery preference. If you are enrolled in MR services through your county, but don’t have your MA Card, the county can help you apply through the County Assistance Office. You must have an MA Card to receive Waiver services. Signing up for the Waiver is only part of the process that will help you obtain services and will in no way deny you the right to live at home. Once you complete this paperwork, you will receive a letter stating whether you are likely to meet the eligibility for Waiver and if funding is available. If there is no funding, you should complete a PUNS form with your Supports Coordinator to identify what services you need and when you need them. You will be placed on the waiting list. When funding is available, you will go through the formal eligibility determination for the Waiver.

**Eligibility Details**

There are three fundamental criteria that must be met in order for an individual to qualify for an ICF/MR level of care. To meet the ICF/MR level of care criteria the individual must:

• Have a diagnosis of mental retardation
• Require active treatment
• Be recommended for an ICF/MR level of care based on a medical evaluation

ICF/MR level of care is indicated only when all three of the criteria are met. The “active treatment” refers to your written plan which shows you benefiting from a professionally developed and supervised program of activities, experiences or therapies that are necessary for assisting you to function at your greatest physical, intellectual, social, or vocational potential.
Level of Care: MR Diagnosis

A determination of a diagnosis of mental retardation must meet all of the following three criteria:

1. A licensed Psychologist, Certified School Psychologist, or a Psychiatrist certifies that the individual has significantly sub-average intellectual functioning that is documented by either:
   a. Performance that is more than two standard deviations below the mean of a standardized general intelligence test;
   OR
   b. Performance that is slightly above two standard deviations below the mean of a standardized intelligence test during a period when the individual manifests impairments of adaptive behavior.

AND

2. A Qualified Mental Retardation Professional (QMRP) certifies that the individual has impairments of adaptive behavior based on the results of standardized assessments of adaptive functioning that show that the individual has either:
   a. Significant limitations in meeting the standards of maturation, learning, individual independence, and/or social responsibility for his or her age and cultural group
   OR
   b. Substantial functional limitation in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self direction, capacity for independent living, or economic self-sufficiency.

AND

3. There is documentation to substantiate that the individual has had these conditions manifest during the developmental period which is between birth and the individual's 22nd birthday.

Level of Care: Criteria for Active Treatment

An individual shall meet the criteria for needing active treatment only when a Qualified Mental Retardation Professional (QMRP), based on review of the individual's social and psychological history, determines that the individual will benefit from a professionally developed and supervised program of activities, experiences, or therapies that are necessary for assisting the individual to function at his or her greatest physical, intellectual, social, or vocational potential. For individuals for whom no further positive growth is demonstrated, the criteria shall be met by the QMRP’s certification that a program of active treatment is needed to prevent regression or loss of current functional status.
The QMRP’s certification of need for services shall be based on a review of the individual’s social, psychological, and medical history. This review shall consist of:

1. A review of notes, observations and reports from educational facilities, human service agencies, hospitals and other reliable sources. The review shall be done in conjunction with the individual’s support team.

2. A review of a current medical evaluation which is completed by a licensed physician, physician’s assistant, or nurse practitioner. The medical evaluation can be the medical evaluation approved by the Department of Public Welfare (Form MA 51) or an examination completed by a licensed physician, physician’s assistant, or nurse practitioner. To be considered current, the medical evaluation must occur within the 365-day period prior to the QMRP certification, detail the individual’s current medical condition, and indicate that the individual is recommended for an ICF/MR level of care.

If questions remain regarding the ICF/MR level of care verification after the review of the available records and history, the QMRP may choose to request a face-to-face meeting with the individual, family, or surrogate.

Level of Care: Medical Evaluation

Individuals meeting the criteria for an ICF/MR level of care must have a medical evaluation completed by a licensed physician not more than 60 days prior to admission to an ICF/MR or before authorization for payment. For Waiver enrollment, the medical evaluation can be the medical evaluation approved by the Department (Form MA 51), or an examination that is completed by a licensed physician, physician’s assistant, or nurse practitioner. To be considered current, the medical evaluation must occur within the 365-day period prior to the QMRP certification, detail the individual’s current medical condition, and indicate that the individual is recommended for an ICF/MR level of care.

Each year a person must be recertified by a licensed physician for ICF/MR level of care to remain eligible for services.

Certification of the individual’s mental retardation and need for active treatment, as well as subsequent re-certification information can be found in two Mental Retardation Bulletins “Need for ICF/MR Level of Care Mental Retardation Bulletin 00-02-13” and “Individual Eligibility for Medicaid Waiver Services Bulletin 00-08-04” available at the Department of Public Welfare web site, http://www.dpw.state.pa.us. All individuals enrolled in a Waiver require annual re-determination of need for an ICF/MR level of care to continue to qualify for services funded under the Waivers. The AE/County Program is responsible to recertify need for an ICF/MR level of care based on the evaluation and certification of a QMRP. The first re-determination of need for an ICF/MR level of care is to be made within 365 days of the individual's initial
determination, and subsequent re-determinations are made within 365 days of the individual’s previous re-determination.

**QUALIFIED MENTAL RETARDATION PROFESSIONAL (QMRP) DETERMINATION**

Individuals 18 years of age and older who are determined likely for an ICF/MR level of care and do not have a surrogate may choose between Waiver-funded home and community-based and ICF/MR services. Every accommodation available to the individual (for example, communication devices, interpreters, or physical assistance as needed) must be used to afford the opportunity to the individual to communicate a preference. This communication will sometimes be non-verbal. The QMRP will make a determination after an appropriate face-to-face assessment in accordance with applicable professional standards whether the individual is able to communicate the individual’s preferences non-verbally and, if so, what that preference is.

**ROLE OF THE SURROGATE**

If the individual has been determined incompetent to make the service delivery preference decision, a surrogate will be chosen as set forth below. The following hierarchy of order will be followed to choose the surrogate for individuals 18 years of age or older:

1. A health care agent designated by the individual.
2. A guardian appointed by the court and given authority to make health care decisions either specifically or by being made plenary guardian (20 Pa. C.S. Chapter 55).
3. In the absence of the above, any of the following, in descending order of priority, may agree to be the surrogate.
   a. The spouse (unless an action for divorce is pending).
   b. An adult child.
   c. A parent.
   d. An adult brother or sister.
   e. An adult grandchild.
   f. An adult who has knowledge of the individual’s preferences and values, including, but not limited to, religious and moral beliefs.

**WAIVER DETAILS**

There are two Medicaid Waivers administered by the Pennsylvania Office of Developmental Programs for Pennsylvanians with mental retardation. Approximately 95% of all funding for the Pennsylvania Mental Retardation system is now Waiver funding. Waiver is a Medicaid funding source for many of the supports and services available through the Mental Retardation system.

The State determines the number of people they will serve in the Waiver program and includes this number in a waiver application or amendment to the Centers for Medicare and Medicaid
Services (CMS). This number then becomes part of the Waiver application or amendment approved by CMS. After the determined number of people receiving services has been reached, a waiting list may be established.

- Two Medicaid Waivers are currently available through the Mental Retardation system:
  1. Consolidated Waiver
  2. Person/Family Directed Supports (P/FDS) Waiver

Your AE/County and County Assistance Office determine your eligibility for all Waiver programs in accordance with state policy and Bulletins.

**IN THE CONSOLIDATED AND P/FDS WAIVERS:**
- The Administrative Entity (AE)/County Program gives preference to people with the greatest need for services. The AE/Counties determine your need for services using the PUNS assessment.
- You have a right to choose among service providers, including the choice to use a Financial Management Services (FMS) agent to direct your own supports. Administrative Entities/Counties may not limit an individual’s ability to choose among qualified, willing Waiver providers. You can switch providers if you are dissatisfied at any time.
- You can apply for the Waiver by talking to your Supports Coordinator or apply on your own by filling out a Waiver Application/Service Delivery Preference form (DP 457) and submitting it to the designated person at the County Office.
- You can only be enrolled in one Waiver at a time.
- If the services you need are greater than what is offered in the P/FDS Waiver, you should complete a PUNS form and request enrollment into the Consolidated Waiver.
- You do NOT have to live in a group home in order to be eligible for the Consolidated Waiver.
- Both Waivers are offered and designed to help you or your family member live a life in the community in their own or natural home.
- Once you are approved for the Waiver you have the right to access, attend and receive funding for programs, supports, and services anywhere in the State.

**THE MAIN DIFFERENCE BETWEEN THE PERSON/FAMILY DIRECTED SUPPORT WAIVER AND THE CONSOLIDATED WAIVER:**
- Under the Consolidated Waiver the plan must be appropriate to meet the person’s needs and there is no individual cap. However, the average statewide cost cannot exceed the cost of serving a similar person in an ICF/MR, and there are some limits for certain services.
- The Person/Family Directed Support Waiver is currently capped at $26,000 per person per year, however, this amount excludes Waiver-funded Supports Coordination services. Please
note that this amount is subject to change through a Waiver amendment. No one can receive Waiver services under the Person/Family Directed Support Waiver that cost more than a total of $26,000 (with the exception of Supports Coordination services).

- Additionally, the Consolidated Waiver includes Licensed Residential Habilitation, which is not currently available in the Person/Family Directed Support Waiver.

It is extremely important that you are aware of the specific Waiver in which you are presently enrolled. If you are not sure of the Waiver in which you are enrolled, contact your Supports Coordinator.

**MEDICAL ASSISTANCE ELIGIBILITY**

The determination of Medical Assistance eligibility should not be confused with the process the County Assistance Office (CAO) undergoes in determining financial eligibility for Waiver funded services. Generally, if you are receiving SSI, you are Medical Assistance eligible.

To be eligible for a Waiver there are financial eligibility requirements. People are financially eligible for the Consolidated or P/FDS Waivers if they receive Medical Assistance. The financial limit for Waiver participants is 300% of the SSI federal benefit. Effective January 2010, this amount is $2,022 per month.

### Waiver Capacity Commitment

Effective July 1, 2009, the Office of Developmental Programs (ODP) changed the way Administrative Entities (AE) manage the enrollment of individuals into the Consolidated and Person/Family Directed Service (P/FDS) Waivers as a result of the findings from the most recent CMS review of the Waivers. Now, ODP sends the AE a Waiver Capacity Commitment letter. In that commitment letter the AE is told how many individuals they may serve on any given day in either the Consolidated or P/FDS waiver. The AE may not exceed the Waiver Capacity, but as individuals are dis-enrolled from the waiver, for whatever reason, the AE has been instructed to fill that Waiver Capacity with the individual who is determined to have the most emergency need according to the Prioritization of Urgency of Need for Services (PUNS) form.

This process replaced the Individual Emergency Status Form (IESF) process previously used by the AE to request more money from ODP to serve an individual in an emergency situation. With the new process, if an unanticipated emergency situation arises for an individual in the community and the AE is not serving the maximum number of individuals according to the Waiver Capacity Commitment Letter, the AE may enroll the individual into the Waiver following normal procedures. If the AE is serving the maximum number of individuals, they can contact ODP to request an increase in their maximum number of individuals to be served which will be considered for approval only if the following criteria are met:
• An individual is at immediate risk to his/her health and welfare due to illness or death of a caregiver.
• An individual living independently experiences a sudden loss of their home (i.e. due to fire or natural disaster).
• An individual loses the care of a relative or caregiver, without advance warning or planning.

An unanticipated emergency must meet one of the criteria listed above and must create imminent risk of institutionalization within 24 hours, substantial harm to self or others, if the individual does not immediately receive services. To be considered by ODP, the AE must have no other resources available.

Throughout the year, adjustments may be made to the AE’s Waiver Capacity Commitment due to changes in the anticipated enrollment needs, county-to-county relocations, special initiatives, budget shortfalls and/or waiting list expansion.

**Waiver Service Definitions: Services available to individuals in the Person/Family Directed Supports Waiver and the Consolidated Waiver**

**WAIVER-FUNDED SUPPORTS COORDINATION**

The following definition and procedure codes for Supports Coordination apply only to those Supports Coordination services funded through the Consolidated and P/FDS Waivers.

Supports Coordination is a critical service that involves the primary functions of locating, coordinating, and monitoring needed services and supports for Waiver participants.

**Locating**

Locating services and supports consists of assistance to the participant and his or her family in linking, arranging for, and obtaining services specified in an Individual Support Plan (ISP), including needed medical, social, habilitation, education, or other needed community services. Activities included under the locating function include all of the following, in addition to the documentation of activities:

• Participate in the ODP standardized needs assessment **process** to inform development of the ISP, including any necessary ISP updates;
• Facilitate the completion of additional assessments, based on the participant’s unique strengths and needs, for planning purposes and ISP development in order to address all areas of needs and the participant’s strengths and preferences;
• Coordinate the development of the ISP;
• Assist the participant in identifying people to serve as part of the ISP team, and offer support to invite other people who may contribute valuable information during the planning process;

• Assist the participant and his or her family in identifying and choosing willing and qualified providers;

• Inform participants about unpaid, informal, generic, and specialized services and supports that are necessary to address the identified needs of the participant and to achieve the outcomes specified in the ISP;

• Provide information to participants on fair hearing rights and assist with fair hearing requests when needed and upon request; and

• Assist participants in gaining access to needed services and entitlements, and to exercise civil rights.

**Coordinating**

Coordinating consists of development and ongoing management of the ISP in cooperation with the participant, his or her family, members of the ISP team, and providers of service. Activities included under the coordinating function include all of the following, in addition to the documentation of activities:

• Use a person centered planning approach and a team process to develop the participant’s ISP to meet the participant’s needs in the least restrictive manner possible;

• Use information from the ODP standardized needs assessment, as well as any additional assessments completed based on the unique needs of the participant, to develop the ISP to address all of the participant’s needs;

• Periodic review of the ISP with the participant, including update of the ISP at least annually and whenever a participant’s needs change;

• Periodic review of the standardized needs assessment through a face-to-face visit with the participant, at least annually or more frequently based on changes in a participant’s needs, to ensure the assessment is current;

• Coordinate support planning with providers of service to ensure consistency of services;

• Coordinate with other program areas as necessary to ensure all areas of the participant’s needs are addressed;

• Contact with family, friends, and other community members to coordinate the participant’s natural support network;

• Facilitate the resolution of barriers to service delivery and civil rights; and

• Disseminate information and support to participants and others who are responsible for planning and implementation of services.
**Monitoring**

Monitoring consists of ongoing contact with the participant and his/her family and oversight to ensure services are implemented as per the participant’s plan. Activities included under the monitoring function include all of the following, in addition to the documentation of activities:

- Monitor the health and welfare of participants through regular contacts at the minimum frequency outlined in Appendix D-2-a of the Consolidated or P/FDS Waiver;
- Monitor ISP implementation through monitoring visits with the participant, at the minimum frequency outlined in Appendix D-2-a of the Consolidated or P/FDS Waiver;
- Visit with the participant’s family, when applicable, and providers of service for monitoring of health and welfare and support plan implementation;
- Respond to and assess emergency situations and incidents and assure that appropriate actions are taken to protect the health and welfare of participants;
- Evaluate participant progress;
- Monitor participant and/or family satisfaction with services;
- Arrange for modifications in services and service delivery as necessary to address the needs of the participant, and modify the ISP accordingly;
- Ensure that services are appropriately documented in HCSIS on the ISP;
- Work with the authorizing entity regarding the authorization of services;
- Communicate the authorization status to ISP team members, as appropriate;
- Validate that service objectives and outcomes are consistent with the participant’s needs and desired outcomes;
- Advocate for continuity of services, system flexibility and integration, proper utilization of facilities and resources, accessibility, and participant rights; and
- Participate in activities related to Independent Monitoring for Quality, such as obtaining consent to participate from the participant, preparing survey information, and follow up activities (“closing the loop”).

**Information and Assistance**

In addition to locating, coordinating, and monitoring, Supports Coordination also includes providing information and assistance in order to help participants decide whether to select Participant Directed Services. For participants who opt to direct their own services, the Supports Coordinator is responsible to provide some assistance. Activities include all of the following, in addition to the documentation of activities:

- Provide participants with information on Participant Direction, including the potential benefits and risks associated with directing services, during the planning process and upon request;
• Assist with the transition to the Participant Direction Service delivery model if the participant is interested in this model, and ensure continuity of services during transition;
• Assist the participant in designating a surrogate as desired, as outlined in Appendix E-1-f of the Consolidated or P/FDS Waiver; and
• Provide support to participants who are directing their services, such as assistance with managing participant-directed services specified in the ISP.

**Excluded Activities**
The following activities are **excluded** from Supports Coordination as a billable Waiver service:
• Outreach that occurs before an individual is enrolled in the Waiver;
• Intake for purposes of determining whether an individual has mental retardation and qualifies for Medical Assistance;
• Direct Prevention Services, which are used to reduce the probability of the occurrence of mental retardation resulting from social, emotional, intellectual, or biological disorders;
• General information to participants, families, and the public that is not on behalf of a waiver participant;
• Travel expenses of the Supports Coordinator may not be billed as a discrete unit of service;
• Services otherwise available under Medicaid and Early Intervention;
• Services that constitute the administration of foster care programs;
• Services that constitute the administration of another non-medical program such as child welfare or child protective services, parole and probation functions, legal services, public guardianship, and special education;
• Direct delivery of medical, educational, social, or other services;
• Delivery of medical treatment and other specialized services including physical or psychological examinations or evaluations;
• The actual cost of the direct services other than Supports Coordination that the Supports Coordinator links, arranges, or obtains on behalf of the participant;
• Transportation provided to participants to gain access to medical appointments or direct Waiver services other than Supports Coordination;
• Representative payee functions;
• Conducting Medicaid eligibility certification or recertification, intake processing, Medicaid pre-admission screening for inpatient care, prior authorization for Medicaid services, and Medicaid outreach (methods to inform or persuade individuals to enter into care through the Medicaid system); and
• Assistance in locating and/or coordinating burial or other services for a deceased participant.
Supports Coordination services may not duplicate other direct Waiver services. Support Coordination Organizations must be conflict-free entities. **Waiver-funded Supports Coordination services may only be provided to Consolidated and P/FDS participants.**

**RESIDENTIAL HOME AND COMMUNITY HABILITATION – LICENSED HOMES**

*****CONSOLIDATED WAIVER ONLY*****

These are direct (face-to-face) and indirect services provided in provider-owned, rented/leased, or operated (i.e. licensed and unlicensed Family Living homes) licensed residential settings. Services are provided to protect the health and welfare of individuals by assisting them in acquiring, retaining, and improving self-help, socialization, and adaptive skills. Services consist of support in the general areas of self-care, communication, fine and gross motor skills, mobility, therapeutic activities, personal adjustment, relationship development, socialization, and use of community resources.

Providers of unlicensed and licensed Residential Habilitation Services are responsible for the full range of transportation services needed by the individuals they serve to participate in services and activities specified in their ISPs. This includes transportation to and from day habilitation and employment services. Transportation is provided as a component of the Residential Habilitation Service, and is, therefore, reflected in the rate. The responsibility for the provision of transportation by the residential habilitation provider stops once the individual has been safely transported to another service setting identified in the approved and authorized ISP. The residential habilitation provider’s responsibility resumes when the other service ends and the individual requires a ride back home.

**Residential Habilitation**

Licensed Residential Habilitation services are only available through the Consolidated Waiver and Base funds. Services consist of support to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings. Residential habilitation is provided for 24 hours a day based on the need of the individual receiving services.

**Family Living Homes**

Family Living Homes are somewhat different than other licensed homes as these settings provide for lifesharing arrangements. Individuals live in host family homes and are encouraged to become contributing members of the family unit. Family living arrangements are chosen by individuals and families in conjunction with host families and in accordance with the individual’s needs. Licensed Family Living Homes are limited to homes in which one or two individuals with mental retardation who are not family members or relatives of family members are living. The primary family living provider is eligible for substitute care to provide relief for the provider,
Residential Enhanced Staffing
Residential Enhanced Staffing may be used in Residential Habilitation settings and involves three possible components, which are treated as add-ons to the traditional Residential Habilitation service:

- Residential Habilitation by licensed nurses (licensed and unlicensed settings)
- Supplemental Habilitation staffing, as part of the licensed Residential Habilitation service, to meet temporary medical or behavioral needs of the individual. **This Consolidated Waiver service must be prior authorized by ODP.**
- Additional Individualized Staffing, as part of the licensed Residential Habilitation service, to meet the long-term individualized staffing needs of the individual when those needs can no longer be met as part of the usual Residential Habilitation staffing pattern. **This Consolidated Waiver service must be prior authorized by ODP.**

Supplemental Habilitation staffing is used to temporarily supplement the licensed Residential Habilitation service (that is licensed under 55 Pa.Code Chapters 3800, 5310, 6400, 6500) to meet the short-term (12 consecutive calendar months or less) unique behavioral or medical needs of the person. For example, this service could be used when an individual is discharged from the hospital with additional needs, and requires a temporary addition of 2 hours of one-to-one staffing each day. **This Consolidated Waiver service must be prior authorized by ODP.**

Additional Individualized Staffing is used to supplement the licensed Residential Habilitation service (that is licensed under 55 Pa. Code Chapters 3800, 5310, 6400, 6500) to meet an individual's long-term behavioral or medical needs as well as other life-changing needs that require Additional Individualized Staffing. Other life-changing needs may include the following situations:

- Individual retires from day program activities or from competitive employment.
- Court-ordered supervision.
- Supervision required as a result of a life-changing circumstance.

This service differs from the Supplemental Habilitation service in that the individual's need for staffing is long-term and the individual's staffing needs can no longer be met as part of the usual Residential Habilitation staffing pattern. Long-term, as it is used in the Additional Individualized Staffing service definition, is defined as a staffing need for one individual that will be required for more than 12 consecutive calendar months until the individual no longer
require the additional staffing. This is an individualized service that may not be used to adjust a provider’s rate. **This Consolidated Waiver service must be prior authorized by ODP.**

**Unlicensed Residential Habilitation (Consolidated and P/FDS Waivers)**

These are direct and indirect services provided to protect the health and welfare of individuals by assisting them in acquiring, retaining, and improving self-help, socialization, and adaptive skills. Services consist of support in the general areas of self-care, communication, fine and gross motor skills, mobility, therapeutic activities, personal adjustment, relationship development, socialization, and use of community resources. The primary family living provider is eligible for substitute care to provide relief, based on the needs of the individual and the primary lifesharer.

This service also includes transportation services that are necessary to enable the individual to access services and resources outlined in the ISP, including transportation to and from day or employment services. The Unlicensed Residential provider is not responsible for transportation to community activities for which another provider is responsible. The Unlicensed Residential provider is not responsible for transportation when the individual is at a Day Habilitation, Prevocational, or Transitional Work service.

Unlicensed Residential Habilitation may be provided in provider-owned, rented, leased homes and family living homes:

- Under 55 Pa. Code §6400.3(f)(7) (for Community Homes), which excludes community homes that serve three or fewer individuals with mental retardation 18 years of age or older who need a yearly average of 30 hours or less direct staff contact per week per home; or
- Under 55 Pa. Code §6500.3(f)(5) (for Family Living Homes), which excludes family living homes that provide room and board for one or two individuals with mental retardation 18 years of age or older who need a yearly average of 30 hours or less direct training and assistance per week per home from the agency, county mental retardation program, or the family.

The 30 hours per week per home is a weekly average in a year of the total services of all individuals who reside in the provider owned, rented, leased or operated home.

All waiver-funded homes must be integrated and dispersed in the community in noncontiguous locations and may not be located on campus settings.

**Home and Community Habilitation (Unlicensed)**

This is a direct service (face-to-face) provided in home and community settings to assist individuals in acquiring, maintaining, and improving self-help, domestic, socialization, and adaptive skills necessary to reside successfully in home and community-based settings. Services consist of support in the general areas of self-care, communication, fine and gross
motor skills, mobility, therapeutic activities\(^1\), personal adjustment, relationship development, socialization, and use of community resources. Habilitation may be provided up to 24 hours a day based on the needs of the individual, to protect the individual’s health and welfare.

Through the provision of this service individuals learn, maintain, or improve skills through their participation in a variety of everyday life activities. These activities must be necessary for individuals to live in the community, to live more independently, or to be more productive and participatory in community life.

When services are provided by agency-based providers, this service also includes transportation services necessary to enable the individual to participate in the home and community habilitation service, in accordance with the individual’s ISP.

Home and Community Habilitation (Unlicensed) may not be provided in licensed service settings, and is a totally separate service from the licensed Residential Habilitation Service; for residential services, see Licensed and Unlicensed Residential Habilitation Services. When an individual in a licensed Residential Habilitation Service is not interested in attending a traditional licensed day program but wants to participate in an integrated community activity with a Home and Community Habilitation (Unlicensed) provider, the Home and Community Habilitation (Unlicensed) service may be rendered to meet this need during the time period usually reserved for participation in a traditional licensed day program. The Home and Community Habilitation (Unlicensed) service will be provided:

- By a willing and qualified Home and Community Habilitation (Unlicensed) services provider.
- Outside of the licensed residential habilitation setting (that is, not on the grounds of a residential habilitation setting licensed through 55 Pa. Code Chapters 3800, 5310, 6400, or 6500).
- To accomplish activities and outcomes as determined by the individual’s ISP team.

Home and Community Habilitation (Unlicensed) is not to be used to provide camp services. Camp 24-Hour and Camp 15-Minutes services for individuals enrolled in the Waivers may only be provided under Waiver-Funded Respite Services. Camp services funded as a Base service must be authorized as Recreation/Leisure Time Activities as per 55 Pa. Code Chapter 6350, Family Resource Services.

The Home and Community Habilitation service may also be used to provide staff assistance to support individuals in the following ways:

\(^1\) Therapeutic activities are those activities designed to help a person acquire, maintain, or improve a skill necessary to live successfully in the home and community.
1. Habilitation provided in home and family settings that are not subject to Department licensing or approval, when the provider of habilitation meets established requirements/qualifications.

2. Support that enables the individual to access and use community resources such as instruction in using transportation, translator and communication assistance, and services to assist the individual in shopping and other necessary activities of community life.

3. Support that assists the individual in developing or maintaining financial stability and security, such as plans for achieving self-support; general banking; personal and estate planning; balancing accounts; preparing income taxes; and recordkeeping.

4. Support that enables an individual to participate in community projects, associations, groups, and functions, such as support that assists an individual to participate in a volunteer association or a community work project.

5. Support that enables an individual to visit with friends and family in the community.

6. Support that enables an individual to participate in public and private boards, advisory groups, and commissions.

7. Support that enables the individual to exercise rights as a citizen, such as assistance in exercising civic responsibilities.

8. Support provided during overnight hours when the individual needs the habilitation service to protect their health and welfare. If the individual only needs supervision during overnight hours, the appropriate service is Companion Services.

There may be multiple outcomes which are supported by this service with different providers or through self-directed opportunities within an individual’s ISP as long as there is documented need with associated outcomes and there are no conflicts or overlaps with regard to day and time of service. For example, an individual may receive Home and Community Habilitation from 6:00 PM to 9:00 PM, Monday through Friday to satisfy an outcome related to participating in activities or utilizing resources that are community-based. The same individual could also be provided with a Home and Community Habilitation service that occurs in the home, scheduled Monday through Friday from 11:30 AM to 12:30 PM to support the individual in achieving an outcome of independent meal preparation.

This service may not overlap with or duplicate Companion Services. Home and Community Habilitation (Unlicensed) and Companion Services have a combined maximum limit of 24 hours (96 15-minute units) per participant per calendar day. This service may be provided at the same time as Therapy, Nursing, and Behavioral Support Services. All providers should coordinate schedules and service delivery to ensure consistency in services to individuals across service settings.
Licensed Day Habilitation, Prevocational Services, Transitional Work Services, and Home and Community Habilitation (unlicensed) services may not overlap in terms of day and time.

**COMPANION SERVICES**

Companion services are provided to individuals living in private residences for the limited purposes of providing supervision and necessary care and minimal assistance that is focused solely on the health and safety of the adult individual (18 and older) with mental retardation. This service is not available to people who are residing in Unlicensed or Licensed Residential Habilitation settings. Companion services are used in lieu of habilitation services to protect the health and welfare of the individual when a habilitative outcome is not appropriate or feasible (i.e. when the individual is not learning, enhancing, or maintaining a skill). This service can be used for asleep hours when only supervision or non-medical or non-habilitative care is needed to protect the safety of the individual with mental retardation. For example, a companion can be used during overnight hours for an individual who lives on their own but does not have the ability to safely evacuate in the event of an emergency. This service can also be used to supervise individuals during socialization or non-habilitative activities when necessary to ensure the individual’s safety. Companions may supervise and provide necessary care and minimal assistance with daily living activities, including grooming, health care, household care, meal preparation and planning, and socialization. This service may not be provided at the same time as any other direct service.

Transportation included in the rate for Companion Services may NOT be duplicated through the inclusion of the transportation service on an individual’s ISP. This means that when Companion Services are provided and transportation is integral to the delivery of that service, transportation funding is included in the rate for that service. In these cases transportation cannot be authorized as a separate service on the ISP or duplicated through the inclusion of a separate transportation service authorized on an individual’s ISP to meet the transportation components of these services.

Companion services paid through FMS for self-directing Waiver participants do not include transportation as part of the rate paid for the service. For self-directing Waiver participants, discrete transportation services may be included on the ISP to meet the transportation needs of the Companion service.

This service is not available for people residing in agency-owned, rented/leased, or operated (i.e. licensed and unlicensed Family Living homes) homes. Companion and Home and Community Habilitation (Unlicensed) Services have a combined maximum limit of 24 hours (96 15-minute units) per participant per calendar day.
**RESpite SERVICES**

Respite services are direct services that are provided to supervise/support individuals on a short-term basis due to the absence or need for relief of those persons normally providing care. Respite services do not cover the care provided to a minor child when the primary caregiver or legally responsible individual is absent due to work. Services are limited to individuals residing in private homes (their own home or the home of a relative or friend).

Individuals can receive two categories of Respite services: 24-hour Respite and 15-minute Respite.

- **24-hour Respite** is provided for periods of more than 16 hours, and is billed using a day unit. Each day unit is defined as a period of time that is more than 16 hours to 24 hours in length.
  - For In-Home Respite, the day unit is calculated from the time the respite worker arrives at the individual’s home to begin providing relief to the normal caregiver until the time the respite worker stops providing relief to the normal caregiver. If an individual attends another service while receiving In-Home Respite, 24 Hours, the time the individual is attending the other service is not calculated towards the number of units that the respite provider renders. In summary, if the individual receives In-Home Respite services from the respite provider more than 16 hours within the 24 hour time period, this is considered a day of respite.
  - For Out-of-Home Respite, 24-Hour or Respite Camp, 24-Hour the the day unit is calculated from the time the individual arrives at the respite setting until the individual returns to their normal living arrangement. If an individual attends another service while receiving respite services at a Respite Out-of Home facility and the individual is expected to return to the respite facility after the other service ends, the time the individual is attending the other service is not calculated towards the number of units that the respite provider renders. In summary, if the individual receives Out-of Home Respite services from the respite provider more than 16 hours within the 24 hour time period, this is considered a day of respite.
  - 24-hour respite is limited to 30 day units per individual per fiscal year, except when extended by the ODP Regional Office based on individual needs.

- **15-Minute Respite** is provided for periods of 16 hours or less within a 24-hour period, and is billed using a 15-minute unit.
  - 15-minute respite is limited to 480 (15 minute) units per individual per fiscal year, except when extended by the ODP Regional Office based on individual needs.

The provision of Respite Services does not prohibit supporting individuals’ participation in activities in the community during the period of respite. The provision of 24-hour respite services does not prohibit individuals’ participation in day and employment services.
Federal and State financial participation through the Waivers is limited to:

Respite Services provided for individuals residing in the individual’s unlicensed home or the unlicensed home of relative, friend, or other family member.

Respite services that are provided by providers or individuals who meet the qualification requirements outlined in Appendix C of the Consolidated and P/FDS Waivers. This requirement extends to all types of respite, including Respite – Camp.

Room and board costs associated with respite care services that are provided in a facility approved (licensed or accredited) by the State that is not a private residence.

The following Respite Service limits apply to all Waiver-funded Respite, which includes Respite Camp Services:

- Thirty (30) day units of 24-hour respite per individual in a period of one fiscal year except when extended by the ODP Regional Office. This requirement is applicable to In-Home Respite – 24 Hours; Respite – Unlicensed Out of Home, 24 Hours; Respite – Licensed Out of Home, 24 Hours; and Respite – Camp, 24 Hours.

- 480 (15 minute) units of 15-minute respite per individual in a period of one fiscal year except when extended by the ODP Regional Office. This requirement is applicable to In-Home Respite – 15 Minutes; Respite – Unlicensed Out of Home, 15 Minutes; Respite – Licensed Out of Home, 15 Minutes; and Respite – Camp, 15 minutes.

Respite services may only be provided in the following location(s):

- Individual's private home or place of residence located in Pennsylvania.
- Licensed or approved foster family home or family living home (55 Pa.Code Chapter 6500) located in Pennsylvania.
- Waiver funded licensed community homes (55 Pa.Code Chapter 6400) may provide respite in a vacant bed within the established approved program capacity without ODP approval.

On a case-by-case basis, ODP may approve the provision of respite services above a site location's approved program capacity for emergency situations only. Written approval to provide respite services beyond the approved program capacity must be obtained from the ODP Regional Waiver Capacity Manager before the provision of respite occurs.

In no circumstance will this emergency approval result in more than 4 individuals receiving services from the Community Home provider in a calendar day, regardless of the site location's licensed capacity.

This respite policy for Community Homes does not alter or change the Respite in a Larger Setting policy that provides an exception process to request respite services be provided in a large non-Waiver-funded setting in which no approved program capacity is established.
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- Licensed Community Residential Rehabilitation Services for the Mentally Ill Home (55 Pa.Code Chapter 5310)
- Unlicensed home of a provider or individual meeting the qualifications.
- Other community settings such as summer camp where the setting meets applicable state or local codes and the provider of service meets the provider qualifications established by the Department. This includes respite provided in Pennsylvania, or anywhere in the 50 United States, the District of Columbia, or the American territories during temporary travel. It also includes Respite Services provided on an ongoing basis by qualified agency providers located in or individual providers residing in Pennsylvania as well as agency or individual providers based in states contiguous to Pennsylvania.

This service is not available for people residing in agency-owned, rented/leased, or operated (i.e. licensed and unlicensed Family Living homes) homes. These services may not be provided in personal care boarding homes, nursing homes, hospitals, or ICFs/MR. Respite may be provided in hospitals and nursing homes through Base funding under Base-Funded Respite Care.

**HOME AND COMMUNITY HABILITATION (UNLICENSED), RESPITE OR COMPANION SERVICES? HOW DO I KNOW WHICH ONE?**

The decision to utilize Home and Community Habilitation (Unlicensed), Respite, or Companion Services is determined by the individual’s assessed need. An individual may use one or all of these services as per his or her assessed needs.

If the necessary service is directly related to the individual working towards an outcome that is skill based, then the correct service to choose is Home and Community Habilitation (Unlicensed).

If the adult individual requires supervision and necessary care and minimal assistance to meet their health and welfare needs, then the correct service to choose is Companion Services. Companion Services are used when there is no habilitative outcome for the individual associated with the delivery of the service. The individual is not learning, enhancing, or maintaining a skill. The outcome related to Companion services only relates to assistance to and supervision of the individual to ensure health and welfare.

Respite Services are chosen as the correct service when those persons normally and primarily responsible to provide care to the individual are absent or need relief from providing care on a short-term basis.
**HOMEMAKER/CHORE SERVICES**

Homemaker services consist of services to enable the individual or the family with whom the individual resides to maintain their private residence. This service can only be provided when a household member is temporarily absent or unable to manage the home, or when no landlord or provider agency staff is responsible to perform the homemaker activities. Homemaker Services must be provided by a qualified homemaker and may include cleaning and laundry, meal preparation, and other general household care. Chore services consist of services needed to maintain the home in a clean, sanitary, and safe condition. This service can only be provided in the following situations:

- Neither the individual, nor anyone else in the household, is capable of performing and financially providing for the function; and
- No other relative, caregiver, landlord, community/volunteer agency, or third party payer is capable of or responsible for their provision.

Chore services consist of heavy household activities such as washing floors, windows, and walls; tacking down loose rugs and tiles; moving heavy items of furniture in order to provide safe access and egress; ice, snow, and/or leaf removal; and yard maintenance. In the case of rental property, the responsibility of the landlord, pursuant to the lease agreement, will be examined prior to any authorization of service. Maintenance in the form of upkeep and improvements to the individual’s residence is excluded from federal financial participation.

This service is limited to 40 hours per individual per fiscal year when the individual and everyone else in the household are temporarily unable to physically perform and financially provide for the homemaker/chore functions. A person is considered temporarily unable when the condition or situation that prevents them from physically performing and financially providing for the homemaker/chore functions is expected to improve. There is no limit when the individual lives independently or with family member(s) or friend(s) who are permanently unable to physically perform and financially provide for the homemaker/chore functions. A person is considered permanently unable when the condition or situation that prevents them from physically performing and financially providing for the homemaker/chore functions is not expected to improve. The ISP team is responsible to determine whether a person is temporarily or permanently unable to physically perform and financially provide for the homemaker/chore functions. The ISP team’s determination should be documented in the ‘Outcome Summary’ section of the ISP.

This service is not available for people residing in agency-owned, rented/leased, or operated (i.e. licensed and unlicensed Family Living homes) homes.
DAY SERVICES
ODP requires that individuals are provided with flexibility in the utilization of day services (to include Unlicensed Home and Community Habilitation utilized for community-based day services, Licensed Day services, Prevocational services, Supported Employment, and Transitional Work services). This flexibility may include the use of different day service options to meet an individual’s needs (ex. Supported Employment three days per calendar week combined with Transitional Work services two days per calendar week), as well as timely revisions to ISPs to accommodate changes in day service needs. The goal is to provide individuals with unique day service combinations to meet individuals’ needs, and help individuals to achieve employment and volunteering outcomes. The flexibility provides a safety net often expressed by families as needed in the event an individual is not successful in maintaining employment.

The following services have a combined total limitation of 40 hours (160 15-minute units) per individual per calendar week based on a 52-week year: Licensed Day Habilitation, Prevocational services, Transitional Work services, and Supported Employment (both the direct and indirect portions of the service).

Licensed Day Habilitation, Prevocational services, Transitional Work services and Home and Community Habilitation (Unlicensed) services may not overlap in terms of day and time.

LICENSED DAY SERVICES
This is a direct service (face-to-face) that must meet the regulatory requirements of 55 Pa.Code Chapter 2380 (Adult Training Facilities) or 6 Pa.Code Chapter 11 (Older Adult Daily Living Centers). Services consist of supervision, training, and support in general areas of self-care, communication, community participation, and socialization. Areas of emphasis include: therapeutic activities, fine and gross motor development, mobility, personal adjustment, use of community resources, and relationship development. The service also includes transportation that is an integral component of the service, for example, transportation to a community activity. The Licensed Day provider is not, however, responsible for transportation to and from an individual’s home, unless the provider is designated as the transportation provider in the individual’s ISP. In this case, the transportation service must be billed as a discrete service.

PREVOCATIONAL SERVICES
This is a direct service (face-to-face) that must meet the regulatory requirements of 55 Pa.Code Chapter 2390 (Vocational Facilities). This service is provided to assist individuals in developing skills necessary for placement in a higher level vocational program and ultimately into competitive employment.

The service may be provided as:
• **Facility-based employment.** Facility-based employment focuses on the development of competitive worker traits through the use of work as the primary training method.

• **Occupational training.** Occupational training is used to teach skills for a specific occupation in the competitive labor market, and includes personal and work adjustment training that is designed to develop appropriate worker traits and teach the understanding of the expectations of a work environment.

• **Vocational evaluation.** Vocational evaluation involves the use of planned activities, systematic observation, and testing to accomplish a formal assessment of the individual, including identification of service needs, potential for employment, and identification of employment objectives.

• **Vocational facility.** A vocational facility is a premise where habilitative employment or employment training is provided to one or more individuals with disabilities.

• **Work activities center.** A work activities center is a program focusing on behavioral and/or therapeutic techniques to enable individuals to attain sufficient vocational, personal, social, independent living skills to progress to a higher level vocational program.

The service also includes transportation that is an integral component of the service, for example, transportation to a work activity. The Licensed Prevocational provider is not, however, responsible for transportation to and from an individual’s home, unless the provider is designated as the transportation provided in the individual’s ISP. In this case, the transportation service must be billed as a discrete service.

**Handicapped employment as defined in Title 55, Chapter 2390 may not be funded through the waivers.** This service may not be funded through either waiver or through Base allocation if it is available to individuals through a program funded under Section 110 of the Rehabilitation Act of 1973, as amended, or section 602 (16) and (17) of the Individuals with Disabilities Education Act (IDEA). Documentation must be maintained in the individual’s file to satisfy assurances that the service is not otherwise available through a program funded under the Rehabilitation Act of 1973 as amended and the IDEA.

**SUPPORTED EMPLOYMENT SERVICES**
Supported Employment services are direct and indirect services that are provided in community employment work sites with co-workers who do not have disabilities for the purposes of finding and supporting individuals in competitive jobs of their choice. Individuals must receive minimum wage or higher for the hours worked in competitive employment.

Supported Employment services consist of paid employment for individuals who, because of their disabilities, need intensive support to perform in a work setting. Supported Employment includes activities needed to sustain paid work by individuals receiving waiver services, including supervision and training. When supported employment is provided at a work site in
which people without disabilities are employed, payment will be made only for the adaptations, supervision, and training required by the individuals receiving waiver services as a result of their disabilities, and will not include payment for the supervisory activities rendered as a normal part of the business setting. Supported Employment services rendered under the waiver are not available under a program funded by either the Rehabilitation Act of 1973 as amended, or IDEA. Documentation must be maintained in the file of each individual receiving these services to satisfy the state assurance that the service is not otherwise available under a program funded under the Rehabilitation Act of 1973 as amended or IDEA. Federal Financial Participation through the waivers may not be claimed for incentive payments, subsidies, or unrelated vocational expenses such as the following:

1. Incentive payments made to an employer of individuals receiving services to encourage or subsidize the employer's participation in a supported employment program;
2. Payments that are passed through to individuals receiving supported employment; or
3. Payments for vocational training that are not directly related to an individual's supported employment program.

Supported Employment services consist of two components: job finding and job support. Job finding may include interview assistance, employer outreach and orientation, resume preparation, job searching, and preparation for job tasks. Other examples of activities that may be associated with job finding include participation in individual planning for employment; development of job seeking skills; development of customer-specific job skills; job analysis; support to learn job tasks; consultation with the Office of Vocational Rehabilitation (OVR), benefits counseling agencies, and provider networks under Ticket to Work on behalf of an individual; assistance in beginning a business; and outreach with prospective employers on behalf of the individual including consultation on tax advantages and other benefits. Job support consists of training individuals in job assignments, periodic follow-up and/or ongoing support with individuals and their employers. The service must be necessary for individuals to maintain acceptable job performance and work habits including assistance in learning new work assignments, maintaining job skills, and achieving performance expectations of the employer. Other examples of activities that may be associated with job support include participation in individual planning for employment, direct intervention with an employer, employment related personal skills instruction, support to relearn job tasks, training to assist individuals in using transportation to and from work, maintenance of appropriate work and interpersonal behaviors on the job, follow-along services at the work site after OVR funded services are discontinued, and technical assistance and instruction for the individual's co-workers that will enable peer support. Job support activities are a direct service to one individual at a time.
Ongoing use of the service is limited to support for individuals that cannot be provided by the employer through regular supervisory channels and/or on-the-job resources that are available to employees who are non-disabled. The provision of job finding services must be evaluated at least once every six calendar months by the ISP team, to assess whether the service is assisting the individual with the outcome of finding community employment. If the service is not assisting the individual with this outcome, the ISP team must identify changes to the Supported Employment service to realize this outcome or other service options to meet the individual’s needs. The provision of job support services must be evaluated at least annually, as part of the ISP process, to determine whether the individual continues to require the current level of authorized services. The ISP must be updated, if necessary, to reflect the team’s determination.

**TRANSITIONAL WORK SERVICES**

Transitional Work services consist of supporting individuals in transition to integrated, competitive employment through work that occurs in a location outside of a licensed facility. Transitional Work service options include:

- **Mobile Work Force.** A Mobile Work Force uses teams of individuals, supervised by a training/job supervisor, who conduct service activities away from an agency or facility. The provider agency contracts with an outside organization or business to perform maintenance, lawn care, janitorial services, or similar tasks and the individuals are paid by the provider.

- **Work Station in Industry.** A Work Station in Industry involves individual or group training of individuals at an industry site. Training is conducted by a provider training/job supervisor or by a representative of the industry, and is phased out as the individual(s) demonstrates job expertise and meets established production rates.

- **Affirmative Industry.** Affirmative Industry is operated as an integrated business, where disabled and non-disabled employees work together to carry out the job functions of the business.

- **Enclave.** An Enclave is a business model where disabled individuals are employed by a business/industry to perform specific job functions while working alongside non-disabled workers.

The service also includes transportation that is an integral component of the service, for example, transportation to a work site. The Transitional Work provider is not, however, responsible for transportation to and from an individual’s home, unless the provider is designated as the transportation provided in the individual’s ISP. In this case, the transportation service must be billed as a discrete service. This service may not be funded through either waiver or through Base allocation if it is available to individuals under a program funded under section 110 of the Rehabilitation Act of 1973, as amended or section 602 (16) and (17) of IDEA. Documentation must be maintained in the file of each individual receiving
these services to satisfy the state assurance that the service is not otherwise available under a program funded under the Rehabilitation Act of 1973 as amended or IDEA.

**TRANSPORTATION SERVICES**

Transportation services are direct services to provide transportation to enable individuals to gain access to Waiver and other community services and resources specified in their approved ISP. This includes transportation as a separate service offering that is provided by Adult Training Facilities, Prevocational Service and Transitional Work service providers who transport individuals to and from their homes and provider sites. It is **not** transportation that is an integral part of the provision of activities within Habilitation service settings nor is it transportation associated with Residential Habilitation services, as transportation in these situations is built into the rate for the habilitation service.

**Transportation (Mile):** This transportation service is rendered by providers, family members, and other qualified licensed drivers. Transportation Mile is used to reimburse the qualified licensed driver who transports the individual to and from services and resources specified in the ISP when using non-agency vehicles. For individuals who self direct their services, Transportation Mile may be used to reimburse an individual’s surrogate who is the employer or the managing employer to transport the individual to and from services and resources specified in the ISP. Mileage reimbursement to agency providers is limited to situations where transportation costs are not included in the provider’s rate for services.

The unit of service is one mile. Mileage will be paid round trip. Mileage that may be reimbursed is calculated as follows:

- Total Mileage required to transport the individual to and from a service or resource specified in the ISP when the individual is physically in the vehicle.
- Mileage required to transport individuals from one service or resource to another service or resource specified in the ISP while the individual is physically in the vehicle.
- Mileage will be reimbursed to the qualified provider for their return trip after the individual was transported to a service or resource and for the trip back to pick up the individual. The mileage to be reimbursed to the qualified provider (when the individual is not in the vehicle) for return trips will be no greater then the mileage required to transport the individual.

The rate for Transportation Mile will be the reimbursement rate established for Department of Public Welfare employees for business travel. The rate paid for mileage is based on the federal reimbursement rate and could change during the fiscal year. Mileage reimbursement to providers is limited to situations where transportation costs are not included in the provider’s rate for services.
When Transportation Mile is provided to more than one individual at a time, the total number of units of service that are to be provided are equitably divided among the individuals for whom transportation is provided.

**Public Transportation:** Public transportation services are provided to individuals to enable them to gain access to services and resources specified in their ISPs. The utilization of public transportation promotes self-determination and is made available to individuals as a cost-effective means of accessing services and activities.

Public transportation tokens and transit passes may be purchased by the AE, AE contracted payment agents, Financial Management Service Organizations, or providers of service. Tokens/passes that are purchased for an individual may be provided to the individual on a daily, weekly or monthly basis.

**Transportation – Per Diem:** This is transportation provided to an individual by provider agencies for non-emergency purposes. The service is designed to provide individuals with access to services and activities specified in their ISP.

**Transportation – Trip:** Transportation provided to individuals (excluding transportation included in the rate for habilitation services) for which costs are determined on a per trip basis. A trip is either transportation to a service/activity from an individual’s home or from the service/activity to the individual’s home. Taking an individual to a service/activity and returning the individual to his/her home is considered two trips or two units of service.

**EDUCATION SUPPORT SERVICES**

Education Support services consist of special education and related services as defined in Sections (15) and (17) of IDEA to the extent that they are not available under a program funded by IDEA or available for funding by OVR. Educational Support services may consist of general adult educational services including community college, university or other college-level courses, classes, tutoring to receive a General Educational Development (GED) degree, and assistance necessary for the person to participate in apprenticeship programs.

**SPECIALIZED SUPPLIES**

Specialized Supplies consist of incontinence supplies that are not available through the State Plan or private insurance. Supplies are limited to diapers, incontinence pads, cleansing wipes, underpads, and vinyl or latex gloves. This service is limited to $500 per individual per fiscal year.

Specialized Supplies may only be funded through the waiver or Base allocation when the service may not be provided under the State Plan or private insurance because the State Plan or private insurance limitations have been reached, or when the service is not covered under the State Plan or private insurance. The Supports Coordinator is
responsible to verify that the State Plan and/or private insurance limitations have been exhausted prior to funding Specialized Supplies through the Consolidated or P/FDS Waiver. Documentation that the services are not available through the State Plan and/or private insurance must be maintained in the individual’s file by the Supports Coordinator. This documentation must be updated on at least an annual basis. The documentation requirement can be met by including detailed information in the person’s hard copy file and/or a service note in HCSIS. In addition, a summary of the documentation should be included in the ‘Outcome Summary’ page of the HCSIS ISP (in the ‘Concerns Related to Outcome’ field) page of the HCSIS ISP, as the information is needed for authorization. The individual and/or their family and the Supports Coordination must work together regarding this requirement. Examples of acceptable documentation include: summary of a telephone conversation with the individual’s insurance provider supported by a copy of the coverage policy; excerpts from benefit statements showing that the service is not available; evidence that the individual is no longer eligible for benefits, such as a termination of coverage letter; etc.

### Therapy Services

Therapy services include the following:

- **Physical Therapy** provided by a licensed physical therapist based on a prescription for a specific therapy program by a physician. The physical therapist develops a recommended plan of care.

- **Occupational Therapy** by a registered occupational therapist based on a prescription for a specific therapy program by a physician. The occupational therapist develops a recommended plan of care.

- **Speech/language Therapy** provided by an ASHA (American Speech-Language-Hearing Association) certified and state licensed speech-language pathologist upon examination and recommendation by an ASHA certified and state licensed speech-language pathologist or a physician.

- **Visual/mobility Therapy** provided by a trained visual or mobility specialist/instructor based on an evaluation and recommendation by a trained mobility specialist/instructor or a physician.

- **Behavior Therapy** provided by a licensed psychologist or psychiatrist based on an evaluation and recommendation by a licensed psychologist or psychiatrist.

Therapy services are direct services provided to assist individuals in the acquisition, retention, or improvement of skills necessary for the individual to live and work in the community, and must be attached to an individualized outcome. The need for the service must be evaluated on a periodic basis, at least annually as part of the ISP process. This evaluation must review
whether the individual continues to require the current level of authorized services and that the service continues to result in positive outcomes for the individual. It is recognized, however, that long-term Therapy services may be necessary due to an individual’s extraordinary medical or behavioral conditions. The need for long-term Therapy services must be documented in the individual’s ISP.

**Nursing Services**

The State Board of Nursing at 49 Pa.Code Chapter 21 provides the following service definition for the practice of professional nursing: "Diagnosing and treating human responses to actual or potential health problems through such service as case finding, health teaching, health counseling, provision of care supportive to or restorative of life and well-being, and executing medical regimens as prescribed by a licensed physician or dentist. The term does not include acts of medical diagnosis or prescription of medical, therapeutic or corrective measures, except as may be authorized by rules and regulations jointly promulgated by the State Board of Medicine and the Board, which rules and regulations will be implemented by the Board."

An individual’s need for nursing services should be based on the individual’s needs assessment results and other appropriate medical professional assessments.

Nursing services are State Medical Assistance Plan services and may only be funded through the waiver or base allocation when the service may not be provided under the State Plan or private insurance because the State Plan or private insurance limitations have been reached, or when the service is not covered under the State Plan or private insurance. The Supports Coordinator is responsible to verify that the State Plan and/or private insurance limitations have been exhausted prior to funding Nursing services through the Consolidated or P/FDS Waiver. Documentation that the services are not available through the State Plan and/or private insurance must be maintained in the individual’s file by the Supports Coordinator. This documentation must be updated on at least an annual basis. The documentation requirement can be met by including detailed information in the individual’s hard copy file and a service note in HCSIS. In addition, a summary of the documentation should be included in the ‘Outcome Summary’ page of the HCSIS ISP (in the ‘Concerns Related to Outcome’ field) page of the HCSIS ISP, as the information is needed for authorization by the AE. The individual and/or their family and the Supports Coordination must work together regarding this requirement. Examples of acceptable documentation include: summary of a telephone conversation with the individual’s insurance provider supported by a copy of the coverage policy; excerpts from benefit statements showing that the service is not available; evidence that the individual is no longer eligible for benefits, such as a termination of coverage letter; and so on.
**Behavioral Support**

This is a service that includes functional assessment; the development of strategies to support the individual based upon assessment; and the provision of training to individuals, staff, parents and caretakers. Services must be required to meet the current needs of the individual, as documented and authorized in the ISP.

The service is performed by an individual with a Masters Degree in Human Services (or a closely related field) or an individual who is under the supervision of an individual with a Masters Degree in Human Services (or a closely related field) and is limited to the following:

- Collection and evaluation of behavioral data;
- Observation of the participant in various settings for the purpose of developing a Behavior Support Plan;
- Collaboration with the participant, their family, and their team for the purpose of developing a Behavior Support Plan that must include positive practices and may not include restraint procedures (physical, chemical, or mechanical) as support strategies;
- Conducting comprehensive functional assessments of presenting issues (e.g. aggression, self-injurious behavior, law offending behavior (sexual or otherwise));
- Development and maintenance of Behavior Support Plans, which utilize positive strategies to support the participant, based on functional behavioral assessments;
- Conducting training related to the implementation of Behavior Support Plans for the participant, family members, and staff;
  - Implementation of activities and strategies identified in the participant’s Behavior Support Plan;
  - Monitoring implementation of the Behavior Support Plan, and revising as needed;
  - Collaboration with the participant, their family, and their team in order to develop positive interventions to address specific presenting issues; and
  - Completion of required paperwork related to data collection, progress reporting and development of annual planning material.

Services may be provided in the office of the Behavioral Support professional, the individual’s home, the location of other authorized services, or in local public community environments necessary for the provision of the Behavioral Support Services. Direct services must be provided on a one-on-one basis.

Behavioral Support services may be provided during the same day and time as other services, but may not duplicate other services. For example, Behavioral Support may be provided during the same day and time as Residential Habilitation, but the Behavioral Support provider may not render services that overlap with the responsibilities of the Residential Habilitation provider.
HOME ACCESSIBILITY ADAPTATIONS

Home Accessibility Adaptations consist of certain modifications to the private home of the individual which are necessary due to the individual’s disability, to ensure the health, security, and accessibility of the individual, or which enable the individual to function with greater independence in the home. The term ‘private home’ includes homes owned, rented, or leased by the following and not owned, rented, or leased from a provider agency:

- The individual with mental retardation.
- Parents or relatives with which the individual resides.
- Family living homes that are privately owned, rented or leased by the host family.

This service may only be used to adapt the individual's primary residence and may not be used to adapt homes that are provider owned, rented, leased, or operated.

Home modifications must have utility primarily for the individual with the disability, be an item of modification that the family would not be expected to provide to a family member without a disability, be an item that is not part of general maintenance of the home, and be an item or modification that is not part of room and board costs as defined in 55 Pa.Code Chapter 6200. Home modifications consist of installation, repair, maintenance, and extended warranties for the modifications; and when necessary to comply with rental/lease agreements, return of the property to its original condition. All modifications shall meet the applicable standards of manufacture, design, and installation. Modifications shall be specific to the individual’s assessed needs.

Modifications shall not be approved to benefit the public at large, staff, significant others, or family members. Modifications or improvements to the home that are of general utility are excluded. Modifications not of direct medical or remedial benefit to the individual are excluded. Adaptations that add to the total square footage of the home are excluded from this benefit. The only exception to this is adaptations to bathrooms that are necessary to complete the adaptation (for example, necessary to configure a bathroom to accommodate a wheelchair). Durable medical equipment is excluded.

Maximum state and federal funding participation is limited to $20,000 per individual during a 10-year period. A new $20,000 limit can be applied when the individual moves to a new home or when the individual transfers to a different mental retardation waiver. The 10-year period begins at the first utilization of authorized Home Accessibility Adaptations. The 10-year period incorporates the previous 9 fiscal years and the current fiscal year. For FY 2010/2011, the 10-year period started in FY 2001/2002 (that is started on July 1, 2001). For tracking purposes, the date, nature, and cost of the most recent Home Accessibility Adaptation should be documented in the ISP in the ‘Physical Development’ field. In situations of joint custody (as determined by an official court order) or other situations where an individual divides their time
between official residences, the adaptations must be allowable services and must be completed within the overall monetary limit of $20,000 for this service.

Modifications to a household subject to funding under the Waivers are limited to the following and must be necessary due to the individual’s disability:

- Ramps from street, sidewalk or house.
- Vertical lifts.
- Portable or track lift systems. A portable lift system is a standing structure that can be wheeled around. A track lift system involves the installation of a “track” in the ceiling for moving an individual with a disability from one location to another.
- Handrails and grab-bars in and around the home.
- Accessible alerting systems for smoke/fire/CO2 for individuals with sensory impairments.
- Electronic systems that enable an individual with limited mobility to control various appliances, lights, telephone, doors, and security systems in their room, home or other surroundings
- Outside railing from street to home.
- Widened doorways, landings, and hallways.
- An additional doorway needed to ensure the safe egress of the individual during emergencies, when approved by the ODP Regional Office.
- Swing clear and expandable offset door hinges.
- Flush entries and leveled thresholds.
- Plexiglas windows for individuals with behavioral issues as noted in the individual’s ISP.
- Slip resistant flooring.
- Kitchen counter, major appliance, sink and other cabinet modifications.
- Bathroom modifications for bathing, showering, toileting and personal care needs.
- Bedroom modifications of bed, wardrobe, desks, shelving, and dressers.
- Stair gliders and stair lifts. A stair lift is a chair or platform that travels on a rail, installed to follow the slope and direction of a staircase, which allows a user to ride up and down stairs safely.
- Workroom modifications to desks and other working areas.

All adaptations to the household shall be provided in accordance with applicable building codes.

**VEHICLE ACCESSIBILITY ADAPTATIONS**

Vehicle Accessibility Adaptations consist of certain modifications to the vehicle of the individual that is used as the primary means of transportation to meet the individual’s needs. These
Vehicle modifications are necessary due to the individual’s disability and to meet an assessed need as documented in the ISP. The vehicle that is adapted may be owned by the individual, a family member with whom the individual lives, or a non-relative who provides primary long-term support to the individual and is not a paid provider agency of such services. This service may also be used to adapt a privately owned vehicle of a family living host family when the vehicle is not owned by a provider agency. This service is not used to adapt provider owned, leased, or rented vehicles or provider operated vehicles used to provide transportation services to individuals.

Vehicle modifications consist of installation, repair, maintenance, and extended warranties for the modifications. Regularly scheduled upkeep and maintenance of the vehicle, including warranties that cover the entire vehicle, except for upkeep and maintenance of the modifications, is excluded.

The Waivers cannot be used to purchase vehicles for the individual, their families or legal guardians; however, this service can be used to fund the portion of a new or used vehicle purchase that relates to the cost of vehicle accessibility adaptations. In order to fund these types of adaptations, a clear breakdown of purchase price versus adaptation price is required.

Maximum state and federal funding participation is limited to $10,000 per individual during a 5-year period. The 5-year period begins with the first utilization of authorized Vehicle Accessibility Adaptations or when the individual transfers to a different mental retardation waiver. The 5-year period incorporates the previous 4 fiscal years and the current fiscal year. For FY 2010/2011, the 5-year period started in FY 2006/2007 (that is, started on July 1, 2006). For tracking purposes, the date, nature, and cost of the most recent Vehicle Accessibility Adaptation should be documented in the ISP in the ‘Physical Development’ field.

These adaptations funded through the Waivers are limited to the following:

- Vehicular lifts
- Interior alterations to seats, head and leg rests, and belts
- Customized devices necessary for the individual to be transported safely in the community, including driver control devices
- Raising the roof or lowering the floor to accommodate wheelchairs

**Assistive Technology**

An item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve an individual’s functioning.

Assistive technology services include direct support to an individual in the selection, acquisition, or use of an assistive technology device, limited to:
• Purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices for the individual;
• Selecting, fitting, customizing, adapting, maintaining, repairing, or replacing assistive technology devices;
• Training for the individual or, where appropriate, the individual's family members, guardian, advocate, staff, or authorized representative on how to use and/or care for the assistive technology;
• Extended warranties; and
• Ancillary supplies, software, and equipment necessary to the proper functioning of assistive technology devices, such as replacement batteries and materials necessary to adapt low-tech devices.

Please note that repair and maintenance of devices and purchases of extended warranties are limited to those devices purchased through the Waivers.

All items shall meet the applicable standards of manufacture, design, and installation. Items shall be specific to the individual's needs and not be approved to benefit the public at large, staff, significant others, or family members. Items reimbursed with waiver funds shall be in addition to any medical supplies provided under the Medicaid state plan and shall exclude those items not of direct medical or remedial benefit to the individual. If the participant receives Behavioral Therapy or Behavioral Support Services, the assistive technology must be consistent with the individual's behavioral support plan.

Assistive technology devices must be recommended by an independent evaluation of the individual's assistive technology needs. The organization or professional providing the evaluation shall be credentialed, licensed, or certified in an area related to the specific type of technology needed, and may not have a fiduciary relationship with the assistive technology provider.

This service excludes durable medical equipment, as defined by Title 55 Pa. Code Chapter 1123 and the Medical Assistance State Plan.

**Assistive Technology may only be funded through the waiver or Base allocation when the service may not be provided under the State Plan or private insurance because the State Plan or insurance limitations have been reached, or when the service is not covered under the State Plan or private insurance. The Supports Coordinator is responsible to verify that the State Plan and/or private insurance limitations have been exhausted prior to funding Assistive Technology services through the Consolidated or P/FDS Waiver. Documentation that the services are not available through the State Plan and/or private insurance must be maintained in the individual's file by the Supports Coordinator.** This documentation must be updated on at least an annual basis. The
documentation requirement can be met by including detailed information in the person’s hard copy file and/or a service note in HCSIS. In addition, a summary of the documentation should be included in the “Outcome Summary” page of the HCSIS ISP (in the “Concerns Related to Outcome” field) page of the HCSIS ISP, as the information is needed for authorization. The individual and/or their family and the Supports Coordination must collaborate to obtain documentation to meet this requirement. Examples of acceptable documentation include: summary of a telephone conversation with the individual’s insurance provider, excerpts from benefit statements showing that the service is not available, evidence that the individual is no longer eligible for benefits, etc.

**Supports Broker Services**

This is a direct (face-to-face) and indirect service to individuals with mental retardation in arranging for, developing, and managing the services they are self-directing through either employer authority (hiring/managing workers) or budget authority (determining worker salaries, shifting funds between approved services and/or providers). Services are provided to assist individuals in identifying immediate and long-term needs, developing community-based options to meet those needs, and accessing identified supports and services. Services also involve practical skills training and information for individuals and surrogates related to directing and managing services. This service is limited to:

- Assistance in identifying and sustaining a personal support network of family, friends, and associates to meet individual needs;
- Assistance in arranging for and effectively managing generic community resources and informal supports to meet individual needs;
- Assistance at planning meetings to ensure the individual’s access to needed quality community resources;
- **In depth** practical skills training for individuals and surrogates related to self-direction and management of qualified support service workers. Training is limited to employer responsibilities (e.g. hiring, managing, and terminating workers; reviewing and approving timesheets; problem solving; conflict resolution);
- Assistance to the individual in managing, monitoring, and reviewing their participant directed budget;
- Development of back-up plans in the event of emergencies and/or unexpected worker absences;
- Training to the individual to help them recognize reportable incidents and help them report the incidents to the Supports Coordinator or provider as required;
- Assistance with paperwork related to the individual’s employer responsibilities as the employer of record or co-employer of support service workers;
• Assistance with budgeting, including review and evaluation of monthly expenditure reports; and
• Providing detailed information and training to individuals about: person centered planning and how it is applied, risks and responsibilities related to self-direction, free choice of willing and qualified providers, individual rights, and use of community and natural supports.

This service is limited to a maximum of 1040 units per individual per fiscal year based on a 52-week year. This service is limited to individuals who are self-directing their services through employer and/or budget authority.

Supports Brokers must work collaboratively with the individual’s Supports Coordinator. The role of the Supports Coordinator continues to involve the primary functions of locating, coordinating, and monitoring of waiver services; the Supports Broker assists individuals and families with being able to self-direct their support. It is important to understand that each role is vital to the support of the individual and their surrogate. It is also important to understand that Supports Coordinators provide information related to self direction to individuals, families, and surrogates; however, Supports Coordinators do not assist individuals, families, and surrogates with the activities associated with self direction.

Supports Broker services are different from Supports Coordination and Supports Brokers may not replace the role or perform the functions of a Supports Coordinator; no duplicate payments will be made.

Supports Broker Services can be provided to individuals that self direct by hiring qualified individual(s) to be the SSW of the Supports Broker Service or by selecting a qualified and willing provider to render the Supports Broker Services.

Supports Broker Services may not be rendered by providers that offer other mental retardation services or that offer mental retardation administrative services (for example, a Health Care Quality Unit or an Independent Monitoring Program). The only exception to this restriction is the ability for both the VF/EA FMS and AWC FMS to provide or pay for PDS, including Supports Broker Services, and to provide the VF/EA FMS or AWC FMS administrative services to individuals who self direct.

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**Services Provided by Family Members**

Many people feel comfortable using family members as providers. Parents, sisters, brothers, grandparents and other relatives often know the person well and are willing to help. If you live in your own home, or in your family’s home, you can hire these dedicated family members to provide some services through the Waivers. The next two pages describe the rules for hiring family as support workers. You may also want to consider hiring friends, neighbors, and other people you know and trust as support. In general, the basic requirements
for support workers is that they are 18 years old, have a criminal background check, are willing to carry out the services in the ISP, have necessary training to implement the ISP and have a valid driver’s license (if they are providing transportation). If you want to hire family and friends, you should read the section on Participant Directed Supports and Financial Management Services in Chapter 3 of this book.

Relatives, legal guardians, and legally responsible individuals may be paid to provide certain services funded through the Waivers, including Participant-Directed Services. The policies related to services by relatives, legal guardians, and legally responsible individuals are outlined below. Please note that there is one set of policies that apply to relatives and legal guardians and a separate policy that applies to legally responsible individuals.

**SERVICES BY RELATIVES AND LEGAL GUARDIANS**

Relatives or legal guardians may be paid to provide services funded through the Waivers, including Participant-Directed Services, on a service-by-service basis. A relative is any of the following who have not been assigned as legal guardian for the individual with mental retardation:

- A parent (natural or adoptive) of an adult
- A stepparent of an adult child
- Grandparent
- Brother.
- Sister
- Half-brother
- Half-sister
- Aunt
- Uncle
- Niece
- Nephew
- Adult child or stepchild of a parent with mental retardation
- Adult grandchild of a grandparent with mental retardation

For the purposes of this policy, a legal guardian is a person who has legal standing to make decisions on behalf of a minor or adult (for example, a guardian who has been appointed by the court).

Relatives and legal guardians may be paid to provide Waiver services when the following conditions are met:

- The service provided is not a function that the relative or legal guardian would normally provide for the individual without charge in the usual relationship among members of a nuclear family.
- The service would otherwise need to be provided by a qualified provider of services funded under the waiver.
- The service is provided by a relative or legal guardian who meets the qualification criteria that are established by ODP in Appendix C-3 of the approved Waivers.
Waiver services that relatives or legal guardians can provide are limited to the following: Home and Community Habilitation (Unlicensed), and Transportation (Mile). Relatives or legal guardians who are not the individual’s primary caregiver may also provide Supports Broker Services and waiver-funded Respite Services when the conditions listed above are met. Relatives and legal guardians may provide base-funded respite services only when the relative or legal guardian does not live in the same household as the individual, and when the conditions above are met.

The primary caregiver is the person or persons who normally provide care to the individual. For example, an adult individual lives with his or her parents and the parents provide the routine and regular care needed by the individual. A brother of the adult individual also lives with the parents but goes to college each day. Typically, the parents would be considered the primary caregiver. The brother may also provide care to the individual when he is not at college, but providing care to the individual is not the brother’s primary responsibility, and he therefore, is not considered a primary caregiver. Another example would be when the individual lives with a mother and a sister. Although the mother is the individual’s parent, she is elderly and unable to provide routine and regular care to the individual. The sister provides the regular and routine care to the individual. In this example, the sister is considered the primary caretaker.

**SERVICES BY LEGALLY RESPONSIBLE INDIVIDUALS**

A legally responsible individual is a person who has legal obligation under the provisions of law to care for another person, including parents of minors (natural or adoptive), spouses, and legally-assigned relative caregivers of minor children. Legally responsible individuals may be paid to provide services funded through the Waivers on a service-by-service basis. Legally responsible individuals may be paid to provide Waiver services when the following conditions are met:

- The service is considered extraordinary care, which means it is not part of the supports the legally responsible individual is ordinarily obligated to provide.
- The service would otherwise need to be provided by a qualified provider of services funded under the waiver.
- The service is provided by a legally responsible individual who meets the qualification criteria that are established by ODP in Appendix C-3 of the approved Waivers.

Waiver services that legally responsible individuals can provide are limited to the following: Home and Community Habilitation (Unlicensed) and Transportation (Mile).

**Travel Policy**

The following services may occur during temporary travel (as defined below):
• Home and Community Habilitation (Unlicensed).
• Residential Habilitation (Licensed and Unlicensed)
• Respite
• Nursing
• Therapy
• Supports Coordination

These services may be provided in Pennsylvania or anywhere in the United States, the District of Columbia, or the American territories during temporary travel. During the temporary travel period, staff that render these services must be employed by a willing and qualified provider that is based in Pennsylvania or in states that are contiguous to Pennsylvania. For services that are Participant Directed, the SSWs that render the service while traveling must be a resident of Pennsylvania or of states that are contiguous to Pennsylvania. The physical location of the company that sells a good is not required to be located in Pennsylvania or in a state contiguous to Pennsylvania.

Temporary travel is defined as a period of time in which the individual goes on vacation or on a trip. The following conditions apply to the travel situation:

• The travel plans are reviewed and discussed as part of an ISP team meeting, and the team identifies safeguards to protect the individual’s health and welfare during travel.
• The roles and responsibilities of the individual receiving services and the staff person(s) for home and community-based services are the same during travel as at home.
• ODP bears no responsibility for travel costs of either the individual or the staff person(s):
  ➢ The individual is responsible to fund their own travel costs through private or non-system funds.
  ➢ Travel costs for staff person(s) may be funded through private funds of family members of the individual receiving services or non-mental retardation-system funds generated through fundraising efforts or other means.
• An individual is limited to previously authorized units for each service while on vacation and other temporary travel.
• All service and program requirements, such as provider qualification criteria and documentation of services, apply during the period of travel. This includes the requirement for licensed residential services that the permanent residential setting must be located and licensed in Pennsylvania.
• The provision of home and community-based services during travel is limited to a period of no more than 30 consecutive calendar days per travel event.
AEs shall ensure that this travel policy is explained to all Waiver participants at the time of Waiver enrollment and reviewed annually at the time of the ISP meeting. The SC shall document this annual review in a service note in HCSIS.

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**Waiver Monitoring**

Supports Coordination for Waiver monitored services is paid for in the Pennsylvania Mental Retardation system as a Waiver service. Supports Coordination ensures that needed services are located, coordinated, and monitored in an effective and efficient manner. Monitoring is to help ensure Waiver participants’ health and welfare, that Individual Support Plans are being implemented as written, and to support the choices and rights of individuals and their families.

Each person must have an Individual Support Plan, which lists the types of services and supports to be provided, how long they will be provided (duration), how often you will receive the services (frequency), and who will be providing the service. The plan is developed through a person-centered process by you and your team. The plan is approved by your AE/County prior to the payment of Federal and State funds for services under the Waiver program. The plan must be updated at least once every 365 days and whenever your needs change.

Your AE/County Program is responsible to see that monitoring occurs with a frequency and duration necessary to ensure services and supports are provided in accordance with your approved Individual Support Plan and to ensure your health and welfare. Only changes to the frequency of Supports Coordination visits may be made, not changes to location. Changes in the frequency of visits may not result in visits that take place less than four face-to-face visits per year if you are in the Consolidated Waiver and two contacts and one face-to-face visit per year if you are in the Person/Family Directed Support Waiver. All changes to the frequency of visits are subject to approval by ODP.

The following are the minimum monitoring requirements:

- If you are receiving at least one service per calendar month under the Consolidated Waiver, your Supports Coordinator must complete three face-to-face meetings with you every three calendar months, consisting of at least one meeting at your home, one meeting at your day service, and one meeting at any place you agree upon.

- If you are not receiving at least one service per calendar month under the Consolidated Waiver, your Supports Coordinator must complete one face-to-face meeting with you every month during the time a monthly service is not provided.

- If you are in the Person/Family Directed Support (P/FDS) Waiver and receiving a monthly service and live with your family, your Supports Coordinator must contact you every three calendar months, and must meet with you face-to-face at least once every six calendar
months. At least one face-to-face monitoring per calendar year must take place in your home.

- If you are in the P/FDS Waiver and you live in another arrangement and are receiving a monthly Waiver service, your Supports Coordinator must contact you at least once every calendar month and meet with you face-to-face at least once every three calendar months. At least one of the face-to-face monitoring visits every six calendar months must take place in your home.

- If you are in the P/FDS Waiver and are not receiving at least one Waiver service per month, your Supports Coordinator must contact you at least once every calendar month, and meet with you face-to-face at least once every three calendar months. At least two of the face-to-face visits per calendar year must take place in your home.

**DETAILS**

During monitoring visits, your Supports Coordinator has a conversation with you and discusses things like:

- Your health and welfare
- Your satisfaction with services
- The quality of your services
- Service outcomes and any barriers

Any differences in the frequency of Supports Coordination monitoring may only be made under the following circumstances:

- You choose to reduce the frequency of Supports Coordination visits;
- Your choice is documented in your Individual Support Plan; and
- There are other mechanisms in place to ensure your health and welfare, and these mechanisms are included in your plan.

The following documentation of the monitoring will be kept in your paper file and/or Home and Community Services Information System (HCSIS) record:

- Dates, places, and times of your meetings with your Supports Coordinator.
- Findings and recommendations related to the implementation of your Individual Support Plan and your health and welfare.
- Information relating to the resolution of corrective action based on the Supports Coordinators findings and recommendations.
CHAPTER 3: ORGANIZING YOUR SUPPORTS

Once you have registered with Mental Retardation system and are aware of the wide range of services and supports available to you, you should think about how to use the information to support and plan for the life you want. This chapter discusses the programs and tools available for you to help organize and individualize your supports. It covers how to choose your provider, how to manage and direct your own supports through Financial Management Services, ODP’s employment initiative, the different types of residential options available and how to plan for the future.

Choosing the Supports I Need

WHO CAN ASSIST YOU IN FINDING SERVICES AND SUPPORTS YOU NEED?

• One way to get help is to contact the MH/MR department in your county. You can find the number for your County Office in the Appendix of this book or the Blue Pages of the phone book. Many adult services and programs are already established and offered in your county. Visit them and ask questions. See if they can provide the services you need. If you have a Supports Coordinator you can contact them to discuss your needs.

• There are a few other ways to figure out who provides services in your area:

  • Use the Office of Developmental Programs’ on-line resource directory [www.dpw.state.pa.us/PartnersProviders/MentalRetardation/003676369.htm](http://www.dpw.state.pa.us/PartnersProviders/MentalRetardation/003676369.htm)

  • Ask your Supports Coordinator.

  • Ask other families and friends.

  • If you receive money from the County MH/MR department, the first thing you need to decide is how you would like your supports and services managed.

• Do you want to select providers to provide services to you?

• Or would you like to self direct your services by becoming an employer or managing employer? If you meet the requirements and live in your own private residence or the residence of family you may be able to use one of the Financial Management Services options to become an employer or managing employer. You should review all of your management options with your Supports Coordinator and team before making a decision. All this information can be found in Pennsylvania’s Guide to Participant-Directed Services.

• If you choose to select one or more traditional providers to manage your services, here are some things to think about when interviewing a provider:
Chapter 3: Organizing Your Supports

- What method ensures that you are treated with dignity and respect by the staff and treated as an individual?
- Are your family and friends encouraged to participate in the planning process?
- What are the staff ratios for the program or is the provider able to meet your individual required staff ratio?
- What is the back-up plan for when regularly scheduled staff are not able to work?
- Are staff properly screened (criminal background and child abuse clearances, driving records, references) and trained?
- What is the average length of staff employment?
- How long does it take to fill staffing vacancies?
- How does the provider ensure the services for which they are authorized and committed to provide are delivered?
- How well does the agency handle individual suggestions, complaints or concerns? Do they welcome suggestions?
- Do the people receiving services play any role in choosing the staff that will work with them?

- Dream and think of innovative ways to create your own plan. Make sure you understand what supports and services are able to be funded by the Office of Developmental Programs or by other sources. How do you do all this?
- First, you need a plan. Make a list of your own needs and desires. If you are in school you can use the IEP/Transition Plan if it meets your needs or you can use your Circle of Support or Team to develop a plan. You can develop your own plan that includes paid and unpaid support (natural supports) and incorporate it into your formal ISP.
- Review what is available: support from Office of Vocational Rehabilitation or an employment service to get a job; groups that need volunteers; a business, church or social organization that could use your help. Do you need in-home supports and/or support for community outings? Will you need transportation? Think about what would be individualized and fulfilling for you.
- You, along with your team including your Supports Coordinator, will develop your Individual Support Plan (ISP).

- Where would you find people to help provide the supports? Unless you use a Financial Management Service (FMS) and become an employer or managing employer, the provider is responsible to find staff.
- Once you select a provider and they agree to provide your services, they are expected to hire the staff you need.
- Some providers will allow you to participate in the staff selection process. Providers are not required to do that so, if it is important to you, you should ask about participation in staff choice when you are selecting a provider/agency.
If you choose to use Participant-Directed Supports and meet the requirements to become an employer or managing employer you will be responsible to recruit staff. If you choose to use the **Vendor Fiscal/Employer Agent (VF/EA)** FMS management option you will become a **common law employer**. If you choose to use the **Agency With Choice (AWC)** management option you will become a **managing employer**. You should read *Pennsylvania’s Guide to Participant-Directed Services* to fully understand the roles and responsibilities of each of these options and how the Financial Management Service Organization/provider will support you so you choose the option right for you. A copy of the guide can be obtained from your Supports Coordinator, the AE/County or from the Partnership website at [www.TheTrainingPartnership.org](http://www.TheTrainingPartnership.org).

- You can also hire someone you know through an agency if they are eighteen (18) years of age or older and have a criminal background check. Hire a relative, friend, or person with whom you are familiar.
- Place an advertisement in the newspaper or with a local college or look to neighbors and relatives. Always make sure you or the agency does a thorough background check on the person, even if you know them personally (Criminal background checks are required in order to have services paid for by federal, state, and/or local funds.).

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### Financial Management Services (FMS)

Formerly known as Intermediary Service Organizations (ISOs)

Financial Management Services (FMS) organizations support people who choose to manage their services and supports through Participant Direction. Financial Management Services (FMS) were created to help you control your own services and supports. FMS are designed to support you to hire your own qualified support workers, create and supervise your services. Currently both models of FMS described below are offered across Pennsylvania.

There are two primary functions that FMS perform:

1. To reduce individuals’/representatives’ employer-related burdens by providing appropriate fiscal and supportive services; and
2. To assure the State and Administrative Entities /County Programs that support services are being provided in compliance with federal, state, and local tax and labor requirements related to the employment of qualified support service workers.

FMS may pay vendor services purchased for individuals (ex. Transportation mile, Assistive Technology/Adaptive Equipment).

FMS provides payroll services for your support service workers and pays federal, state and any local taxes, workers compensation premiums and unemployment insurance on your behalf.
ODP has created the *Pennsylvania’s Guide to Participant-Directed Services* in order to help you understand what Participant-Direction means and which services you can direct. There is more in-depth information about FMS in the guide. A copy of this guide can be found at: [www.TheTrainingPartnership.org](http://www.TheTrainingPartnership.org) or [www.odpconsulting.net](http://www.odpconsulting.net).

There are two models of FMS in place in the Pennsylvania’s Mental Retardation system:

1. **Vendor Fiscal/Employer Agent (VF/EA)**. Under the Vendor Fiscal/Employer Agent (VF/EA) model, you are the common law employer. The VF/EA FMS receives approval from the IRS to be an “employer agent” on your behalf for the limited purposes of handling employment and income taxes. Using this model, you will be able to:
   - Recruit and hire your qualified support service workers;
   - Determine worker schedules;
   - Determine worker tasks and how and when they will be performed;
   - Orient and train workers;
   - Manage the daily tasks performed by workers; and
   - Dismiss your workers when appropriate.

   Acumen Fiscal Agent, LLC is currently contracted with the Commonwealth as the statewide VF/EA forwaiver funded people.
   - Acumen Fiscal Agent
     4542 E Inverness Avenue, Suite 210
     Mesa, AZ 85206
     Toll Free: 866-717-6251
     [www.acumenfiscalagent.com](http://www.acumenfiscalagent.com)

2. **Agency with Choice (AWC) FMS**. In this model the AWC FMS is the legal employer. You are the managing employer, meaning you direct your workers daily activities. This means that you and the AWC will be co-employers. As managing employer you are able to work with the FMS to:
   - Recruit and refer your potential support workers to the FMS for hire;
   - Provide and/or participate in training your workers;
   - Determine worker schedules;
   - Determine worker tasks and how and when they will be performed;
   - Manage the daily tasks performed by workers; and
   - Dismiss workers when necessary.
   - For more information regarding the Agency With Choice in your area, please contact your Administrative Entity. You can also find a listing of the current AWC’s on the Partnership website [www.TheTrainingPartnership.org](http://www.TheTrainingPartnership.org)
Choosing Where You Want to Live

Deciding the best home or residential setting is a difficult, emotional process whether you are a self-advocate or a family member wishing to help. It requires thought and consideration to the needs of the individual and it is extremely important to consider the whole individual, including his or her strengths and weaknesses. This process will include taking an honest, objective look at the individual’s communication skills, medical and physical needs, and socialization skills. There is always a balance between the need to keep our loved one safe and the need to help them flourish as a member of the community. Supports Coordinators, providers and advocates can assist the individual and his or her family to assure a smooth and thought out process.

There are several residential options available and each one has both strengths and weaknesses, depending on the needs of the individual seeking placement. These options include: Community Group Homes, Supportive Living, Life Sharing through Family Living, Reverse Family Living and owning your own home.

The following is a description of the current residential options and is meant as a guide to help you become acquainted with the types of programs available.

**COMMUNITY GROUP HOMES**

The Community Group Home offers 24 hour supervision in a home environment for individuals who would like to learn and develop skills necessary to achieve a greater level of independence. This type of residential program offers supports customized to meet individual needs, desires and outcomes. Family members of individuals receiving services are encouraged to continue to play active roles. Services include:

- 24 hour staff supervision
- Coordination of educational, vocational, medical, mental health, social and financial services
- Advocacy
- Transportation and recreational activities

A concern that you may want to consider is the fact of rotating staff schedule and needs of other individuals living in the home.

**SUPPORTED LIVING**

Supported Living is a residential option available to those individuals requiring less than 30 hours of staff support per week. These individuals reside in apartments or homes of their own and staff provides support to them as needed. Supports include: assistance to medical appointments, money management skills, cooking skills, and community integration.

A concern that you may want to consider is the individual’s ability to function with minimal supports.
LIFE SHARING THROUGH FAMILY LIVING

Lifessharing, also known as family living, offers people the opportunity to live with and receive support from a non-relative family or companion in the community. The agency selected to provide this service will seek to ensure compatible matches and provide supports for ongoing stability of this new family unit. Lifesharing providers are thoroughly screened and trained, and the host companion/family is supported by the agency provider. For some people who have grown up or always lived in a conventional family setting, Lifesharing can be an option that offers continuity, familiarity, and quality of life. For others, Lifesharing can bring new meaning and sense of belonging. The Office of Developmental Programs (ODP) is working to expand the use of Lifesharing based on its cost effectiveness, flexibility, and individualized approach.

A concern that you may want to consider is the fact that it can take time to find the right match between the individual and the host companion/family.

Licensed Lifesharing can be funded as Licensed Residential Habilitation through the Consolidated Waiver. Unlicensed Lifesharing can be funded through Home and Community Habilitation in both the Consolidated and Person/Family Directed Support Waivers. Base funding can also be used to fund Lifesharing for non-waiver participants.

Beginning in January 2006, ODP instructed County Programs/AE’s to institute practices to ensure people in need of a residential service are given the opportunity to consider Lifesharing before choosing a traditional group home, ICF/MR or other residential service options. At this time, there are over 2,000 people living in Lifesharing settings across the state. No more than two (2) people can live with one Lifesharing family or companion and most Lifesharing arrangements are licensed. Anyone, regardless of age, moving out of their current residence, including people moving from one residential program to another, should be given information about Lifesharing and an opportunity to meet a Lifesharing agency representative before choosing any other type of residential program funded by ODP.

Beginning in Fiscal Year 2007-08, ODP began a new initiative to provide Lifesharing and other Everyday Living opportunities to people who need residential support. Over 800 people have been served in this program to date. Other Everyday Living options include support to individuals who want to live with friends and with members of their birth family.

There is also a Lifesharing Subcommittee of the Planning Advisory Committee (PAC), which can be helpful to families who want to understand how Lifesharing works. Contact persons for the Subcommittee are:

CENTRAL REGION:
SARAH SHAW, SKILLS OF CENTRAL PA ............................................... 814-272-0341 x 217
JAMES MALESKY, ............................................................................... 717-635-2711
A Lifesharing point person has been designated in each AE/County and ODP Regional Office. These persons can be contacted if families have any questions about Lifesharing, including development of Lifesharing capacity within their AE/County. A list of ODP Regional office numbers are as follows:

**Western Region:**
- Dan Morfenski, Touch-Stone Solutions: 814-337-1259
- Darlene McConnell, Fayette Resources: 814-372-2115

**Central Region:**
- 717-772-6507

**NE Region:**
- 570-963-4749

**SE Region:**
- 215-560-2242

**Bulletin Reference for Lifesharing issues:**

<table>
<thead>
<tr>
<th>Subject</th>
<th>Bulletin #</th>
<th>Effective Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifesharing Through Family Living</td>
<td>00-05-04</td>
<td>8/8/2005</td>
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</tbody>
</table>

**Reverse Family Living**

Reverse Family Living is an individual specific program designed for individuals who have met with challenges in either the Community Group Home or Family Living setting. This home is owned by the provider and set up to provide a family setting with one live-in staff person providing services. If the staff person decides that he or she can no longer provide the services, the individual remains in the home and a new caregiver is hired.

**Owning Your Own Home**

An individual can own his/her own home and not have that counted against him/her as an asset; however, if they sell or rent the home the income counts as an asset. Carefully planned trust funds can be set up so an individual can inherit a family home and contract with a provider for care.
A concern for this arrangement is the need to have professional guidance from someone familiar with Medical Assistance Laws and trust planning when setting up this type of trust.

**You are encouraged to visit each of these programs and obtain firsthand knowledge as to the advantages and disadvantages of each choice. When you plan your visit prepare a list of questions to assure that your visit is productive.**

### Employment

Beginning in January 2006, the Office of Developmental Programs (ODP) instructed County Programs/AE’s to institute standard practices to promote employment through the Individual Support Plan and budget process. These practices are in place for all youth and young adults, age 16-26, and for all adults receiving vocational training in a workshop who want a job. Persons who do not fall into these groups should still have access to employment supports, and should discuss it with their Supports Coordinators.

County Programs/AE’s are responsible to ensure that people are:

- Advised about the availability of employment supports and services
- Given the opportunity to choose employment services and supports first before other types of adult training
- Given the opportunity to meet with employment providers and people who have jobs as a result of their own personal choice.

The ODP issued an *Employment Manual* for AE/County Programs in 2006 that can be useful to families and other stakeholders on ways to promote employment. A copy of this is available by contacting the ODP Customer Service Number at 888-565-9435 or downloading from the Partnership’s website [www.TheTrainingPartnership.org](http://www.TheTrainingPartnership.org)
An employment point person has been assigned to each ODP Regional Office and each AE/County. People are urged to contact their point person for further information. The phone numbers of the ODP Regional offices are:

**Western Region**: .............................................................................. 412-565-5144  
**Central Region**: ............................................................................... 717-772-6507  
**NE Region**: ....................................................................................... 570-963-4749  
**SE Region**: ......................................................................................... 215-560-2242

In fiscal year 2005-06, ODP began to fund AE/Counties to promote employment for youth and young adults in ten (10) AE/Counties. The program expanded to other AE/Counties in subsequent years and currently supports 24 pilot employment projects in FY 2009-10. Each of these pilot projects offers supported employment services for up to 10 youth and young adults per AE/County in conjunction with intensive supported employment services provided by the Office of Vocational Rehabilitation (OVR). As a condition of participation, AE/Counties participate in an employment coalition that includes family, provider agency and self-advocate representation, together with OVR and school district representation. The purpose of the coalitions is to continuously improve employment outcomes for transitioning youth and young adults through a collaborative process. Contact your AE/County to learn more about the pilot projects and to become involved in a coalition. A list of pilot AE/Counties follows.

<table>
<thead>
<tr>
<th>SE Region Pilot Counties</th>
<th>NE Region Pilot Counties</th>
<th>Central Region Pilot Counties</th>
<th>Western Region Pilot Counties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philadelphia</td>
<td>Berks</td>
<td>Bedford</td>
<td>Allegheny</td>
</tr>
<tr>
<td>Chester</td>
<td>Bradford Sullivan</td>
<td>Blair</td>
<td>Armstrong-Indiana</td>
</tr>
<tr>
<td>Montgomery</td>
<td>Lehigh</td>
<td>Cambria</td>
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<td>Northampton</td>
<td>Centre</td>
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<td></td>
<td>Luzerne-Wyoming</td>
<td>Cumberland-Perry</td>
<td>Erie</td>
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<tr>
<td>Carbon-Monroe-Pike</td>
<td>Dauphin</td>
<td>Lycoming-Clinton</td>
<td>Fayette</td>
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<td></td>
<td></td>
<td>Lebanon</td>
<td>Venango</td>
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The Federal government has funded various agencies in Pennsylvania to provide Work Incentives, Planning and Assistance (WIPA) to SSI and SSDI recipients who want to work.
Changes in State and Federal law have made it possible for SSI and SSDI recipients to begin working or return to work while continuing to receive benefits. WIPA counselors stationed across the state are available to provide no-cost consultations to individuals and families in determining how work will affect their Social Security, Medical Assistance and other benefits. Contact numbers are as follows:

**Western PA and Southern Allegheny Region – AHEDD** ............... 866-902-4333 Ext 191  
**Central and Northeastern PA - Goodwill Passabco** .............. 866-541-7005  
**Southeastern PA – Disability Rights Network (DRN)** ............... 800-692-7443 Ext 309

From 2006-2009, ODP continued a focused initiative under the P/FDS Waiver to promote employment of youth and young adults transitioning into adult life. Under this initiative almost 1,100 young adults received employment and community inclusive support after leaving high school based on needs established through the Individual Support Planning process.

**Bulletin References for Employment Issues**

<table>
<thead>
<tr>
<th>Subject</th>
<th>Bulletin #</th>
<th>Effective Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>ODP Policy on Employment</td>
<td>00-05-07</td>
<td>12/20/2005</td>
</tr>
<tr>
<td>Employment for Individuals in ICFs/MR</td>
<td>00-06-08</td>
<td>4/5/2006</td>
</tr>
<tr>
<td>Medical Assistance for Workers with Disabilities in the Community Mental Retardation Program</td>
<td>00-03-23</td>
<td>11/25/2003</td>
</tr>
</tbody>
</table>

**Future Planning (Why Should I Plan for the Future?)**

Future planning means taking a long hard look at what will happen to you when your family or caregiver is unable to provide the supports you need on a daily basis. Often, plans are not made before a crisis occurs, and that is when emergency placements and unplanned decisions are made by your AE/County. While your life and routine will be disrupted, it can be minimized by paying attention to detail and setting plans in place before life altering emergencies occur.

- Use the Self Determination model (making your own choices) to develop an overall plan.
  
  With Self Determination principles you develop your own programs and find people/professionals who can help you create the life you want and hire them. When you are in charge and have a well-defined plan developed, you make services and supports available to meet your standards. You do not have to accept what is available. The simple action of identifying people to work directly with you will create highly personalized programs.
and supports driven by you to attain the highest quality of everyday life. Directly finding your own support staff or people with whom you want to work has the potential to positively impact the capacity issue plaguing the Pennsylvania Mental Retardation system. Make sure you, your family or caregiver has created a Will and Estate Plan with planners experienced in this specialty area. Disabilities Rights Network has a document available to assist you with planning – the DRN can be reached by calling 800-692-7443 [Voice] or 877-375-7139 [TDD], or by visiting http://drnpa.org. Take the time to write out the following and keep this information in a special place:

- List of medications
- Your daily routine – This information would make your life easier and smoother if a hasty transition needs to occur.
  - What makes you happy?
  - What is your routine?
  - What do you do during the day?
  - What do you do when you come home from work or program?
  - What do you do for fun?
  - What makes you angry?
  - How can we stop frustrations and bad experiences from becoming major problems?
  - Who is your Doctor, Therapist, Supports Coordinator, Provider, Supporter? Make a list with their names, addresses and phone numbers and keep it in a convenient location.
  - Develop a list of your family and friends and include their phone numbers and addresses.

- There are options if you want to hire your own support workers to ensure those workers get paid for the services they provide. Two options are:

  - An organization can hire staff you refer to them. The organization is called an Agency with Choice FMS and is the “Employer of Record”.
  - You could become the “Employer of Record” and use a Vendor Fiscal/Employer Agent FMS, and the AE/County would reimburse your support workers for services provided to you.
CHAPTER 4: UNDERSTANDING YOUR RIGHTS

There are times when you will disagree with a decision or action made by the Administrative Entity/County. This chapter will outline steps you can take when you have a disagreement at the county level, what processes are in place to resolve conflicts, describe your rights in the process and discuss the Hearings and Appeals procedures for Waiver participants.

What to do When You Have a Problem:
County Level Dispute Resolution

WHAT SHOULD I DO IF I HAVE A PROBLEM WITH SERVICES THROUGH THE MENTAL RETARDATION SYSTEM?

If you have a problem, contact your Supports Coordinator (SC) first. Make sure you have clearly identified the problem and thought about how you would like it resolved. Speak frankly about the problem. If it is still not resolved, you can ask to discuss the issue with the Supports Coordinator Supervisor. If that doesn’t resolve the issue, you can go up the chain of command to the County Program Supervisor in the Mental Health/Mental Retardation (MH/MR) office.

If you are not sure your SC or Administrative Entity (AE)/County Program are following the rules, you can call the Office of Developmental Programs (ODP) customer service line (888-565-9435) for information and answers to questions about state policies and processes.

BASIC ADVOCACY TIPS

• Create and maintain a file of all paperwork related to your MR services.
• Get copies of all the applications and forms you fill out.
• Keep a log book to track phone calls and conversations with your Supports Coordinator, provider, or any other person involved in your planning or services.
• Always take someone (a friend or advocate) to meetings with you.
• Have someone take notes during meetings.
• When you discuss an issue, set a timeline for resolution and mark it on your calendar and in your phone log so you will know when to expect an answer. If you don’t have a response by that date, call to follow up.
• Ask for all decisions affecting your services in writing.
• Be persistent.
• Know your rights.
• If you have questions about ANYTHING, ask!
What can I do if my County MH/MR Program says I am not eligible for Mental Retardation services?

You have the right to appeal under the Local Agency Law (see below) when services through the County Program are denied, reduced or terminated. Each County Program must have a clearly defined, written policy and procedure for this appeals process. The process includes an administrative review procedure and will result in a written decision. You can ask your County for a copy of the policy and procedure.

This means that if you apply for Mental Retardation services in your county and are told you are not eligible, you have the opportunity to disagree with this decision. If you are denied eligibility for MR services, you will get a written notice explaining why you were denied.

LOCAL AGENCY LAW

The appeals process steps are as follows:

- Each County Program will appoint an impartial reviewer to hear the issues and arguments.
- A hearing will be scheduled – and can be recorded at no cost to you. You can also request a transcript of the hearing (at your expense).
- You can provide testimony, documentation and new information during the hearing. The reviewer can ask you questions.
- The County can also present information and facts about the decision.
- You can ask questions of the County Program.

What can I do if the County decides to reduce or cut my Family Support or Base services?

If you had been receiving services through Base-funding (Family-Driven Support, Family Support Services, etc.) and they are reduced or terminated, you can have a meeting with the County Program representatives, the Supports Coordination Organization and the provider, if appropriate, to attempt to resolve the issue.

If that doesn’t resolve the problem, each County has written procedures that explain how to appeal the denial or termination of services and supports. The local appeals process is the same as outlined in the previous section (LOCAL AGENCY LAW) for denial of services. When you receive written notice from the County that your services will be ending, you should also get information about the appeals process.

If you have been told over the phone or in a meeting that your supports are being reduced or terminated, you should request that in writing. The County is required to give written notice.
Unlike Waiver recipients, the County Program and/or provider can discontinue services due to lack of money and you are not entitled to have the services remain in place while you appeal the decision through the county process. However, you should argue and request that services remain until resolution.

Within 30 days of the hearing date, you will receive written notice of the decision. If you are not happy with the results, you can go on to the Court of Common Pleas.

If you request and are denied Base services, you also have appeal rights through Local Agency Law as described above.

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### Appeals for Persons with MR when Home and Community-Based Waiver services are Denied, Reduced, Suspended or Terminated

This section will briefly summarize the administrative appeals process within the Department of Public Welfare (DPW) available to individuals with mental retardation and their families or surrogates who apply for and/or receive services under the Consolidated Waiver or the Person/Family Directed Support (P/FDS) Waiver. **Please note that the information in this section is not intended to be and does not constitute legal advice.**

Some initial words of encouragement: An appeal costs you nothing but a little time and a little effort and has the potential to gain or retain important services for you or your family member. For most Waiver participants and applicants, the appeal is the first time you have a neutral person reviewing your case. History has shown that an appeal can often succeed even when an individual, family member or surrogate has no attorney or lay advocate and chooses to represent him- or herself.

### WHAT CAN YOU APPEAL?

Your right to appeal is very broad. You have the right to appeal any decision with which you are not satisfied that affects your services as well as the right to appeal any action, inaction, or delay with which you are dissatisfied. The following list reflects some common reasons for Waiver applicants or participants to pursue appeals, but it is by no means an exhaustive list:

- You are not allowed to apply for Waiver services at all.
- After you apply for Waiver services, you are told that you are not eligible because you do not have mental retardation, you do not need an ICF/MR level of care, or you do not meet the financial guidelines.
- You are told that you are eligible for Waiver services, but there is no available funding or waiver capacity now because of a waiting list. You should note, however, that although an unreasonable delay in the provision of services may be appealable, the state can (and does) maintain a waiting list for Waiver services and it is lawful to do so. As a result, an
appeal that is simply based on your placement on the waiting list is unlikely to succeed. However, it is your right to still file an appeal. In addition, you can also appeal your “PUNS” prioritization if you think that you should be categorized as a higher priority (such as “emergency” or “critical” rather than “planning”). Such an appeal, if successful, would result in your being placed higher on the waiting list.

• You are accepted into a Waiver, but you are denied services that you think are necessary to meet your needs or you are not provided services in an amount or for a time period that you think will be sufficient to meet your needs. You should note, however, that there is a monetary cap on the amount of services that can be provided under the Person/Family Directed Support (P/FDS) Waiver. If you are in the P/FDS Waiver and you are denied services or are provided with less service than you think you need because it would exceed the financial cap, an appeal is unlikely to succeed. However, it is still your right to file an appeal.

• Your Individual Support Plan (ISP) reflects all of the services that you think you need in the amount and for the duration you need, but you are not actually provided with those services.

• You are denied your choice of Waiver service provider.

• After you have been enrolled in the Waiver and approved for a certain service or certain level of service, you are informed that the amount of your services will be reduced or one or more of your services will be terminated.

• After you have been enrolled in the Waiver, you are informed that you have been or will be terminated from the Waiver entirely.

• You are not given written notice of any of the above actions or decisions.

You are not prevented from filing an appeal simply because you agreed to services in the ISP or signed the ISP.

**WHEN MUST YOU FILE YOUR APPEAL?**

Timelines are extremely important in the appeals process. Non-compliance with the deadlines for filing appeals can lead to the dismissal of the appeal or to your loss of “aid pending appeal.”

• **Deadline to Receive “Aid Pending Appeal”** – If you are appealing a decision that would change, reduce, suspend or terminate services that you had previously been authorized to receive, you have the right to continue to receive those services in the same amount, duration, and scope while your appeal is pending if you file an appeal of the decision to change, reduce, suspend or terminate the services within 10 calendar days of the mailing date of the written notice (or, if you did not receive notice at least 10 days before the effective date of the action, you can receive aid pending appeal if you filed your appeal within 10 days of being informed of the action). Keep the envelope with the notice you received.
• **General Appeal Deadline** -- You must file your appeal within 30 calendar days of the mailing date of the written notice (not the date on which you received the notice). Your appeal must be received within the 30-calendar day deadline, so you need to submit it before 30 calendar days expires if you are mailing it.

• **Deadline When You Have Not Received a Written Notice** -- If you did not receive a written notice of a decision, you have 6 calendar months from the date of the action or failure to act to file an appeal. If you want a written notice that tells you the reason for the decision, you should write to the Administrative Entity/County and tell it to either provide you with the services you want or with a written denial and the reasons for the denial. A sample letter is included as Attachment 1. If you take that route and receive the written denial, the deadlines for appeal (30 calendar days generally or 10 calendar days to continue to receive your services) are applicable.

• If you are afraid that you are going to miss the deadline to submit an appeal or to receive aid pending appeal, you can file an appeal by telephone. If a verbal appeal is submitted within the deadlines above, it will be considered timely as long as you follow up with a written appeal within three days. If you do not file a written appeal within three days, your appeal may be dismissed as untimely or you may lose your right to aid pending appeal. When you file your appeal by telephone, you can ask for assistance to file the written appeal. When you follow up with a written appeal, make certain that your written appeal states when you submitted your telephone appeal and, if appropriate, that you want aid pending appeal.

**WHAT SHOULD YOU WRITE IN YOUR APPEAL?**

ODP has a “**Fair Hearing Request Form**” also known as “**Form DP 458**” that you should use to submit your Waiver-related appeal. This form should be included with any written notice of decision that you receive from the Administrative Entity/County. You can also request the form from your Supports Coordinator or Administrative Entity/County. You should submit the form to the Administrative Entity/County, which will forward it to DPW’s Bureau of Hearings and Appeals. You must complete the information on the form, stating:

• **The specific actions or inactions that you are appealing.** For example: a determination that you are not eligible for the Waiver because you do not have mental retardation; a denial of your request for Prevocational services; authorization of only 20 days of overnight Respite instead of the 30 days you requested; termination of your Chore services, etc.

• **Whether you want a face-to-face or a telephone hearing.** It is recommended that you ask for a face-to-face hearing if it is at all possible for you to get to one of the six locations where fair hearings are held: Philadelphia, Pittsburgh, Harrisburg, Erie, Wilkes-Barre, and Reading.
• **Whether you need a language interpreter or other accommodations.** There is a place in the form for you to request a language interpreter (such as Spanish or sign language) or other type of communication assistance or accommodation (for example, a TTY if some witnesses will provide testimony by telephone or large print documents for someone with a visual impairment).

• **Don’t forget to sign the form.** The appellant (that is, the individual with mental retardation) or his or her surrogate or both must sign the form. If the appellant can only make a mark as a signature, two witnesses (such as family members) must also sign.

Along with your completed and signed Form DP 458, you should include a **cover letter**. The cover letter should include any information not in the form. For example, you might want to indicate how much time you think you will need (most hearings require at least two hours) and reiterate your need for any accommodations. You should also include a copy of the denial notice. See Attachment 2 for a sample cover letter.

**WILL THERE ALWAYS BE A HEARING?**

After you submit your request for a hearing to the Administrative Entity/County (by completing and signing Form DP 458), it will be forwarded within 3 working days to both DPW’s Bureau of Hearings and Appeals and to the appropriate Regional Office of DPW’s Office of Developmental Programs (ODP). This allows the opportunity for a **“service review”** in some instances.

As part of the service review, the Regional Office will review the reasons for appeal and any additional information, and may contact the individual, family, surrogate, or the AE/County Program for clarification. ODP, through the Regional Office, will then make a determination as to whether, in its view, the decision is consistent with Waiver requirements, regulations, and pertinent ODP Bulletins. ODP’s Regional Office will mail its determination to the individual or family, the AE/County, and DPW’s Bureau of Hearings and Appeals within 15 calendar days following receipt of the appeal.

The Regional Office review allows ODP an opportunity to correct errors before the matter proceeds to a hearing. If the Regional Office requires that a service be provided to the individual, the AE/County must initiate those services within 30 days of the service review unless otherwise specified in the Regional Office’s determination or unless the AE/County Program seeks and receives an extension from the Regional Office.

The AE/County must offer you a **“pre-hearing conference.”** You are not required to agree to such a conference. If you do agree to the conference, neither you nor the AE/County is required to change your respective positions. The pre-hearing conference is to discuss the appeal issue and give additional information if appropriate.
WHAT SHOULD YOU DO TO GET READY FOR THE HEARING?
If the matter is not resolved, DPW’s Bureau of Hearings and Appeals will notify you at least 10 days in advance of the date and time when your hearing will take place.

As you prepare for the hearing, you need to focus on what you need to prove. What you need to prove will vary, depending on the nature of the issue you appealed.

Many Waiver appeals involve individuals who are in a Waiver, but who have been subject to denials (totally or in the requested amount or duration), reductions, suspensions, or termination of services. In appeals of these issues, you will need to prove:

• You are in the Waiver (or, if the issue involves application and financial eligibility that you sought to apply or did apply and were denied).
• You asked for the service or item.
• You either: (1) were denied the service (or it was not provided in the sufficient amount) or the service was initially approved and subsequently reduced, suspended, or terminated, or (2) you received no response to your request.
• The service item you need is available through the Waiver and the applicable ODP Service Definitions. Bring a copy of the Waiver and Service Definitions, available through DPW’s website or The Partnership’s website, www.TheTrainingPartnership.org.
• The problems or consequences that you will face if you do not get the necessary services.
• If you are in the P/FDS Waiver that the requested services (together with your approved services) will not exceed the financial cap.

Witnesses
After you list all the elements that you need to prove your appeal, you should identify witnesses and gather documents you will need to submit as proof for each element. Witnesses can include, for example, you, your family members, surrogate, friends, your providers, and your Supports Coordinator.

Note: Make sure to contact any necessary witnesses—especially doctors or other health care professionals with particularly busy schedules—to be sure that they will be willing and available to support you with testimony at the hearing. Even if you’ve requested a face-to-face hearing, some witnesses can testify by telephone or submit affidavits if they are unable to appear in person at the hearing.

Documents
Documents may include, for example, the current version of the relevant Waiver (Consolidated or P/FDS); the current version of the Service Definitions used for the Waivers; letters of medical necessity from your doctor or other relevant health care provider; any written requests that you made to receive the service; written denials by the AE/County; or your Individualized Supports Plan.
According to DPW, the AE/County Program should provide you with relevant documents and the names of staff members or other witnesses who will be present at the hearing as soon as possible after the appeal is filed. However, if you do not receive that information or if you need additional information, you have the right to submit a Records Request to gather documents to which you might not otherwise have access. DPW regulations allow you to request records from the AE/County (or, if appropriate, the AE or BSU). You can use this right to request, for example, any and all records they plan to use at the hearing and a list of witnesses they plan to present at the hearing. You should send this Records Request by registered mail with a return receipt requested to be sure that you can prove it was received. A sample Records Request is included as Attachment 3.

You can request a subpoena to get documents from other parties, such as a provider. To get a subpoena, you need to contact the Administrative Law Judge (known as the ALJ or, sometimes, as the hearing officer).

You may also choose to write a brief to submit to the Administrative Law Judge at the hearing. The brief can summarize why you think the decision was wrong factually and/or legally.

If you are having problems preparing for the hearing, contact the Administrative Law Judge. You may request that the hearing be postponed and give the reason for the request. The ALJ may approve the request. Usually, you will only be permitted to extend the time for a hearing (known as a continuance) only once, but if you have good reason for an additional extension you can request one from the Administrative Law Judge.

**WHAT WILL HAPPEN AT THE HEARING?**

The Administrative Law Judge is in charge of the hearing and is responsible to make sure that he or she gets all the information needed to make a fair decision. The hearing proceeds in the following order:

1. The Administrative Law Judge will briefly describe the hearing procedure.
2. The appellant (you) or your surrogate will be asked to state the issues to be resolved by the hearing.
3. The AE/County will present its evidence and witnesses first.
   a. *Objections* – If you sent a Records Request to ask for records and a list of witnesses, you can (and should) object to any witnesses whose names were not provided to you in advance of the hearing or to any documents you did not receive copies of if you sent a Records Request and requested those documents. Show the Administrative Law Judge a copy of your Records Request and the return receipt and tell him or her that the regulations do not allow use of records or witnesses when you requested the information and did not receive it.
b. *Questions* – You have the right to ask questions of the witnesses presented by the AE/County after they have completed their testimony. If you are not sure of what the answer to your question will be, it is often safest not to ask the question.

4. After the AE/County Program is finished, you will have the opportunity to have your witnesses testify and to present your documents. Make sure that the Administrative Law Judge has a copy of each document and knows that you want it to be considered as evidence. The AE/County has the right to question your witnesses.

5. The Administrative Law Judge can ask anyone questions at any time during the hearing.

6. Before the end of the hearing, you can ask the Administrative Law Judge for the opportunity to send additional evidence or written arguments. Usually, if the Administrative Law Judge grants your request, you must submit the additional information within 5 calendar days, but in special cases you might be given up to 30 days to submit the additional evidence. If you send additional information, make certain that you also send a copy to the AE/County Program.

**WHEN SHOULD I EXPECT A DECISION?**

The Administrative Law Judge is supposed to issue a decision on your appeal *within 90 calendar days after you filed your appeal*. However, if the hearing was delayed because of your request (for example, if you asked for and received a continuance), the days during that delay will not count toward the 90 calendar-day period. For this reason, it is important to request delays only if it is really necessary and to make the delay as short as possible.

If the Administrative Law Judge does not issue a decision within the 90 calendar days (plus any additional days due to delays resulting from your request for delay), then you have the right to begin to receive the service that is the subject of the appeal. This is known as “interim assistance.” For example, if you appealed your denial of Homemaker services, more than 90 calendar days have passed since the date you filed your appeal, and you did not cause any delays during that period, then you have the right to begin receiving those Homemaker services until the Administrative Law Judge issues his decision. If you are found to be eligible for interim assistance, the assistance will begin within 48 hours of the request and will continue until the Administrative Law Judge decides the appeal. A sample request for interim assistance is included as Attachment 4.

**WHAT WILL HAPPEN IF I WIN THE APPEAL?**

If the Administrative Law Judge rules in your favor on the appeal, the AE/County Program must generally implement the decision within 30 calendar days unless otherwise specified in the decision. The AE/County can seek further extensions from the ODP Regional Office.

The AE/County also may request reconsideration from the Secretary of Public Welfare.
WHAT CAN I DO IF I DO NOT WIN THE HEARING?

Reconsideration
If you are not happy with the final decision issued by the Administrative Law Judge, you can file a request for reconsideration with the Secretary of Public Welfare.

- A request for reconsideration must be filed within 15 calendar days of the date of the Administrative Law Judge's decision. The request must be made in writing and state the basis for your disagreement with the decision. Although you should address the request to the Secretary, you must send it to the Director of DPW's Bureau of Hearings and Appeals, who will forward the request along with the entire file to the Secretary.

- The Secretary has the authority to change the Administrative Law Judge's decision if it is not consistent with policies or requirements, but the Secretary cannot change the facts that the Administrative Law Judge has found to be true.

Pennsylvania Commonwealth Court
You can also file an appeal of the Administrative Law Judge's decision in Pennsylvania Commonwealth Court. You must file your court appeal within 30 days of the date of the hearing officer’s decision -- even if you have already filed a request for reconsideration that is pending.

Trying Again
There is nothing that prevents you from trying again with the County MH/MR Program. If your appeal involved your ineligibility for the Waiver, then you can try to reapply for the Waiver. If your appeal involved specific services in the Waiver, you can re-request those services. This strategy, obviously, can be most fruitful when there are changes in the facts or there has been an opportunity to gather more information to support your claim. For example, if you have regressed or otherwise suffered harm in the interim that you have not had the service, then those factors might be sufficient to result in a different decision.

WHO CAN I CONTACT FOR ASSISTANCE?
Although many people represent themselves or proceed at hearings without a lawyer or advocate, it can be helpful to have a lawyer or advocate present at these hearings. Your local legal services program might be able to provide you with free legal help. You also can contact the Disability Rights Network of Pennsylvania at 800-692-7443 or 877-375-7139 (TTY) or the Pennsylvania Health Law Project 800-274-3258 to get some basic information about appeals and the telephone numbers of local legal services organizations.
Attachment 1

SAMPLE REQUEST FOR SERVICES/Demand for Denial Letter

April 1, 2009
MR Coordinator/Director
Address of AE/County Program
Re: John Doe’s Request for Services Under the Person/Family Directed Support Waiver

Dear MR Coordinator/Director:

I am writing to request that you immediately provide the following services to John Doe through the Person/Family Directed Support Waiver:

- Homemaker/Chore services three nights per week to provide housekeeping, cooking, and shopping.
- Home Accessibility Adaptation in the form of a stair glide to allow Mr. Doe to use the second floor in the house.

If you do not approve these services, please immediately issue a written denial as required by DPW regulations, 55 PA Code Chapter 275, and send a copy to me, as I am assisting Mr. Doe with this issue. If Mr. Doe does not hear from you by April 21, 2009, I will assume that you are denying this request and will request a fair hearing.

Sincerely,

cc: Supports Coordinator
    ODP Regional Office
    Advocate or Attorney (if applicable)
April 1, 2009  
MR Coordinator/Director  
Address of AE/County Program  
Re: John Doe’s Appeal and Request for Fair Hearing  

Dear MR Coordinator/Director:  

I am writing to appeal the denial dated March 25, 2009. In that written notice, you say that Mr. Doe’s Homemaker/chore services will be reduced to one visit per week. I am writing to appeal that decision, to request a fair hearing, and to request that the three visits per week that Mr. Doe currently receives remain in place during the appeal.  

I request a face-to-face hearing be held at the office closest to Mr. Doe’s home. I request that the hearing be scheduled for at least 2 hours.  

I request that you provide any documents in large print to accommodate Mr. Doe’s visual disability.  

I have enclosed a signed copy of DPW Form DP 458, as required.  

Sincerely,  

Enclosed: DPW Form DP 458  
cc: ODP  
ODP Regional Office  
Supports Coordinator  
Advocate or Attorney (if applicable)
SAMPLE RECORDS REQUEST
April 1, 2009
BY REGISTERED MAIL
MR Coordinator/Director
Address of AE/County Program
Re: Request for Records and Other Information from the County MR Program

Dear MR Coordinator/Director:

Pursuant to 55 Pa. Code § 275.3(a)(3), please immediately provide me with copies of the following items at the above address regarding the appeal of [individual's name] involving the denial of his [type of service] under the [Consolidated or P/FDS] Waiver:

1. Any and all documents on which the [name of county] MH/MR Program relied upon to deny services to [individual's name], including, but not limited to, the following: county, state, or federal regulations, manuals, statements of policy, Bulletins, contracts or other agreements between the Department of Public Welfare and/or any service providers involved in this appeal.

2. A current copy of Pennsylvania's [Consolidated or P/FDS] Waiver

3. Any and all documents concerning whether [insert type of denied service] is covered or coverable or reimbursable in any form under the Waiver, including, but not limited to, the following: county, state, or federal regulations, manuals, statements of policy, Bulletins, contracts or other agreements between the Department of Public Welfare and/or any service providers involved in this appeal.

4. Any and all documents concerning due process and appeal procedures available to MR service recipients, including, but not limited to, the following: county, state, or federal regulations, manuals, statements of policy, Bulletins, contracts or other agreements between the Department of Public Welfare and/or any service providers involved in this appeal.

5. Any and all documents concerning the decision that is the subject of this appeal, including, but not limited to, the following: notes of meetings, telephone calls, correspondence, e-mail, electronic or facsimile transmission, HCSIS entries, or other conversations or communications.

6. Any and all documents that provide evidence that [individual's name] was accepted into the Waiver, including, but not limited to, the following: file notes, payment records, vouchers,
contracts with case management services, and other providers of waiver services.

7. Any and all documents that indicate what amount has been budgeted and spent on [individual's name] for Waiver services since his [or her] acceptance into the Waiver, including, but not limited to, the following: file notes, payment records, vouchers, contracts between DPW and any and all providers involved in this appeal. [Note that this request is geared mainly to people in the P/FDS Waiver]

8. Any and all documents that indicate the financial cap for what could be spent on Waiver services for [individual's name], including, but not limited to, the following: file notes, payment records, vouchers, contracts with case management services, and any and all other providers of waiver services, letters, Bulletins, or other information. [Note that this request is geared mainly to people in the P/FDS Waiver]

9. Information concerning the names, experience, and credentials of any personnel participating in the decision to deny MR services to [individual's name].

10. Information concerning the names, experience, and credentials of any and all witnesses who the [name of county] AE/County will present at the hearing on this matter.

11. Any and all documents or other evidence which the [name of county] AE/County will present at the hearing in this matter.

12. Any and all documents concerning [individual's name] generated in the last two years, including, but not limited to, the following: correspondence, notes, or other items which are part of any file, case record, or other data (including HCSIS information) maintained or possessed by the [name of county] AE/County Program or case management service provider, individual service plans, any and all requests for MR services, denials of MR services, and fair hearing and appeals proceedings.

Again, please mail these documents to me at the following address: [insert your address]. Please note that I can also be reached either by phone at [insert phone number here] or e-mail [insert e-mail address here] if you have any questions or concerns.

Sincerely,
SAMPLE REQUEST FOR INTERIM ASSISTANCE

April 1, 2009
MR Coordinator/Director
Address of AE/County Program
Re: John Doe’s Request for Interim Assistance

Dear MR Coordinator/Director:

As you know, John Doe appealed his denial of Homemaker services under the Person/Family Directed Support (P/FDS) Waiver. It has now been 90 calendar days since his appeal was filed, but final administrative action has not yet been taken on his appeal. Accordingly, I am writing to request that interim assistance begin immediately pursuant to 55 PA Code § 275.4(d). Interim assistance in this matter should take the form of immediate authorization of three visits per week of Homemaker services.

Thank you for your attention to this request.

Sincerely,

cc: ODP Regional Office
Supports Coordinator
CHAPTER 5: QUALITY

This chapter explains the systemic processes ODP has in place to monitor and ensure quality.

What is Quality?

Quality can be defined as a self-determined life that is fulfilling: your services and supports meet your needs, and the people helping you and providing you with service and supports are able to support you in a way that allows you to live the life that you want. Since you can now manage the funding through your Individual Support Plan and budget, you are in charge of the services and supports you purchase. You can choose the providers that provide your services. You can recruit, hire, or fire qualified support services workers. Therefore, it is important for you to remember if the people providing your services do not meet your expectations, you have the right to change your mind, your plan, and the people you hired or the providers you selected.

Independent Monitoring for Quality (IM4Q)

In 1997, ODP’s Multi-Year Plan presented eight recommendations for change and improvement in the Pennsylvania Mental Retardation system. Among these recommendations was the creation of local independent monitoring teams, which resulted in the development of Independent Monitoring for Quality (IM4Q).

IM4Q is intended to determine individual and family satisfaction and outcomes through a confidential and voluntary interview process with independent IM4Q teams. IM4Q teams are composed of paid and trained family members, people with disabilities, and interested others who interview people receiving services and their families.

Over 6000 IM4Q interviews are conducted annually across the state. Considerations based on these interviews are shared with Counties/Administrative Entities (AEs), which are responsible to ensure that the considerations are addressed to the satisfaction of the individual and the family. Copies of annual statewide and individual AE/County IM4Q reports that contain aggregate results from these interviews are used by the ODP and AEs to continuously improve services and support within the ODP Quality Framework. Copies of these reports are available on request by contacting the ODP Customer Service Line at 888-565-9435 or 866-388-1114 (TTY).

Each County/ AE has a designated IM4Q Coordinator who can be contacted for additional information, including County/AE IM4Q reports. Each ODP Regional Office also has an
IM4Q Program Coordinator who can be contacted for additional information. Contact information for the ODP Regional Offices are:

<table>
<thead>
<tr>
<th>Region</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>CENTRAL</td>
<td>717-772-6507</td>
</tr>
<tr>
<td>NE</td>
<td>570-963-4749</td>
</tr>
<tr>
<td>SE</td>
<td>215-560-2242</td>
</tr>
<tr>
<td>WESTERN</td>
<td>412-565-5144</td>
</tr>
</tbody>
</table>

The IM4Q interview was designed to be conducted by people with intellectual disabilities, families, and interested others. Monitors are independent from the services and local systems they are monitoring. Independent Monitoring teams are comprised of at least two people, one of whom is an individual with a disability or a family member. These teams conduct face-to-face interviews using questions that measure quality of life in the areas of satisfaction, dignity and rights, choice and control, relationships, and community inclusion. The teams also record their impressions of the individual’s life conditions and interview families, guardians, and friends. Family members and individuals with disabilities are encouraged to become part of their local monitoring activities. Contact your AE/County Program or ODP Regional Office if you are interested in finding out more information on IM4Q in your local area.

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**Health Care Quality Units (HCQUs)**

Pennsylvania established eight regional, non-profit Health Care Quality Units (HCQUs) to assist with improving the health of people with mental retardation. The organizations provide training and technical assistance to community support and medical providers to help both systems serve people with MR and other health conditions. The HCQUs also provide training and technical assistance to counties, MR providers, and health care providers to help them improve people’s access to health services.

The Health Care Quality Units collect and analyze health status data to inform systemic health improvement efforts. The HCQUs assess a sample of individuals each year to track their health status and access to medical services. The participants, family members, and providers are notified if an individual’s profile identifies areas that may require intervention. Health Risk Profile results are reviewed at the provider, county, and regional levels to inform quality improvement initiatives.

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**Incident Management**

The primary goal of incident management is to assure that when an incident does occur, the immediate and ongoing response will be adequate to protect you. Anyone who receives funds from the Mental Retardation system—either directly or indirectly to provide or secure services
or supports for people—or resides in an Office of Developmental Programs (ODP) licensed facility is afforded the protections of the incident management policy. Providers who receive funds or are licensed by ODP must report incidents which are defined in the Mental Retardation Bulletin Number 6000-04-01.

If you observe or suspect abuse, neglect, or any inappropriate conduct, whether services are provided out of the home or in the home, you should contact your Supports Coordinator, or call the ODP Customer Service Number at 888-565-9435. In the event of death of a person living in a residential setting, the family will be notified by the Supports Coordinator or provider.

When you receive services in your home from a provider or contracted staff, they must report incidents that occur when they are present in your home. The following are the types of incidents that are reportable: abuse (physical, psychological, sexual, verbal, improper or unauthorized use of restraint), death, disease reportable to the Department of Health, emergency closure, emergency room visit, fire, hospitalization, individual-to-individual abuse, injury requiring treatment beyond first aid, law enforcement activity, missing person, misuse of funds, neglect, psychiatric hospitalization, rights violation, suicide attempt, medication errors, and restraints. Please see the Bulletin for the definitions for each type of incident.

The providers must report suspected or alleged abuse immediately. They must also report the death of anyone to whom they are providing services. When you are only receiving Supports Coordination services, the Supports Coordinator will report incidents of suspected abuse, neglect and death whenever they learn of them.

If you have questions on the Incident Management Policy please contact your Supports Coordinator.
CHAPTER 6: 
BUREAU OF AUTISM SERVICES

Mission Statement

The mission of the Bureau of Autism Services is to develop and manage services and supports to enhance the quality of life for Pennsylvanians living with Autism Spectrum Disorders and to support their families and caregivers. The Bureau of Autism Services, BAS, will carry out its mission through the creation and administration of adult service delivery models, through the development of resources to support individuals with autism and their families, and through collaboration with other DPW offices and government agencies.

Values

- Support those living with an ASD throughout the life span
- Support those living with an ASD across the spectrum
- Families need our support
- Every person living with an ASD can have an improved quality of life given the right supports delivered by trained staff
- BAS’ goal is to increase independence and self-sufficiency
- Need to explore innovative models

About the Bureau of Autism Services

In recent years, the number of individuals in Pennsylvania diagnosed with an autism spectrum disorder (ASD) has risen. A 2007 study (PDF download)∗ from the federal Centers for Disease Control and Prevention indicates that one in 150 children have some form of autism. A recent study in Pennsylvania** shows that in 2005 there were a total of 19,862 individuals across the lifespan diagnosed with ASD living in the Commonwealth and that by 2010 that number will have increased to at least 25,000. Pennsylvania will see a significant increase in the number of adults with autism, growing by 179% to more than 3,800 in 2010 and to more than 10,000 by 2014.

In response to growing difficulties in meeting the needs of individuals with autism in Pennsylvania, Estelle B. Richman, then the newly appointed Pennsylvania Secretary of Public


** Pennsylvania Autism Census Report, available by visiting www.autisminpa.org or calling 866-539-7689
Welfare, created the Autism Task Force in 2003. This Task Force, which is comprised of over 250 family members of people living with autism, service providers, educators, administrators and researchers, was charged with developing a plan for a new system for individuals living with autism and their families that would make Pennsylvania a national model of excellence in autism service delivery.

One of the most important strategic goals of Pennsylvania’s Autism Task Force, which published its final report in 2004, was to create a program office within the Pennsylvania Department of Public Welfare to focus on the challenges faced by individuals with developmental disabilities. The creation of the Office of Autism Affairs, which was transformed into the Bureau of Autism Services in early 2007 within the Office of Developmental Programs has helped the Department of Public Welfare take great strides towards this goal.

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Services and Supports Available through the Bureau of Autism Services: ACAP and the Adult Autism Waiver

**BAS Adult Programs**

One of the primary goals of the Bureau of Autism Services is to develop autism-specific programs for adults with an ASD not served by any system, the second solution suggested by the Autism Task Force (DPW, 2004). BAS has developed two innovative programs to provide additional choices to individuals with an ASD: the Adult Autism Waiver and the Adult Community Autism Program (ACAP). These programs are the first of their kind in the nation!

Both programs are designed to help adults with an autism spectrum disorder (ASD) participate in their communities in the way that they want to. The goals of both programs are to:

- Increase the person’s ability to care for themselves
- Decrease family/caregiver stress
- Increase quality of life for both the person and the family
- Provide specialized supports to adults with an ASD based on need
- Help adults with an ASD reach their employment goals
- Support more involvement in community activities
- Decrease crisis episodes and psychiatric hospitalizations

There are some key features that make the Adult Autism Waiver and ACAP different from other programs available to adults with an ASD in Pennsylvania:

- Specifically designed to meet the needs of adults with an autism spectrum disorder (ASD)
- Administered at the state level directly by BAS
- Do not use IQ as an eligibility factor
- Providers required to complete autism-specific training and meet standards
• Clinical and technical assistance available to enrolled providers
• Service planning and measures of success based on individual goals
• Services based on proven approaches to help individuals realize their goals

There are some differences between the two programs. The **Adult Autism Waiver** is a traditional HCBS waiver designed to provide long-term services and supports for community living, tailored to the specific needs of adults with an ASD. The Adult Autism Waiver does not include physician services. On the other hand, **ACAP** is not a waiver. It is a managed care program that includes some innovative approaches to service provision. It provides physician, behavioral, and community services through an integrated approach to create a coordinated system of supports. The chart below outlines some other distinguishing features of each program.

<table>
<thead>
<tr>
<th>Adult Autism Waiver</th>
<th>Adult Community Autism Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available statewide</td>
<td>Currently available in 4 counties</td>
</tr>
<tr>
<td>Priority given to individuals not receiving ongoing state/federally funded services</td>
<td>ACAP becomes the participant’s health plan</td>
</tr>
<tr>
<td>Participant retains Health Choices; physical health services not included as a waiver service</td>
<td>Integrated physical/behavioral health and community services</td>
</tr>
<tr>
<td>Choice of an enrolled provider for all services</td>
<td>Keystone Autism Services and their network of providers (e.g. primary care physicians) provide most services</td>
</tr>
<tr>
<td>Does allow for residential 24/7 care if a need is determined through assessment</td>
<td>At intake, participant cannot require 16 or more hours of awake support</td>
</tr>
</tbody>
</table>

**WHAT ROLE DOES THE INDIVIDUAL WITH AN ASD PLAY IN THE BAS ADULT PROGRAMS?**
The participant is at the center of all service planning and service delivery. During the service planning process participants share their goals, likes and dislikes to help determine what services they will receive. Once enrolled in the Adult Autism Waiver or a cap, the participant is actively involved in the services they receive and their ongoing services plan.

**WHAT ROLE DO FAMILIES PLAY IN THE BAS ADULT PROGRAMS?**
Families have the opportunity to provide information during the service planning process and to provide feedback about the program. Decreased family stress is one goal of both program and is assessed each year.
HOW DO I APPLY FOR THE ADULT AUTISM WAIVER OR THE ADULT COMMUNITY AUTISM PROGRAM?

All application requests must be made through the Bureau of Autism Services’ toll free number at 866-539-7689. Applications may not be requested by email and are not available on-line.

Call the toll free number and leave a message with the following information:

- Name of person who wishes to apply
- Telephone number
- Address
- County of residence
- If you are calling on the behalf of the person who wishes to apply also leave your name and daytime phone number.

NOTE: Keystone Autism Services cannot accept requests for applications for ACAP.

Please visit www.autisminpa.org for more details about next steps in the application process for each program.

Below are responses to some frequently asked questions about the Adult Autism Waiver and the Adult Community Autism Program (ACAP). If you can’t find the information you are looking for here, you can find more information and answers to Frequently Asked Questions including Program Overviews, Eligibility, federal Level of Care, Application Processes, Services, and Provider Networks, by visiting www.autisminpa.org

You can also call 866-539-7689 or email the BAS program offices directly:

- **Adult Autism Waiver**: RA-odpautismwaiver@state.pa.us.
- **ACAP**: RA-acap@state.pa.us

You can also contact Keystone Autism Services (the ACAP service provider) at 717-412-7400 or 877-501-4715, Monday through Friday, 9 a.m. to 5 p.m. to speak to someone directly about ACAP services, or visit their website at Keystone Autism Services - Adult Community Autism Program or www.keystoneautism.org

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**Adult Community Autism Program (ACAP)**

Pennsylvania’s Adult Community Autism Program (ACAP) is specifically designed to help adults with an autism spectrum disorder (ASD) participate in their communities in the way that they want to. The participant is at the center of all service planning and service delivery. The goals of the program support the development of peer and social networks, help adults with an ASD reach employment goals, and support more involvement in community activities. Overall, the services are designed to increase the quality of life for both the person and his/her family.
The Bureau of Autism Services (BAS), DPW has selected Keystone Autism Services (KAS), an agency of Keystone Human Services, to implement the ACAP program. KAS and its network of providers will also be providing most of the services. Currently, ACAP can serve 200 people who live in Dauphin, Cumberland, Lancaster and Chester counties.

**WHAT ARE THE ELIGIBILITY REQUIREMENTS FOR THE ADULT COMMUNITY AUTISM PROGRAM (ACAP)?**

In order to be eligible for ACAP, a person must meet the following criteria:

- Be 21 years of age or older
- Be eligible for Medical Assistance
- Have a diagnosis of an autism spectrum disorder (ASD)
- Be certified as meeting Medical Assistance program clinical eligibility for Intermediate Care Facility (ICF) services in the Commonwealth of Pennsylvania
- Not be enrolled in a Medical Assistance Home and Community Based Waiver program at the time of enrollment
- At the time of enrollment, be able to live in a community without sixteen (16) or more awake paid and unpaid staff and supervision hours per day without presenting a danger to self or others or a threat to property
- Not exhibit levels of extremely problematic behaviors that would present a danger to self or others or threat to property
- Reside in the service area at time of application
- Not be enrolled in a Medical Assistance Managed Care Organization (MCO) at the time of enrollment in the plan

**IF I AM FOUND ELIGIBLE FOR ACAP HOW LONG CAN I REMAIN IN THE PROGRAM?**

There is no time limit or maximum age limit. Participants are assessed each year to ensure they continue to meet all eligibility requirements.

**ASSESSMENT AND INDIVIDUAL SERVICE PLANS**

Individual needs and interests are used by the participant and their team to develop an Individual Service Plan (ISP). The ISP team includes the Supports Coordinator, a Behavioral Health Specialist, the participant, the participant’s legal guardian (if applicable), and anyone else the individual or legal guardian chooses to have involved. The ISP specifies the services a participant will receive, the reason(s) those services are needed, and the goals and objectives of the services.
SERVICES THAT ARE OFFERED IN ACAP INCLUDE:
All physician services (including emergency services provided by a physician, psychiatric services, and direct access to a woman’s health specialist to provide women’s routine and preventive health care services)

- Certified Registered Nurse Services
- Intermediate Care Facility (ICF services)
- Nursing Facility Services
- Non-emergency medical transportation to services covered under the
- Medical Assistance Program
- Optometrists’ services
- Chiropractors’ services
- Audiologist services
- Dentist services
- Health Promotion and Disease Prevention services
- Medical supplies and durable medical equipment
- Prosthetic eyes and other eye appliances
- Hospice services
- Mental health crisis intervention services
- Outpatient psychiatric clinic services
- Respiratory services
- Targeted Case Management
- Assistive Technology
- Behavioral Support (similar to Behavioral Specialist Services in the Adult Autism Waiver)
- Community Transition Services
- Crisis Intervention Services
- Adult Day Habilitation
- Environmental Modifications
- Family Counseling
- Habilitation
- Homemaker/Chore services
- Non-Medical Transportation
- Personal Assistance Services
- Pre-vocational Services
- Residential Support (similar to Residential Habilitation)
- Respite
- Supported Employment
- Supports Coordination
- Visiting Nurse
- Additional services determined necessary
- Physical, Occupational, Vision and Mobility, and Speech therapies (group and individual)
Other ACAP services covered under Medical Assistance: Inpatient Facility, Ambulatory Surgical Center, Home Health Care, Clinic- including family planning, Transportation, Renal Dialysis Center, Laboratory, X-ray Clinic, Pharmacy

The Adult Autism Waiver

The Adult Autism Waiver is a Medicaid program that provides home and community-based services specifically designed to help adults with an autism spectrum disorder (ASD) participate in their communities in the way they want to. Like the Consolidated and Person/Family Directed Supports Waivers in the Office of Developmental Programs, the Adult Autism Waiver is funded through a combination of state monies and federal monies. The Adult Autism Waiver was initially approved to serve 200 participants statewide. A request to increase this number to 300 was submitted to the Centers for Medicare and Medicaid Services (CMS) in spring 2010.

What are the eligibility requirements for the Adult Autism Waiver?
In order to be eligible for the Adult Autism Waiver, a person must be age 21 or older, a resident of Pennsylvania (or planning to be a resident at the time of enrollment) and meet certain diagnostic, financial and functional eligibility criteria listed below. Priority is given to people not already receiving ongoing state-funded or state and federally-funded long-term care services.

Diagnostic Criteria:
• Must have a diagnosis of an autism spectrum disorder (ASD), which includes:
  ➢ Autistic Disorder
  ➢ Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)
  ➢ Asperger Syndrome
  ➢ Childhood Disintegrative Disorder
  ➢ Rett’s Disorder

Financial eligibility:
• Must meet Medicaid Medical Assistance resource and income limits for waiver programs in Pennsylvania
• The income limit is currently 300 percent of the Supplemental Security Income Federal Benefit Rate. More information on the Federal Benefit Rate can be found at www.ssa.gov.

Functional eligibility:
• Must have substantial functional limitations that are likely to continue indefinitely in three or more of the major life activities listed below. These functional limitations, which must be evident before the person reaches the age of 22, include limitations in:
  ➢ self-care
understanding and use of receptive and expressive language
learning
mobility
self-direction
capacity for independent living

**CAN SOMEONE WITH A DIAGNOSIS OF AN INTELLECTUAL DISABILITY (ALSO CALLED MENTAL RETARDATION) ENROLL IN THE ADULT AUTISM WAIVER?**
Yes, as long as they meet all the eligibility criteria listed above.

**IF I AM ALREADY RECEIVING SERVICES, CAN I STILL APPLY FOR THE ADULT AUTISM WAIVER?**
Yes. A person can request an application while receiving services from another waiver program, but once a person is enrolled in the waiver they will have to disenroll from the other waiver program. However, timelines are coordinated so that you will continue to receive services from the old programs until the new one starts.

The Adult Autism Waiver is designed, however, to give preference to people who do not now get any state-funded or state and federally-funded ongoing services. Applicants are grouped in a criteria category:

- **Priority 1**: Those not already receiving state-funded or state and federally-funded home and community-based services.
- **Priority 2**: Those currently enrolled in state-funded or state and federally-funded home and community-based services.

Everyone who is placed into a priority category will receive a status letter to confirm that category. BAS maintains separate lists of people requesting an application based on their priority status. No applications will be sent out to people on the Priority 2 list until everyone on the Priority 1 list has had their application processed. This means that it may be a while before people who are already on a waiver receive an application for the Adult Autism Waiver.

**IF I AM FOUND ELIGIBLE FOR THE ADULT AUTISM WAIVER HOW LONG CAN I REMAIN IN THE PROGRAM?**
There is no time limit or maximum age limit. Participants are assessed each year to ensure they continue to meet all eligibility requirements.

**ASSESSMENT AND INDIVIDUAL SUPPORT PLANS**
Individual needs and interests are used by the participant and their team to develop the Individual Support Plan (ISP). The ISP Team includes the Supports Coordinator, the individual, and anyone else the individual chooses to have involved. The ISP specifies the services a
participant will receive, the reason(s) those services are needed, and the goals and objectives of the services. All plans must be reviewed and approved by the Bureau of Autism Services.

**IS THERE A MAXIMUM AMOUNT (CAP) OF WAIVER FUNDED SERVICES A PARTICIPANT CAN RECEIVE?**

No. There is no overall limit (cap) on waiver-funded services. Some services have limits on the number of service hours provided within a specific time frame. In addition, there is a lifetime limit on spending for home modification and assistive technology. Adult Autism Waiver participants receive services based on individual need. More information on service limits can be found at [www.autisminpa.org](http://www.autisminpa.org)

**SERVICES PROVIDED THROUGH THE AUTISM WAIVER INCLUDE**

- Assistive Technology
- Behavioral Specialist Services
- Community Inclusion
- Community Transition Services
- Day Habilitation
- Environmental Modifications
- Family Counseling
- Family Training
- Job Assessment and Finding
- Nutritional Consultation
- Residential Habilitation
- Respite
- Supported Employment
- Supports Coordination
- Temporary Crisis Services
- Therapies
  - Counseling
  - Occupational Therapy
  - Speech and Language Therapy
- Transitional Work Service
Service Descriptions

The service definitions below are a summarized explanation of all the services available through the Adult Autism Waiver. For a complete copy of the Adult Autism Waiver document and complete service definitions visit www.autisminpa.org.

ASSISTIVE TECHNOLOGY
This is an item or piece of equipment that is used to help a person be more independent in their daily life activities, including communicating.

• This service includes help in choosing and learning to use the item or equipment. It also includes yearly service and batteries if needed.

• Equipment that costs $500 or more must be recommended by a professional. There is a limit of $10,000 over the participant’s lifetime, including repair or replacement of the item or piece of equipment.

Some examples are: voice output devices, food preparation aids, modified computer keyboard and vibrating wristwatch.

BEHAVIORAL SPECIALIST SERVICES (BSS)
This service provides support to people with behaviors that make it difficult for them to be active in their community and to live at home, including behaviors that may be disruptive or destructive.

• A Behavioral Specialist provides this service. The Behavior Specialist has training in how to understand why a person may be having difficulty.

• The Behavioral Specialist creates a plan called the Behavioral Support Plan. The Behavioral Support plan helps everyone who is in regular contact with the waiver participant to support him or her. This service includes training family members and providers in how to support the participant and teach him or her skills to be more independent.

• The BSS works closely with the Supports Coordinator to make sure that other services are provided according to the Behavioral Support Plan.

• This service also includes creating a Crisis Intervention Plan. The Crisis Intervention Plan explains how to help the participant if he or she is going into a crisis. Everyone who is in regular contact with the participant who gets this service should know how to use the Crisis Intervention Plan. The BSS agency has someone available 24 hours/day, 7 days/week to help if a participant goes into crisis.

An example of Behavioral Specialist Service is the development of a plan to teach a participant to ask for a break from an activity when he/she needs one.
COMMUNITY INCLUSION

• This service helps a person to gain the skills needed to live in the community.

• This service includes things that will help a person improve his or her activities of daily living (ADLs). ADLs are things usually done at home, such as bathing, dressing, and eating, or doing housework, managing money, and cooking.

• This service also includes teaching and improving skills that will help him or her to be active in their community. These are things like socializing, getting to know the neighborhood where he or she lives, or participating in community activities such as hobbies, shopping or attending an event.

• The types of community inclusion activities a participant will do depend on his or her Individual Support Plan (ISP). The activities will be ones that are needed to help a participant reach a certain goal written into the ISP.

• Community Inclusion can take place in a person’s home or in community locations such as libraries or stores.

• Community Inclusion, Day Habilitation, Supported Employment, and Transitional Work Services are limited to 50 hours combined per calendar week.

An example of community inclusion is teaching a person with disabilities to use public transportation to get to and from work

COMMUNITY TRANSITION SERVICES

Community Transition Services offer occasional financial assistance with moving from an institution into the community.

• This service is for one time only types of expenses such as moving costs, security deposits, or basic household furnishings.

• It is only for participants who will be directly responsible for their own living expenses.

• Community Transition Services do not include monthly rent, food, or regular utility charges.

• A Supports Coordination agency will make the payment directly for the waiver participant.

An example of a Community Transition Service is payment of the security deposit on a new apartment so that a person can move out of a state hospital.

DAY HABILITATION

This service is meant to teach skills to give the participant more independence. It is much like the Community Inclusion Service except that it is provided only in adult training facilities. Day Habilitation helps a person acquire the daily living skills needed to live in the community.

• This service can include personal assistance in completing Activities of Daily Living (ADL’s include bathing, dressing, and eating, or doing housework, managing money, and cooking). However, the goal of Day Habilitation is to improve the participant’s ability to do things on his or her own.
• This service also helps the participant develop and improve communication, their ability to make decisions and make choices, ask for the help they need and skills needed to successfully live in the community.

• Day Habilitation service includes transportation to and from the Day Habilitation facility and Day Habilitation activities.

• This service is normally provided for 6 hours or less per day, 5 days a week on a regularly scheduled basis.

• Community Inclusion, Day Habilitation, Supported Employment, and Transitional Work Services are limited to 50 hours combined per calendar week.

An example of Day Habilitation is learning to prepare a meal while at the adult training facility.

ENVIRONMENTAL MODIFICATION
These are physical changes made to a person’s home which are required for a person to remain safe and free from harm and/or live with more independence.

• Changes are limited to these:
  ➢ Alarms and motion detectors on doors, windows, and/or fences
  ➢ Brackets for appliances
  ➢ Locks
  ➢ Changes that need to be made to the home and vehicle that help with a person’s special sensitivity to sound, light, or other environmental conditions
  ➢ Outdoor gates and fences
  ➢ Plastic windows
  ➢ Electrical switches and sockets placed out of reach
  ➢ Home or vehicle adaptations for participants with physical disabilities, such as ramps, grab bars, widening of doorways, or modification of bathroom facilities

• Changes costing over $1,000 must be recommended by an Occupational Therapist; a Speech, Hearing, and Language Therapist; a Behavioral Specialist; or another professional.

An example of an environmental modification is an alarm installed on the front door that sounds when it is opened.

FAMILY COUNSELING
This service provides counseling to waiver participants and their families and/or caregivers to build a healthy and stable family relationship.

• This services aims to either keep the waiver participant in the family home or have the participant return to the family home.

• The Adult Autism Waiver may not pay for services which another party, such as the family members’ health insurance, is responsible for paying.
• This service is limited to 20 hours per year. The year begins on the date the Individual Support Plan is authorized.

An example of need for Family Counseling is when the family is going through a very stressful period, like after the death of a loved one.

**FAMILY TRAINING**

This service provides training to family members and caregivers to teach them how to help the waiver participant build skills that will improve his or her ability to live independently.

• Training is included in the following areas:
  ➢ Communication skills
  ➢ Stress reduction
  ➢ Self-direction (making decisions and choices)
  ➢ Daily living skills
  ➢ Socializing

• This service does not include training in the use of assistive technology devices, which is included in the Assistive Technology service.

• This service also does not include the training necessary for family members to carry out the behavioral support plan or crisis intervention plan, which is included in the Behavioral Specialist Service.

An example of family training is teaching family members to encourage the participant to ask for help instead of guessing what the participant needs.

**JOB ASSESSMENT AND FINDING**

This service helps waiver participants to find paid or volunteer work in the community.

• Job assessment includes:
  ➢ A review of the participant’s work history, interests, and skills to determine what types of jobs and/or training will be best
  ➢ Provider’s suggestions of what kinds of jobs in the community match the participant’s skills, abilities, and interests
  ➢ Situational assessments or tryouts where the participant performs certain types of job tasks to see if he or she has the ability and/or interest to do that particular type of job.

• Job Finding includes:
  ➢ Finding a specific job that matches the participant’s skills and interests with an employer’s needs
  ➢ Successful job finding in a permanent job placement where the participant has worked for at least 30 days
If the participant also is getting Behavioral Specialist Services, then Job Assessment and Job Finding should be done in a way that includes using the behavioral support plan and the crisis intervention plan.

An example of Job Assessment and Job Finding is being tested for different job skills, sharing areas of interest or experience that might be helpful in a job, and applying for a job with an employer who has already been contacted by the job finding provider.

**Nutritional Consultation**

This service provides help to waiver participants who have food allergies, food sensitivities, or serious nutritional deficiencies. The nutritional consultation helps participants and their families and caregivers develop a diet and plan meals that will meet the need for healthy eating habits.

An example of Nutritional Consultation is getting meal planning help and advice for a participant who avoids fruits and vegetables, or whose food choices are limited because of food texture.

**Residential Habilitation**

This service is provided for participants who need to be in a supervised setting all the time, including overnight. The participant who receives this service lives in a licensed Community Home or Family Living Home owned by the provider. This service is meant to teach skills to give the participant more independence so that the participant will be able to move to a private home setting in the future.

- Residential Habilitation is provided in two types of facilities: Licensed community homes (group settings) and Licensed Family Living Homes
  - This service can include personal assistance in completing ADLs (ADLs are things such as bathing, dressing, and eating, or doing housework, managing money, and cooking) however, the goal of Residential Habilitation is to reduce the need for personal assistance by improving the participant’s ability to do things on his or her own.
  - This service also helps the participant develop and improve: communication, their ability to make decisions and make choices, ask for the help they need and skills needed to successfully live in the community.
- Day Habilitation service includes transportation to and from the Day Habilitation facility and Day Habilitation activities.

At least once every three months, the Supports Coordinator, with the participant, must review whether goals are being met and check whether goals for this service should be changed in the Individual Support Plan. A participant receiving Residential Habilitation services can also get other waiver services, except for Respite.

An example of someone using the Residential Habilitation service is living in a Community Home, using Transitional Work Services and Community Inclusion services during part of the day, learning skills to become more independent, and spending holidays with their family at the family home.
**RESPITE**

This service gives a participant’s unpaid caregiver a short break from caretaking duties when the caregiver is unable to do so because of unusual circumstances.

- This service may be provided in or out of the participant’s home.
- Respite provides assistance in completing Activities of Daily Living (ADLs include bathing, dressing, and eating, or doing housework, managing money, and cooking).
- The Respite service provider must try to follow the participant’s regular schedule of activities.
- The use of Respite can be any combination of in-home or out-of-home respite, as long as the cost is not more than $6,000 during the Individual Support Plan year.

An example of the use of Respite is when a caregiver has jury duty and must be out of the house for a few hours at a time they would usually be home, or needs to be away overnight to attend to a family emergency.

**SUPPORTED EMPLOYMENT**

This service provides ongoing help in keeping a job once the waiver participant has found employment.

- Supported employment is used to lessen the need for help by supporting the participant to be successful at work without special help.
- This service is provided for participants who, because of their disability, need ongoing support to function in a work setting.
- Supported Employment is delivered in a community job setting, either volunteer or paid, which includes co-workers who are not disabled.
- Community Inclusion, Day Habilitation, Supported Employment, and Transitional Work Services are limited to 50 hours combined per calendar week.

An example of Supported Employment is having staff accompany the participant to work until they have learned the routine of the work place, providing help to meet co-workers and helping the boss and co-worker to become familiar with the participant. Then the staff can accompany the participant less often, but be available to provide extra support if needed.

**SUPPORTS COORDINATION**

The Supports Coordinator makes sure that the participant is receiving the services to which he or she is entitled.

Supports Coordination is made up of four major parts:

1. **Assessments** Every year before developing the Individual Support Plan (ISP), the Supports Coordinator will ask the participant and/or family members to complete three tests—the Scales of Independent Behavior-Revised (SIB-R), the Parental Stress Scale (PSS) (if the participant lives with family members) and the Quality of Life Questionnaire (QOL.Q).
2. **Individual Support Plan (ISP)** The Supports Coordinator must call a meeting of the Planning Team to create the participant’s Support Plan. The team is made up of the Supports Coordinator, the participant getting services and other people chosen by the participant. A participant may ask current service providers to attend the Planning Team meeting, especially a Behavioral Specialist provider. The services in the ISP should be based on the participant’s goals and needs.

3. **Monitoring** The Supports Coordinator should visit or call the participant or his or her family at least once every month. They have to visit the participant either at home or outside of home while they are getting services, at least once every three months. During those visits or calls, the Supports Coordinator will check to see that the participant is getting the services that are on his or her ISP, and that the providers of those services are doing what they are supposed to be doing. The Supports Coordinator also checks that the participant is doing well.

4. **Coordination of non-waiver services** The Supports Coordinator also helps the participant find and access services that they may need that are not part of the Adult Autism Waiver. Some of those services might be: finding a doctor or dentist, applying for job training and finding services offered by the participant’s community (town or county).

An example of the use of Supports Coordination service is to contact the Supports Coordinator whenever there is an important change in the needs of the participant, or if the participant or family has a concern about the services received through the Waiver.

**TEMPORARY CRISIS SERVICES**

This service provides additional staff to help a participant after a crisis. A crisis may exist when the participant’s safety is at risk and services cannot be provided without additional staff.

- This service is used for those unexpected circumstances when a temporary increase in staff is needed to allow the participant to carry out their normal activities.

- Temporary Crisis Services staff will support the family and/or staff in the following areas:
  - Community Inclusion
  - Residential Habilitation
  - Day Habilitation
  - Family Living Home

- The Bureau of Autism Services (BAS) decides whether someone needs temporary crisis services, based on information from the Supports Coordinator, the Behavioral Specialist (if the participant gets that service) and the rest of the Individual Support Plan (ISP) team. BAS will review the need for this service at least once a week.

- This service is meant to be temporary. If a participant needs this service several times, his or her ISP should be reviewed to understand why the participant is having a crisis so often.
• Only 540 hours of this service may be used in any 12-month period.

An example of Temporary Crisis service is an additional staff member is added when the participant goes out to the mall as part of his or her community inclusion service, following the participant’s discharge from a psychiatric hospital stay.

**THERAPIES**

These services are provided by healthcare professionals and are intended to enable the waiver participant to maintain his or her ability to perform Activities of Daily Living (ADL).

• Therapies in the Adult Autism Waiver include:
  - *Occupational Therapy* provided by a registered occupational therapist; can include assistance with a participant’s assistive technology or environmental modification needs
  - *Speech/Language Therapy* provided by a licensed speech therapist or certified audiologist
  - *Counseling* provided by a licensed psychologist or psychiatrist who will deliver the service directly to the waiver participant

An example of therapies is a Speech/Language therapist who helps a participant learn to change his or her tone of voice depending on where they are or what they are saying.

**TRANSITIONAL WORK SERVICES**

This service provides job opportunities in which the participant is working alongside other people with disabilities. This service is meant to transition participants to jobs in the community with mostly non-disabled co-workers.

• Transitional Work services options include:
  - *Mobile work force* – This uses teams of workers who perform their work away from the agency or facility that employs the team. This includes work such as maintenance, lawn care, janitorial services, and other such tasks. The Transitional Work Services Provider contracts with an organization or business to provide the job but participants are paid by the waiver service provider.
  - *Work station in industry* – This involves individual or group training of individuals at an industry site. Training is run by the waiver provider or by a representative of the industry. Training is phased out as the waiver participant obtains the skills needed to perform the job and meet production standards.
  - *Affirmative industry* – This refers to an integrated operation where disabled and non-disabled individuals work together on the same job tasks.
  - *Enclave* – This is a business model where disabled individuals are hired by a business/industry to perform specific tasks while working alongside non-disabled workers.

• Community Inclusion, Day Habilitation, Supported Employment, and Transitional Work Services are limited to 50 hours combined per calendar week.
An example of Transitional Work services is participation in a mobile work force team where the participant learns job skills like being on time, taking direction from a supervisor and specific skills like yard maintenance which could be used in getting a job in the future.

Can Family Members Provide Services?

FAMILY MEMBERS

Family members are defined as parents, children, stepparents, stepchildren, grandparents, grandchildren, brothers, sisters, half brothers, half sisters, aunts, uncles, nieces or nephews and may provide Community Inclusion and Respite as employees of a provider agency providing these services.

Any family member may provide the above services, except a person who lives with the participant may not provide Respite. Legal guardians who are family members may provide the services listed above. Legal guardians who are not family members may not provide waiver services.

Services provided by family members must:

- meet the definition of a service/support;
- be necessary to avoid institutionalization;
- be a service/support that is specified in the Individual Support Plan (ISP);
- be provided by a person who meets the provider qualifications and training standards specified in the waiver for that service;
- be paid at a rate that does not exceed that which would otherwise be paid to a provider of a similar service;
- NOT be performing an activity that the family would ordinarily perform or is responsible to perform.

The ISP will document that the above criteria are met whenever a family member provides the service.

A family member who is employed as a service provider through an agency will comply with the following:

- The family member may not provide more than 40 hours of services in a seven-day period. Forty hours is the total amount regardless of the number of individuals the guardian serves under the Waiver;
- The family member must maintain and submit time sheets to the agency provider and other required documentation for hours worked.
Monitoring Requirements

HOW DOES THE BUREAU OF AUTISM SERVICES MONITOR PROGRAM QUALITY?

Adult Autism Waiver
Monitoring of the program is an ongoing process throughout the year and includes the following: reports, on-site reviews, interviews with participants, quarterly quality reviews, and oversight of provider qualifications (including training). Participants are interviewed to find out if they are getting the services in their plan, if they are happy with their services, and if they are treated well by their providers. BAS also checks to make sure participants are healthy and safe. Families can also help with monitoring quality.

Adult Community Autism Program
Monitoring of the program is an ongoing process throughout the year and includes the following: reports, on-site reviews, interviews with participants, an annual quality review by an outside agency, quality performance outcome measures, and oversight of provider qualifications (including training). Participants are interviewed to find out if they are getting the services in their plan, if they are happy with their services, and if they are treated well by their providers. BAS also checks to make sure participants are healthy and safe. Families can also help with monitoring quality.

Fair Hearing
The State provides an opportunity to request a Fair Hearing under 42 CFR Part 431, Subpart E to individuals:

• who are not given the choice of home and community-based services as an alternative to the institutional care;
• are denied the service(s) of their choice or the provider(s) of their choice; or,
• whose services are denied, suspended, reduced or terminated. The State provides notice of action as required in 42 CFR §431.210.

PROCEDURES FOR OFFERING OPPORTUNITY TO REQUEST A FAIR HEARING.
The Bureau of Autism Services (BAS) will notify an individual in writing that he or she has a right to a fair and impartial hearing when one of the following occurs:

• An individual is determined ineligible for the Autism Waiver;
• An applicant or participant is not given the choice between community and institutional services (i.e., between Home and Community Based Services through the Autism Waiver
and Intermediate Care Facility for Persons with Other Related Conditions (ICF/ORC) or Intermediate Care Facility for Mental Retardation (ICF/MR) services);

• A participant is denied the provider(s) of their choice; or

• Actions are taken to deny new or additional services, or actions are taken to suspend, reduce, or terminate existing services to a participant.

In addition, during the initial planning meeting, the Supports Coordinator reviews the right to fair hearing procedures verbally. The participant/participant’s representative signs off on the Service Delivery Preference Form indicating that they have received the Bulletin and understand their rights to fair hearing. The Supports Coordinator will review the right to fair hearing procedures verbally during the annual review of the ISP and at any time requested by the participant or the participant’s representative and/or when services are changed in the ISP.

If BAS is reducing, suspending, or terminating services, the recipient will have 10 days from the receipt of the notice to appeal the change. If the participant appeals during those 10 days, DPW will not reduce, suspend, or terminate services; services will continue while the appeal is pending.

BAS will maintain documentation of notices of adverse actions and all fair hearing requests. The Department of Public Welfare, Bureau of Hearings and Appeals also maintains documentation of appeals and appeal decisions in accordance with Title 55 Pa. Code Chapter 275.

See Chapter 4: Understanding Your Rights for more information.

Additional Services and Supports Available through the Bureau of Autism Services: ASERT Regional Collaboratives; Mini-Grants

AUTISM SERVICES, EDUCATION, RESEARCH AND TRAINING REGIONAL COLLABORATIVES (ASERT)

A primary recommendation of the Pennsylvania Autism Task Force commissioned in 2004, these regional collaboratives were created to enhance the lives of Pennsylvanians with autism of all ages and abilities by improving regional access to quality services and interventions, providing information and support to families, training professionals in best practices and facilitating partnerships among providers of services throughout the Commonwealth.

WHAT DOES ASERT STAND FOR?

Autism Services – Ensure that people living with autism and their families, in every part of the Commonwealth, can access quality supports and interventions that are based on best practices and provided by trained professionals
Education – Develop educational materials relative to an autism spectrum disorder (ASD) and disseminate to families, providers and other stakeholders

Research – Research yielding practical and measurable results that contribute to enhance quality of life for people with autism and provide evidence-based information for use by families and service providers

Training – Increase the capacity of professionals with expertise in providing services and supports to individuals with an autism spectrum disorder (ASD) and their families

How are the ASERTs Supporting Individuals with an ASD in their Regions?

The ASERT partnerships were created to enhance the lives of Pennsylvanians with autism by improving regional access to resources, services and training. Here are a few highlights of projects in each region that are doing just that!

Eastern ASERT: 4000+ individuals in the autism community touched by their projects
Statewide Regional Needs Assessment; Early Screening and Diagnostic project; Training for Clinicians in functional assessment and Positive Behavior Support; Adult Social Skills training; online resource site

Central ASERT: 3600+ individuals in the autism community touched by their projects
Staffed Autism Resource Center (call-in support/online resource site); Social Skills Training; Supporting Non-Verbal Adults program; Co-morbid Medical Issues lecture series; participation in regional events

Western ASERT: 1000+ individuals in the autism community touched by their projects
Training for Pediatricians/EI, Clinicians (functional assessment), Diagnosticians (ADOS), Mental Health professionals; Sleep and Diagnostic Studies; Clinical consultations; Summer Treatment program; Biobehavioral Certificate program; online resource site

For the most current detailed overview of ASERT partners, initiatives, and how to contact them, please visit www.autisminpa.org

Family and Individual Mini-Grants
The Family and Social Issues Subcommittee Report of the Autism Task Force recommended the creation of services and support systems specifically for persons with autism and their families throughout the lifespan (especially including family support services and respite). As of 2009, the Bureau of Autism Services supported 6,395 individuals with autism and their families through this opportunity and estimates supporting an additional 2000+ throughout Pennsylvania in 2010.
Although not a long-term solution, the purpose of this program is to reach out and serve individuals and families that are not able to access existing support systems for various reasons, e.g. eligibility criteria, age, waiting lists, etc. In order to be eligible, the applicant and/or the individual with an ASD may not be receiving any other family support services, including Waiver funded services, Family-Driven Support Services, services funded under Individual Support Plans, county-based funds from MH/MR or other similar services or funding. Individuals who receive BHRS/Wraparound and/or Early Intervention services are eligible for this grant.

Priority is given to applicants who have not previously received this grant from the Bureau of Autism Services. Second priority is on a first come, first served basis. Total funding for these mini-grants is limited and not everyone who applies will be funded.

Grant funds may be used for respite/child care, summer camp, recreational or community programs, conferences/workshops and safety modifications. Please see the application for specific information.

Applications are only accepted by mail during the grant application period which is generally from late February to late April. Specific dates are indicated on the application.

Availability of this and other BAS grant opportunities in the future is dependent on the availability of resources. For information about this or other grant opportunities, the application process, deadlines, and Frequently Asked Questions (FAQ), please visit the Bureau Website: www.autisminpa.org

If you do not have internet access, we suggest utilizing your local library or you may call the BAS toll-free line 866-539-7689 and leave a message requesting information.
Moving from school to adulthood can be very difficult and stressful. Successful transition requires deliberate, thoughtful planning and knowledge of services and supports available for adults with disabilities. This chapter offers an overview of the transition services available through school, a Transition Checklist, and information about agencies and resources for families and individuals.

### Transition Checklist

**Strategies to have in place prior to the IEP and Transition planning**

- My initial planning formally begins at my 14th birthday
- I’ve had vocational testing to determine strengths and likes
- I’ve had a variety of job and community options that allowed me to explore what I really like to do
- I have the required evaluations, assessments and reports needed by other agencies upon graduation
- I have a REAL LIFE goal upon graduation

**People who need to be at the IEP meeting**

- Myself
- My parents or family members
- My teacher
- My school representative
- My MH/MR Supports Coordinator
- My Work Experience Coordinator
- The Office of Vocational Rehabilitation Counselor
- An advocate or friend who can assist in planning

**Registrations and Applications that must be completed**

- I’ve contacted my local community MH/MR and registered for services
- I’ve filled out a PUNS form with my Supports Coordinator or Case Manager and I know my category
- I’ve filled out the Service Preference and Waiver Application form
- I’ve contacted my local community Center for Independent Living to find out about other supports
- I’ve requested services from the Office of Vocational Rehabilitation
- I’m maintaining contact with the agencies, especially during the last year of school
Chapter 7: Transition

Planning Using Self-Determination Principles
___I’ve set a date for our first meeting
___I’ve contacted the important people in my life to be there
___The team spent time talking and dreaming about what I would like to do upon graduation and what other services or supports I need in order to have a fulfilled life
___My team explored other creative community resources and job options (generic)
___The team set goals
___The team looked at what was needed to make these goals and plans happen
___Each individual member of the team took responsibility for their part of the goal or plan
___We incorporated my Plan into the IEP.
___The team gathers several times as needed and makes changes when necessary. Remember, the Plan changes because our life changes.

Legislative Information
___This is the name and number of my State Representative___________________
___This is the name of my State Senator ________________________________
___I have made legislative contact

TO JOIN THE PENNSYLVANIA WAITING LIST CAMPAIGN CONTACT:

PENNSYLVANIA WAITING LIST CAMPAIGN
4540 BEST STATION ROAD
SLATINGTON PA 18080
PHONE/FAX: 610-767-2437
SSTASKO@PAWAITINGLISTCAMPAIGN.ORG

TRANSITION TO ADULTHOOD
Transition planning is required for all students with disabilities, beginning at age 14, who qualify for Special Education Services. The planning process should include a coordinated effort between the school, the student, the family and any adult system that may be accessed for ongoing support when the student graduates or leaves school. The adult service systems are dramatically different than school age services and you will need to get connected to those agencies during this time. Many adult service systems have waiting lists for services. Unlike school, you are not entitled to services just because you qualify and are eligible. You will need to become informed about what supports are available through the various programs and apply now.
WRITING A VISION STATEMENT
Write a vision statement describing what your life will look like 5-10 years from now. Make sure you include all the important things in your life that you want to have. You should think about where you want to live, whether it is with your family, on your own, or in a more supportive environment. Consider all possibilities for jobs or continuing your education, whether that may be a college or a trade school. Think about the people you want to be a part of your life, including friends, family and romantic relationships. Outline the activities or hobbies you want to participate in as an adult. Write down how you want to spend your time (for example, community groups, volunteering, churches, or sports). Once you have a good idea of how you want to live, you begin working with your teachers, your family, and others that can support you in making your vision a reality.

THE TRANSITION INDIVIDUAL EDUCATION PROGRAM (IEP)
Transition planning and services are required by Pennsylvania regulations (Chapter 14) to be addressed in the Individualized Education Program (IEP) of the student in the year in which the student turns 14 years of age. Planning can begin earlier if the IEP team decides it is appropriate. The IEP team should design a coordinated program based on the desired long term outcomes of the student. These plans must address:

• Post-Secondary Education and Training
• Employment
• Independent Living

Based on your vision, interests and goals, the team will incorporate educational services and activities starting at age 14 to move you toward the life you want upon graduation. Your IEP will be reviewed and updated each year to measure progress and modify or add new goals, activities and objectives to the plan. You are entitled to stay in school through age 21 to help you meet your goals.

THE TRANSITION TEAM
You are the leader of your team; after all, this is a plan for your life! The other members of the team include:

• Parents/guardians, other family members and friends
• Representatives from adult service systems
• School Personnel
  ➢ Teachers and school support staff
  ➢ Transition Coordinator
  ➢ Special Education Director
  ➢ Social Workers
  ➢ Therapists
WRITING YOUR PLAN

Your plan should be a coordinated set of activities which:

- Is designed to move you from school to adult life
- Is based on your individual needs taking into account your strengths
- Includes instruction, community experience, employment assessment, development of employment and work on daily living skills.

A coordinated set of activities is a long-range plan for adult life. This plan should reflect all the activities, experiences and services that need to occur to help you prepare for the move to adult life. It needs to incorporate your current levels of educational performance, information from a variety of assessments including vocational assessments, and annual IEP goals that address your needs.

Your plan should be comprehensive and based on your individual strengths and needs. You will participate in a variety of assessments to inform the plan. They may include: achievement and/or aptitude tests, adaptive behavior/daily living assessments, employability tests, interest inventories and other informal assessments. Some services and activities can focus on developing work related skills, seeking employment, exploring careers, taking apprenticeship training and finding actual employment. You may also look into college or other post-secondary settings of interest to you. Using community resources such as grocery stores, libraries, and public transportation should be addressed. Other community activities that may be part of the transition plan are securing a driver’s license, applying for an ID card, joining a community recreation center, participating in civic organizations, and youth groups.

Implementing your plan may involve agencies such as the Office of Vocational Rehabilitation (OVR) or the Office of Developmental Programs (ODP), among others. The following pages include community agencies and contacts that may be helpful during this time and as you move into the adult service system.
RESOURCES

Steps to Getting the Best Transition Program for Your Child

**PARENT TRAINING AND RESOURCE CENTERS**

*The Parent Education and Advocacy Leadership Center (PEAL)*
The Parent Education and Advocacy Leadership Center (PEAL) was established in October 2005 as an organization of parents of children with disabilities reaching out to assist other parents of children with disabilities and special health care needs and professionals. The PEAL Center began as the parent training and information center (PTI) serving 43 counties in central and western Pennsylvania with a focus on education and community supports. The staff of the PEAL Center PTI provides two services to parents, youth and professionals: individual assistance and referral to parents and professionals to help identify needed resources and assistance to parents to resolve disputes with schools; and training to ensure parents understand and can navigate the special education process and have knowledge of best practices. The PEAL Center offers training on education issues in the 43 counties covered by the parent training and information center, and training on health care issues and home and community supports statewide. Visit PEAL at [http://www.pealcenter.org](http://www.pealcenter.org) or call 866-950-1040.

*Parent Education Network (PEN)*
PEN is part of a national system of Parent Training and Information Centers (PTIs), serving North Central, South Central, Northeast, Southeast and Philadelphia, Pennsylvania. They are funded by the US Department of Education and the Pennsylvania Department of Education. 2009 marks their 25th anniversary of service to parents of children with disabilities. PEN is a coalition of professionals and parents of children representing a range of disabilities and ages. They are committed to serving parents of all special needs children—birth to adulthood; including parents of children in pre-school, regular education classes, educational/residential placement, adult systems and those children not yet identified as needing service. PEN provides technical assistance, information, skill development trainings, workshops and referral services to parents to help children reach their full potential in educational, vocational and community settings. Their website is designed to support Pennsylvania parents of children with special needs, but information and links are included on Federal Special Education, National Disability Issues and Resources, and Special Education Legal links that will also pertain to parents and individuals with disabilities in other states. Their primary objective is to support parents. Please feel free to call them for further information or assistance. Visit PEN at [http://www.parentednet.org](http://www.parentednet.org) or call 800-522-5827.
COMMUNITY PARENT RESOURCE CENTERS

Hispanos Unidos para Niños Excepcionales (HUNE)
Hispanos Unidos para Niños Excepcionales (HUNE) is a not for profit organization established in 1998. They provide free bilingual English and Spanish training, technical assistance and individual assistance to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with children. HUNE empowers parents of exceptional children to obtain a free and appropriate quality education for their children and other children with disabilities. They provide training programs on all aspects of Special Education and Support, including Transition Services. HUNE provides training, supports and limited individual assistance for parents of exceptional children. HUNE serves, but is not limited to, Hispanic parents. Visit HUNE at http://huneinc.org or call 215-425-6203.

The Mentor Parent Program, Inc.
The Mentor Parent Program is a community-based parent project created in 1989 by parents of children with special needs to support, assist and provide expertise to parents in rural northwest Pennsylvania. The Mentor Parent Program exists to provide support and services to parents of children with disabilities through a coalition of united efforts of parents, educators, service providers, and professionals to effectively meet the needs of children with disabilities in the rural Appalachian region of Pennsylvania. If you are a parent or professional who needs information or support, the Mentor Parent Program can help you. The program is operated by parents who understand your questions and concerns. Visit the Mentor Parent Program at http://www.mentorparent.org or call 888-447-1431.

Special Education Consult Line
The Special Education Consult Line is a program of the Department of Education, Bureau of Special Education, for use by parents or parent support organizations to answer questions about school-related concerns, special education, and the complaint system. It is designed to be a one-stop service for parents concerning special education services and programs. Please call 800-879-2301.

COMMUNITY AGENCY CONTACTS AND SERVICES
To contact any of the offices below via TTY, please call the PA Relay Center at 800-654-5984.

Pennsylvania Department of Labor and Industry, Office of Vocational Rehabilitation (OVR)
The mission of the OVR is to assist Pennsylvanians with disabilities to obtain or keep a job. OVR is an eligibility-based program. VR services are provided by vocational rehabilitation counselors located in 21 local district offices across the state. Visit OVR at www.dli.state.pa.us and click on “disability services” or call 800-442-6351, (TTY) 866-830-7327.
Pennsylvania Department of Labor and Industry, Bureau of Workforce Development Partnership

The Bureau oversees the coordination of employment and training services for the Commonwealth under the Workforce Investment Act of 1998. Services are provided to adults and youth through 23 Local Workforce Investment Areas comprised of 80 CareerLink Centers located throughout the state. Visit CareerLink at [www.pacareerlink.state.pa.us](http://www.pacareerlink.state.pa.us) or call 717-783-8945.

Pennsylvania Department of Public Welfare, Bureau of County, Children and Youth Programs

Pennsylvania’s child welfare system is county administered and state supervised. Child welfare and juvenile justice services are organized, managed, and delivered by County Children and Youth agencies and County Juvenile Probation offices, respectively. Visit the Bureau of County Children and Youth Programs at [www.dpw.state.pa.us/About/OCYF/](http://www.dpw.state.pa.us/About/OCYF/) or call 717-783-0629.

Pennsylvania Department of Public Welfare, Office of Developmental Programs (ODP)

ODP provides individuals with mental retardation and autism, and their families, the services and supports they need to participate fully in community life. Visit ODP at [www.dpw.state.pa.us/About/ODP/](http://www.dpw.state.pa.us/About/ODP/) or call 717-787-3700.

Pennsylvania Department of Public Welfare, Office of Mental Health and Substance Abuse Services (OMHSAS)

OMHSAS maintains a comprehensive, community-based mental health system of care for every county in the Commonwealth based on the Child and Adolescent Service System Program (CASSP). OMHSAS provides positive outcomes for children/adolescents and their families with, or at risk of, mental health problems. Visit OMHSAS at [www.dpw.state.pa.us/About/OMHSAS/](http://www.dpw.state.pa.us/About/OMHSAS/) or call 877-356-5355.

Pennsylvania Department of Public Welfare, Medical Assistance (MA)

Medical Assistance is a federal/state financed health insurance program. This agency provides medical assistance to low-income persons who are 65 or older, blind, disabled, or are members of families with dependent children, or are qualified pregnant women. Contact the County Board of Assistance Office in your county or at [www.dpw.state.pa.us/About/OMAP/](http://www.dpw.state.pa.us/About/OMAP/) or call 717-787-1870.

Pennsylvania Department of Health, Bureau of Family Health

The Bureau facilitates access to health and rehabilitative services for eligible children. For a list of services and eligibility requirements visit [www.health.state.pa.us](http://www.health.state.pa.us). In addition, the Special Kids Network, System of Care Program, 877-986-4550, can assist communities in creating and
improving services for children and youth with special health care needs. Information and referral services for individuals with special health care needs are provided through the Health and Human Services Call Center, www.helpinpa.state.pa.us or call 717-346-3000.

**Pennsylvania Department of Health, Bureau of Drug and Alcohol Programs (BDAP)**
The Department of Health provides licensed drug and alcohol services for adolescents. Service delivery is based on the intervention need of the individual. Information on accessing services is available through each Single County Authority (SCA) or the county Drug and Alcohol Office. Call 717-783-8200 or visit BDAP’s website at http://www.portal.state.pa.us/portal/server.pt/community/drug___alcohol/14221

**Pennsylvania Juvenile Court Judges’ Commission (JCJC)**
The Commission is responsible for advising juvenile courts concerning the proper care and maintenance of delinquent children; establishing standards governing administrative practices and judicial procedures used in juvenile courts; establishing personnel practices and employment standards for probation offices; collecting, compiling, and publishing juvenile court statistics; and administering a Grant-in-Aid Program to improve county juvenile probation services. Visit the JCJC website at www.jcjc.state.pa.us or 717-787-6910.

**Social Security Administration (SSA)**
SSA facilitates the payment of social security benefits to eligible individuals with disabilities. There are two major categories: (1) Social Security Disability Income (SSDI) for eligible individuals who meet insured status by nature of disability including medical requirements and adult children with disabilities; and (2) Supplemental Security Income (SSI) for eligible children and adults that meet specific medical and income criteria. Visit the SSA website at www.ssa.gov or call 800-772-1213.
WORK INCENTIVE PLANNING ASSISTANCE PROGRAM (WIPA)

Pennsylvania Directory
CENTRAL AND NORTHEAST

- Corey Nelson, Project Director
  Goodwill Industries of Mid-Eastern PA
  310 N. Wyomissing Ave
  Reading, PA 19607
  Toll Free: 866-541-7005
  corey@passabco.com

- Berks, Carbon, Lehigh and Northampton
  Louise Harmer, Work Incentive Coordinator
  Goodwill Industries of Mid-Eastern PA
  Tilghman Square Shopping Center
  4650 Broadway, Suite 6131
  Allentown, PA 18104
  Toll Free: 866-541-7005
  lharmer@passabco.com

- Bradford, Centre, Clearfield, Clinton, Columbia, Juniata, Lycoming, Mifflin, Northumberland, Montour, Potter, Snyder, Sullivan, Tioga and Union
  Linda Jacka-Frantz, Work Incentive Coordinator
  Goodwill Industries of North Central PA
  424 B Westerly Parkway Plaza
  State College, PA 16801
  Toll Free: 866-541-7005
  lfrantz@passabco.com

- Adams, Cumberland, Dauphin, Franklin, Perry and Schuylkill
  Lynnette Shirk, Work Incentive Coordinator
  Goodwill Industries of Central PA
  1150 Goodwill Drive, PO Box 3155
  Harrisburg, PA 17105
  Toll Free: 866-541-7005
  lshirk@passabco.com

CHESTER, LANCASTER, LEBANON AND YORK
- Chester, Lancaster, Lebanon and York
  Jeffrey Nace, Work Incentive Coordinator
  Goodwill Industries of Southeastern PA
  1048 North Plum Street
  Lancaster, PA 17601
  Toll Free: 866-541-7005
  jeff@passabco.com

SOUTHEASTERN

- Bucks, Delaware, Montgomery and Philadelphia
  Phyllis Hilley, Project Director
  DRN, WIPA Program
  Community Work Incentives Coordinator
  Disability Rights Network
  1414 North Cameron Street, Suite C
  Harrisburg, PA 17103
  Toll Free: 800-692-7443 x309
  philley@drnpa.org

WESTERN

- John Miller, Project Director
  AHEDD
  3300 Trindle Road
  Camp Hill, PA 17011
  Toll Free: 866-902-4333 x118
  ssa.bpao@ahedd.org
SOUTHERN ALLEGHENIES

- Indiana, Cambria, Blair, Huntingdon, Fulton, Bedford, Somerset, and Jefferson
  - Kris McNutt, Work Incentive Coordinator
  - AHEDD
  - PO Box 1231, Indiana, PA 15701
  - 724-479-0711
  - Toll Free: 866-889-4281
  - wic.sapa@ahedd.org

NORTHWESTERN

- Erie, Crawford, Mercer, Lawrence, Venango, Clarion, Forest, Elk, Cameron, McKean, and Warren
  - Joel Brecht, Work Incentive Coordinator
  - AHEDD
  - PO Box 1167, Erie, PA 16512
  - 814-456-0995
  - Toll Free: 866-627-8610
  - wic.nwpa@ahedd.org

SOUTHWESTERN

- Allegheny, Beaver, Butler
  - Jason Melvin, Work Incentive Coordinator
  - AHEDD
  - 900 Sarah Street, Suite 202
  - Pittsburgh, PA 15203
  - 412-381-3313
  - Toll Free: 866-302-4333
  - wic.swpa@ahedd.org

- Armstrong, Fayette, Greene, Washington, and Westmoreland
  - Joy Smith, Work Incentive Coordinator
  - AHEDD
  - PO Box L, Irwin, PA
  - Toll Free: 866-802-4333
  - wic.swcpa@ahedd.org

The Ticket to Work and Work Incentive Improvement Act (TWWIIA) authorized the Social Security Administration to establish cooperative agreements with organizations to provide Work Incentive Planning Assistance. For more information or areas not listed, contact Social Security Administration, 800-772-1213, or www.ssa.gov

TRANSITION RESOURCES

Transition Services:
http://nichcy.org/EducateChildren/transition_adulthood/Pages/Default.aspx

When Youth with Special Health Care Needs Transition to Adulthood:

Transition Planning for Youth with Special Needs–Community Support Guide:
www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf

Transition to Adulthood–A Timeline of Important Transition Steps:
http://depts.washington.edu/healthtr/Timeline/adulthood.htm
Resources

Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities: [www.ed.gov/about/offices/list/ocr/transition.html](http://www.ed.gov/about/offices/list/ocr/transition.html)


The Pennsylvania Department of Health Transition Health Care Checklist: [www.health.state.pa.us/transitionchecklist](http://www.health.state.pa.us/transitionchecklist)

Community for transition issues: [www.sharedwork.org/](http://www.sharedwork.org/)

**TRANSACTION AND SELF ADVOCACY**

Speaking for Ourselves
[http://www.speaking.org/index.html](http://www.speaking.org/index.html)

**EMPLOYMENT SITES**

Work Incentive Planning Assistance Programs (WIPAs)
[www.workworld.org/wwwebhelp/wipa.htm](http://www.workworld.org/wwwebhelp/wipa.htm)

**WIPAs in Pennsylvania**

- AHEDD
  - 3300 Trindle Road
  - Camp Hill, PA 17011
  - Tel. (717) 763-0968

- Goodwill Industries of Central PA, Inc.
  - 1150 Goodwill Drive
  - Harrisburg, PA 17105
  - Tel. (866) 541-7005

- Disability Rights Network
  - 1414 N. Cameron Street, Suite C
  - Harrisburg, PA 17103
  - Tel. (800) 692-7443 ext. 309

Vocational Assessments

School to Work Act and IDEA
[www.vcase.org/Pieces/EquiWork.pdf](http://www.vcase.org/Pieces/EquiWork.pdf)

Free consulting designed to increase the employability of people with disabilities
[www.jan.wvu.edu/](http://www.jan.wvu.edu/)

Office of Vocational Rehabilitation
[www.dli.state.pa.us/landi/cwp/view.asp?a=128&Q=168255](http://www.dli.state.pa.us/landi/cwp/view.asp?a=128&Q=168255)

Working Order – Supports entrepreneurs who have a disability
# Resources

## Benefits, Estate Planning and Trusts

**How do you apply for Social Security Benefits**  
www.ssa.gov/pubs/10029.html

**Trust and Estate Planning**  
http://www.achieva.info/trustservices.php

## Home Ownership - Housing

**Home Ownership**  
http://www.hud.gov/local/pa/homeownership/buyingprgms.cfm

**Home Ownership for People with Disabilities**  
www.familyvillage.wisc.edu/general/homeownership.html

**To find your local Housing Authority**  
www.affordablehousingonline.com/housingauthority.asp?State=PA

## Miscellaneous

**Parent Education Network**  
www.parentednet.org

**Office of Developmental Programs 888-565-9435**  
http://www.dpw.state.pa.us/ServicesPrograms/

**Inclusion resource**  
www.kidstoggether.org

**Pennsylvania Training and Technical Assistance Network**  
http://www.pattan.k12.pa.us/

**Education Law Center (215) 238-6970 or (412) 258-2120**  
http://www.elc-pa.org/

## Publication Sites

**Transition Publications**  
www.nichcy.org/pubs/transum/ts10txt.htm - publications

**Amazon Publications for Transitioning Students with Disabilities**  
ASSISTIVE TECHNOLOGY RESOURCES

**Pennsylvania's Initiative on Assistive Technology (PIAT)**
Institute on Disabilities
http://disabilities.temple.edu
Student Center - Suite 411 S
1755 N.13th St.
Philadelphia, PA 19122
(800) 204-PIAT (7428) Voice/TTY (in-state only); (215) 204-9371 Fax
Contact: Sandi McNally
Email: smcnally@temple.edu
Counties Served: Philadelphia, Bucks, Chester, Montgomery, Delaware

**Pennsylvania Assistive Technology Foundation**
http://www.patf.us/
1004 West 9th Avenue, 1st Floor
King of Prussia, PA 19406
484-674-0506 (voice)
888-744-1938 voice (toll-free)
484-674-0510 (fax)
Email: patf@patf.us

**Community Resources for Independence**
http://www.crinet.org
2222 Filmore Avenue
Erie, PA 16506
(800) 530-5541 Voice
(814) 838-7222 Voice
(814) 838-8115 TTY
(814) 838-8491 Fax
Email: Roseanna@crinet.org
Contact: Roseanna Wayne
Counties Served: Clarion, Crawford, Erie, Forest, Mercer, Venango, Warren

**Three Rivers Center for Independent Living**
http://www.trcil.org
900 Rebecca Avenue Pittsburgh, PA 15221
(800) 633-4588 Toll Free
(412) 371-7700, ext. 111 Voice
(412) 371-6230 TTY
(412) 371-9430 Fax
Email: khuwe@trcil.org
Contact: Kevin Huwe
Counties Served: Allegheny, Armstrong, Beaver, Butler, Indiana, Lawrence, Westmoreland

**Life and Independence for Today**
http://www.liftcil.org
503 East Arch Street Saint Marys, PA 15857
(800) 341-5438 Voice
(814) 781-3050 Voice
(814) 781-1917 Fax/TTY
Email: liftinr@liftcil.org
Contact: Dawn Park
Counties Served: Cameron, Clearfield, Elk, Jefferson, Mckean, Potter

**United Cerebral Palsy of Central Pennsylvania**
http://www.ucpcentralpa.org
925 Linda Lane, Camp Hill, PA 17011
(888)-790-3925 Toll free
(717) 737-3477 Voice
(717) 737-3564 TTY
(717) 737-9416 Fax
Email: jwardle@ucpcentralpa.org
Contact: Jackie Wardle
Counties Served: Adams, Cumberland,
Dauphin, Franklin, Fulton, Huntingon, Juniata, Lebanon, Mifflin, Perry, Snyder, York

United Disabilities Services
www.udservices.org
1901 Olde Homestead Lane
P.O. Box 10485
Lancaster, PA 18702
(800) 995-9581 Voice
(717) 358-1254 Voice
(717) 358-1258 TTY
(717) 358-1253 Fax
Email: carols@udservices.org
Contact: Carol Sneath
Counties Served: Berks, Carbon, Lancaster, Lehigh, Luzerne, Monroe, Northampton, Schuylkill

Center for Independent Living of Northcentral PA
http://www.cilncp.org
210 Market Street, Suite A
Williamsport, PA 17701
(800) 984-7492; (570) 327-9070 Voice
(570) 327-5254 TTY
(570) 327-8610 Fax
Email: kswimley@cilncp.org
Contact: Karen Swimley

United Cerebral Palsy of Northeastern Pennsylvania
www.ucpnepa.com
425 Wyoming Avenue
Scranton, PA 18503
(877) 827-8324 Northeastern PA only
(570) 347-3357 Voice
(570) 347-3117 TTY
(570) 341-5308 Fax
Email: ucptech@yahoo.com
Contact: Linda Mesavage
Counties Served: Bradford, Lackawanna, Pike, Susquehanna, Wayne, Wyoming

Tri-County Patriots for Independent Living
www.tripil.com
69 East Beau Street
Washington, PA 15301
(724) 223-5115 Voice
(724) 228-4028 TDD
(724) 223-5119 Fax
Email: donya@tripil.com
Contact: Donya Bernier
Counties Served: Bedford, Blair, Cambria, Fayette, Greene, Somerset, Washington
APPENDIX A: FORMS

Prioritization of Urgency of Need for Services (PUNS), Home and Community Based or ICF/MR Application Service Delivery Preference Form (DP 457) and Fair Hearing Request Form (DP 458)
Appendix A: Forms

PUNS Form

Prioritization of Urgency of Need for Services (PUNS)

Individual Data
Date of Meeting: __/__/____
Date Created: __/__/____
Date Finalized: __/__/____
First Name: __________________
Last Name: __________________
Gender: ______
MCI: __________
County/Joinder: ______________
Birth Date: __/__/____
Date mailed to the family: __/__/____

Reason for update or review:
___ New
___ Comes off waiting list—all needs met
___ Moved to another county
___ Moved to another state
___ Change of category (emergency, critical, planning)
___ Discharged from the county program (person withdraws or is no longer interested in receiving services)
___ Annual update (no change in supports needed)
___ Died
___ Change of supports needed (more or less) – unchanged category

Participant Information: (Signature may be found on original document)

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Page 1 of 5
# Pennsylvania's Pre-Planning Assessment

## Prioritization of Urgency of Need for Services (PUNS)
For the following items, indicate the reason for need by answering yes or no for all questions

<table>
<thead>
<tr>
<th>Emergency Need (Person needs out-of-home supports immediately)</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Family/caregiver no longer able to provide care placing the individual’s health and/or safety at risk</td>
<td></td>
</tr>
<tr>
<td>2. Death of a caregiver with no other supports available</td>
<td></td>
</tr>
<tr>
<td>3. Person has been committed by the court or is at risk of incarceration without supports (could be to a state center, group home or other residential situation)</td>
<td></td>
</tr>
<tr>
<td>4. Person is in an intolerable living situation or placement, immediately needs a new place to live (current place is exceedingly inappropriate (e.g. shelter, prison, acute care hospital or person is homeless, etc.))</td>
<td></td>
</tr>
<tr>
<td>5. Additional supports are needed immediately to protect the person’s health and safety or to keep him/her from being placed in a state center, nursing home, large ICF/MR or other congregate care setting due to behavioral needs, physical needs or other situations</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emergency Need (Person needs in-home supports, day supports or other supports immediately)</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Family/caregiver needs immediate support to keep their family member at home (short term – for 90 days or fewer)</td>
<td></td>
</tr>
<tr>
<td>7. Family/caregiver needs immediate support to keep their family member at home (long term)</td>
<td></td>
</tr>
<tr>
<td>8. Individual needs immediate support to stay in their own home/family home (short term – for 90 days or fewer)</td>
<td></td>
</tr>
<tr>
<td>9. Individual needs immediate support to stay in their own home/family home (long term)</td>
<td></td>
</tr>
<tr>
<td>10. Individual needs immediate support to maintain his/her employment situation, obtain support employment or achieve a post-school employment outcome</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Critical Need (Person needs support within two years)</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Person has a caregiver age 60+ and will need supports within the next two years</td>
<td></td>
</tr>
<tr>
<td>2. Person has an ill caregiver who will be unable to continue providing care within the next two years</td>
<td></td>
</tr>
<tr>
<td>3. Person has behavior(s) that will warrant additional supports within the next two years</td>
<td></td>
</tr>
<tr>
<td>4. Individual personal or physical care needs cannot be met by current family/caregivers or the person’s health has deteriorated and supports will be needed within the next two years</td>
<td></td>
</tr>
<tr>
<td>5. There has been a death or other family crisis (e.g. illness, divorce), requiring additional supports within the next two years</td>
<td></td>
</tr>
<tr>
<td>6. Person has a caregiver who would be unable to work if supports are not provided</td>
<td></td>
</tr>
<tr>
<td>7. Person or caregiver will need an alternative living arrangement within the next two years</td>
<td></td>
</tr>
<tr>
<td>8. Person has graduated or left school in the past 5 years</td>
<td></td>
</tr>
<tr>
<td>9. Person is graduating from high school within the next two years and will need in-home, day or other supports</td>
<td></td>
</tr>
<tr>
<td>10. Person is graduating from high school within the next two years and will need an alternative place to live</td>
<td></td>
</tr>
<tr>
<td>11. Person is living in an inappropriate place (e.g. foster care beyond age 21, poor roommate mix, etc.) and will need supports within the next two years</td>
<td></td>
</tr>
<tr>
<td>12. Person moved from another county where they were receiving residential, day or in-home supports (non-waiver funds only)</td>
<td></td>
</tr>
<tr>
<td>13. Person is receiving day supports that are inappropriate to meet their needs</td>
<td></td>
</tr>
</tbody>
</table>

Page 2 of 5
## Appendix A: Forms

### INSERT CONSUMER NAME HERE  CONFIDENTIAL

<table>
<thead>
<tr>
<th>Critical Need (Person needs support within two years)</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 Person moved from another state where they were receiving residential, day or in-home supports</td>
<td></td>
</tr>
<tr>
<td>15 The county/administrative entity has plans to assist the person in moving within the next two years (from a state center, nursing home, state hospital or other residential setting)</td>
<td></td>
</tr>
<tr>
<td>16 Person is losing eligibility for DHS/C&amp;Y supports within the next two years</td>
<td></td>
</tr>
<tr>
<td>17 Person is losing eligibility for EPSDT/BIHRS supports within the next two years</td>
<td></td>
</tr>
<tr>
<td>18 Person is losing eligibility for OBRA/Nursing home supports within the next two years</td>
<td></td>
</tr>
<tr>
<td>19 Person is losing eligibility for ICF/MR supports within the next two years due to a change in resources or level of care needs</td>
<td></td>
</tr>
<tr>
<td>20 Person is losing eligibility for residential treatment facility within the next two years</td>
<td></td>
</tr>
<tr>
<td>21 Person is losing eligibility for residential supports received in an approved private school within the next two years</td>
<td></td>
</tr>
<tr>
<td>22 Person is leaving jail, prison or other criminal justice setting within the next two years</td>
<td></td>
</tr>
<tr>
<td>23 Individual will need support to stay in his/her own home/family home within the next two years</td>
<td></td>
</tr>
<tr>
<td>24 Person has been identified as ready for discharge within the next two years (from a state hospital, nursing home or other residential setting)</td>
<td></td>
</tr>
</tbody>
</table>

### Planning for Need (Person’s need for service is more than two years away but less than five years away) | Yes/No |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Family/caregiver is or will be 60+ years of age and will need supports in the next 2-5 years</td>
<td></td>
</tr>
<tr>
<td>2 Person lives in a large setting, and person/family has expressed a desire to move (or the county/administrative entity plans to move the person)</td>
<td></td>
</tr>
<tr>
<td>3 Known need for supports more than two years away. Specify: Enter Date Needed: (MM/DD/YYYY):</td>
<td></td>
</tr>
<tr>
<td>4 Person or family/caregiver will need increased supports in the next 2-5 years. Enter Date Needed: (MM/DD/YYYY):</td>
<td></td>
</tr>
<tr>
<td>5 Person is losing eligibility for C&amp;Y/DHS supports within 2-5 years. Enter Date Needed: (MM/DD/YYYY):</td>
<td></td>
</tr>
<tr>
<td>6 Person is losing eligibility for EPSDT/BIHRS support (including therapeutic foster care) within 2-5 years. Enter Date Needed: (MM/DD/YYYY):</td>
<td></td>
</tr>
<tr>
<td>7 Person is losing eligibility for residential treatment facility supports within 2-5 years. Enter Date Needed: (MM/DD/YYYY):</td>
<td></td>
</tr>
<tr>
<td>8 Person is losing eligibility for residential supports provided in an approved private school placement within 2-5 years. Enter Date Needed: (MM/DD/YYYY):</td>
<td></td>
</tr>
<tr>
<td>9 Person will be graduating from high school in the next 2-5 years. Enter Date Needed: (MM/DD/YYYY):</td>
<td></td>
</tr>
<tr>
<td>10 Person lives in a residential setting that is more restrictive than what is needed</td>
<td></td>
</tr>
</tbody>
</table>
EXISTING SUPPORTS AND SERVICES
Answer Yes/No for supports that are currently in place, including both MR or Non-MR supports (Non-MR supports include education and generic).

<table>
<thead>
<tr>
<th>Individual Supports</th>
<th>MR Supports</th>
<th>Non MR Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite supports (24 hour)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respite supports (&lt;24 hour)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other therapies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post secondary/adult education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Habilitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistive technology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaker/chores supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental accessibility (e.g. adaptations to home or vehicle)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other individual supports</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Transportation</th>
<th>MR Supports</th>
<th>Non MR Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation (including trip/mileage reimbursement, para-transit, etc.)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vocational Supports</th>
<th>MR Supports</th>
<th>Non MR Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community employment (Supported, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-Vocational Supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Day Supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other day supports (e.g. volunteering, community experience)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Residential Supports</th>
<th>MR Supports</th>
<th>Non MR Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family living/life sharing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foster care (children only)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual home owned/leased by the person with &lt;24 hour staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual home owned/leased by the person with 24 hour staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agency group home or apartment &lt;24 hour staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agency group home or apartment 24 hour staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other institution with &gt;15 people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private ICF/MR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demiociary care/personal care boarding home (adult foster care)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assisted living</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transitional housing/respite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other residential/housing supports</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Appendix A: Forms**

**Insert Consumer Name Here**

**Confidential**

### Supports Needed
For the following items, indicate if support is needed by answering yes or no for all questions.

<table>
<thead>
<tr>
<th>Individual Supports (Date of first request in this category)</th>
<th>Support Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite supports (24 hour)</td>
<td></td>
</tr>
<tr>
<td>Respite supports (&lt;24 hour)</td>
<td></td>
</tr>
<tr>
<td>Occupational therapy</td>
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<tr>
<td>Speech therapy</td>
<td></td>
</tr>
<tr>
<td>Other therapies</td>
<td></td>
</tr>
<tr>
<td>Post secondary/adult education</td>
<td></td>
</tr>
<tr>
<td>Habilitation</td>
<td></td>
</tr>
<tr>
<td>Assistive technology</td>
<td></td>
</tr>
<tr>
<td>Homemaker/chores supports</td>
<td></td>
</tr>
<tr>
<td>Environmental accessibility (e.g., adaptations to home or vehicle)</td>
<td></td>
</tr>
<tr>
<td>Other individual supports</td>
<td></td>
</tr>
</tbody>
</table>

### Transportation (Date of first request in this category) | Support Needed |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation (including trip/mileage reimbursement, para-transit, etc.)</td>
<td></td>
</tr>
<tr>
<td>Other transportation supports</td>
<td></td>
</tr>
</tbody>
</table>

### Vocational Supports (Date of first request in this category) | Support Needed |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior supports</td>
<td></td>
</tr>
<tr>
<td>Community employment (supported, etc.)</td>
<td></td>
</tr>
<tr>
<td>Pre-Vocational Supports</td>
<td></td>
</tr>
<tr>
<td>Adult Day Supports</td>
<td></td>
</tr>
<tr>
<td>Other day supports (e.g., volunteering, community experience)</td>
<td></td>
</tr>
</tbody>
</table>

### Residential Supports (Date of first request in this category) | Support Needed |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Family living/life sharing</td>
<td></td>
</tr>
<tr>
<td>Individual home owned/leased by the person with &lt;24 hour staff</td>
<td></td>
</tr>
<tr>
<td>Individual home owned/leased by the person with 24 hour staff</td>
<td></td>
</tr>
<tr>
<td>Agency group home or apartment &lt;24 hour staff</td>
<td></td>
</tr>
<tr>
<td>Agency group home or apartment 24 hour staff</td>
<td></td>
</tr>
<tr>
<td>Other residential/housing supports</td>
<td></td>
</tr>
</tbody>
</table>

Page 5 of 5
Dear Mr./Mrs. [Individual’s Last Name]:

Enclosed is a copy of your current Prioritization of Urgency of Need for Services (PUNS) form that is now in the Office of Mental Retardation’s (OMR) Home and Community Services Information System (HCSIS). This PUNS form should accurately reflect your current or anticipated need for services based on information you/your family provided to [name of SC entity] on [date of PUNS meeting]. This form will be updated with you/your family anytime your needs change, but at least annually. Should your situation change, please notify me as soon as possible to initiate a revision to your PUNS form.

If you do not agree with the information included on this PUNS form, you should inform me as soon as possible. Please note your concerns on the PUNS Disagreement Form and return it to me. I will work to satisfactorily resolve your concerns with the assistance of my Supervisor. If you continue to have concerns, a County Program/Administrative Entity representative will work with you to attempt to resolve your concerns. If the disagreement continues, you may utilize the county’s dispute resolution process.

The PUNS form itself cannot be formally appealed through the Department of Public Welfare’s (DPW) Bureau of Hearings and Appeals process. If you are enrolled in either the Person/Family Directed Supports (PFDS) or Consolidated Waivers and you are not getting the waiver-eligible services you believe you need because your waiver-eligible services have been reduced, suspended, denied or terminated, you or your legal representative have the right to appeal. You can appeal through the DPW’s Bureau of Hearings and Appeals if you are in either of the waivers. Information on how to file an appeal can be obtained from your Supports Coordinator. If you are not enrolled in a waiver, you must use the county dispute process to resolve your disagreement. Please contact me for assistance in accessing these processes.

The information you provided will be used by the County/Administrative Entity to plan for both budgeting as well as the delivery of supports and services. If you have any questions about the information on your PUNS form or the information included in this letter, please call me at [phone number of SC].

Sincerely,

Support Coordinator
PUNS Disagreement Form

(Return to your Supports Coordinator if you disagree with the information on your PUNS form)

Name of Person: _______________________

Name of Person Initiating Disagreement Process (if different): _______________________

Date: _______________________

Reason for Disagreement: ____________________________________________________________

Disagreement Process

<table>
<thead>
<tr>
<th>Name and Role</th>
<th>Date</th>
<th>Resolved?</th>
</tr>
</thead>
<tbody>
<tr>
<td>SC:</td>
<td></td>
<td>Y □ N □</td>
</tr>
<tr>
<td>If not, why not?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SC Supervisor:</td>
<td></td>
<td>Y □ N □</td>
</tr>
<tr>
<td>If not, why not?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>County/AE Rep:</td>
<td></td>
<td>Y □ N □</td>
</tr>
<tr>
<td>If not, why not?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix A: Forms

Understanding the ODP in PA: Mental Retardation and Autism Services 129

Home and Community-Base or ICF/MR Application and Service Delivery Preference Form

I. CONFIRMATION OF UNDERSTANDING

I. ______________________________, have been informed of the following:

a. That I am likely to require the level of care provided in an Intermediate Care Facility for people with Mental Retardation (ICF/MR). I understand that this is based on a preliminary determination of eligibility for ICF/MR level of care, and that the determination will be subject to formal review.

b. About feasible home and community-based service alternatives to services provided in an ICF/MR

c. About my right to indicate a preference for home and community-based services funded under the Waiver as an alternative to services provided in an ICF/MR and about my rights to a fair hearing before the Department of Public Welfare, Bureau of Hearings and Appeals.

In declaring my preference for home and community-based services funded under the Waiver or ICF/MR,

I. ______________________________, understand the following:

a. That I must meet Department of Public Welfare eligibility standards to receive services funded by the Waiver or ICF/MR.

b. That a fair hearing and appeal will not be granted if I am appealing changes caused solely by state or federal law or regulation requiring a change in the type of services available.

c. That completion of Service Delivery Preference does not guarantee services. Availability of State and Federal funds control the allocated resources for individuals to be served in the Waiver.

II. DESIGNATION OF SERVICE PREFERENCE

My service preference is: (initials or mark of individual, surrogate, or QMRP beside one option)

Home and community-based services funded under the Waiver

Services in an ICF/MR

None at this time (If this option is chosen, Section III. does not apply.)

III. APPLICATION

Please indicate agreement and understanding of the following: (initials or mark of individual, surrogate, or QMRP beside each option)

I. ______________________________, hereby make application to be considered for the above indicated services for individuals with mental retardation.

I. ______________________________, understand that by submission of this application, I can expect a formal assessment of my need for services by the County/Administrative Entity.
Appendix A: Forms

IV. PARTICIPANT INFORMATION AND SIGNATURES

A. Individual. (This section must be completed for the individual who is requesting services).

INDIVIDUAL NAME:

ACCESS NUMBER:

CURRENT STREET ADDRESS:

CITY:  STATE:  ZIP:  TELEPHONE NUMBER:  

SIGNATURE:  DATE:

B. Surrogate. (This section must be completed when the individual’s surrogate signifies the preference for Waiver or ICF/MR services on the individual’s behalf.)

NAME:

STREET ADDRESS:

CITY:  STATE:  ZIP:  TELEPHONE NUMBER:  

SIGNATURE:  DATE:

C. Independent Qualified Mental Retardation Professional. (This section must be completed by the independent qualified mental retardation professional who is responsible to document the individual’s preference for Waiver or ICF/MR services).

NAME:

AGENCY:

STREET ADDRESS:

CITY:  STATE:  ZIP:  TELEPHONE NUMBER:  

SIGNATURE:  DATE:

D. County MH/MR Program/Administrative Entity Designee. (This section must be completed by the County MH/MR Program/Administrative Entity that offers the individual or surrogate the preference for Waiver or ICF/MR services).

COUNTY DESIGNEE NAME:

TITLE:

AGENCY STREET ADDRESS:

CITY:  STATE:  ZIP:  TELEPHONE NUMBER:  

SIGNATURE:  DATE:
INSTRUCTIONS AND NOTICE OF RIGHT TO FAIR HEARING

HOME AND COMMUNITY-BASED WAIVER SERVICES OR ICF/MR SERVICES FOR INDIVIDUALS WITH MENTAL RETARDATION

If you are applying for Waiver services or services in an Intermediate Care Facility for the Mentally Retarded (ICF/MR), or if you object to an action taken affecting your claim for Waiver services, you have the right to a county or local pre-hearing conference with the County Program or Administrative Entity and a Fair Hearing before the Department of Public Welfare, Bureau of Hearings and Appeals, if:

- The individual with mental retardation who is determined likely to meet an ICF/MR level of care and is enrolled in Medical Assistance or surrogate1 is not given the opportunity to express a service delivery preference for either Waiver-funded or ICF/MR services.
- The individual or surrogate is denied the individual’s preference of Waiver-funded or ICF/MR services.
- Based on a referral from the Administrative Entity (AE) or County Program, a Qualified Mental Retardation Professional (QMRP) determines that the individual does not require an ICF/MR level of care as a result of the level of care determination or re-determination process and eligibility for services is denied or terminated.
- The individual or surrogate is denied Waiver-funded service(s) of the individual’s choice, including the amount, duration, and scope of service(s).
- The individual or surrogate is denied the individual’s choice of willing and qualified Waiver provider(s).
- A decision or an action is taken to refuse, suspend, reduce, or terminate a Waiver-funded service authorized on the individual’s ISP.

---

1 Not everyone can make legally binding decisions for themselves. This would include minor children and some adults who have substantial mental impairment. In these instances, a substitute decision-maker may be identified under State law. Substitute decision-makers have various legal titles, but for the purposes of this bulletin, they will be referred to as “surrogates.” “Surrogates” include the following:

- Parents of children under 18 years of age under the common law and 35 P.S. § 10101.
- Legal custodian of a minor as provided in 42 Pa.C.S. § 6357.
- Health care agents and representatives for adults as provided in 20 Pa.C.S. Ch. 54.
- Guardians of various kinds as provided in 20 Pa.C.S. Ch. 55 (as limited by 20 Pa.C.S. § 5521(f)).
- Holders of powers of attorney of various kinds as provided in 20 Pa.C.S. Ch. 56.
- Guardians of persons by operation of law in 50 P.S. §4417(c).

Any of these would be considered “legal representatives” as the Center for Medicaid and Medicare Services uses that phrase. Please see Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria (www.cms.hhs.gov/HCBS/02_QualityToolkit.asp).

DP 458 3/08
FAIR HEARING REQUEST FORM
HOME AND COMMUNITY-BASED WAIVER SERVICES FOR INDIVIDUALS WITH MENTAL RETARDATION

This application is from the Department of Public Welfare, Office of Developmental Programs. If you need language assistance, free of charge, please call 1-888-565-9435.

TO: DEPARTMENT OF PUBLIC WELFARE
BUREAU OF HEARINGS AND APPEALS
THE COUNTY MHMR PROGRAM OR ADMINISTRATIVE ENTITY WILL FORWARD THIS APPEAL TO THE APPROPRIATE BUREAU OF HEARINGS AND APPEALS OFFICE LISTED ON PAGE 3

FROM: NAME OF APPELLANT: DAY TELEPHONE NUMBER:
MAILING ADDRESS:

SIGNATURES:
APPELLANT:

WITNESS: (APPELLANT’s Male/Female)

I hereby request a Fair Hearing before the Department of Public Welfare, Bureau of Hearings and Appeals. I am requesting this appeal on behalf of the following individual who is applying for or receiving home and community-based services funded under a Medicaid Waiver for individuals with mental retardation.

NAME OF INDIVIDUAL APPLYING FOR OR RECEIVING SERVICES:

MEDICAID ACCESS NUMBER OF INDIVIDUAL APPLYING FOR OR RECEIVING SERVICES:

I REQUEST THIS APPEAL BASED ON THE FOLLOWING ACTIONS:

I REQUEST THE FOLLOWING REMEDIES TO RESOLVE THIS APPEAL (EXPLAIN):

NAME OF INDIVIDUAL’S SURROGATE (Applicant):
MAILING ADDRESS:
DAY TELEPHONE NUMBER:
RELATIONSHIP TO INDIVIDUAL:

SIGNATURE OF INDIVIDUAL’S SURROGATE (Applicant):

PLEASE INDICATE WHICH TYPE OF HEARING YOU ARE REQUESTING: (See Instructions For More Information)

☐ TELEPHONE HEARING
(Applicant and Administrative Entity or County Program will be at different telephone numbers)
Applicant Number ( )

☐ TELEPHONE HEARING
(Applicant and the Administrative Entity or County Program will be at the same telephone number)

☐ FACE-TO-FACE HEARING
(Applicant and the office of Bureau of Hearings and Appeals will be at one location for the hearing. The Administrative Entity or County Program will participate in the hearing via telephone. This type of telephone hearing is expected to be an available option for individuals or surrogates in April 2008 or soon thereafter.)

Please indicate below if information is needed in a language other than English and specify the language. Indicate any communication assistance (interpreter, device, sign language) or other accommodation that you require at the hearing:


DP 458 3/08

132 Understanding the ODP in PA: Mental Retardation and Autism Services
APPENDIX B: RESOURCES AND CONTACTS

The Office of Developmental Programs maintains a Customer Service Number that you can call for information, to request publications, or if you have concerns. The number is 888-565-9435 or go online at www.dpw.state.pa.us

Centers for Medicare and Medicaid Services (CMS), formerly known as Health Care Financing Agency (HCFA), is the Federal funder for the Medicaid Waiver in Pennsylvania. If you need information or have concerns you can call: 215-861-4204 or go online at www.cms.hhs.gov
Calling Your County and Regional ODP Offices

Sometimes you cannot get the help you need through your local MH/MR office and you might need to call the Regional Office of Developmental Programs to answer your questions. The following is a list of offices by region:

**WESTERN REGION 412-565-5144**

<table>
<thead>
<tr>
<th>Office</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allegheny Co. MH/MR Program</td>
<td>412-350-3695</td>
</tr>
<tr>
<td>Armstrong-Indiana MH/MR Program</td>
<td>724-548-3451</td>
</tr>
<tr>
<td>Beaver County Office of MH/MR</td>
<td>724-847-6225</td>
</tr>
<tr>
<td>Butler County MH/MR Program</td>
<td>724-284-5114</td>
</tr>
<tr>
<td>Cameron-Elk MH/MR Dept.</td>
<td>814-772-8016</td>
</tr>
<tr>
<td>Clarion County MH/MR/D&amp;A Adm.</td>
<td>814-226-1080</td>
</tr>
<tr>
<td>Clearfield-Jefferson MH/MR.</td>
<td>814-265-1060</td>
</tr>
<tr>
<td>Crawford County MH/MR Program</td>
<td>814-373-2620</td>
</tr>
<tr>
<td>Erie County MH/MR Program</td>
<td>814-451-6860</td>
</tr>
<tr>
<td>Fayette County MH/MR Program</td>
<td>724-430-1370</td>
</tr>
<tr>
<td>Forest-Warren Dept. of Human Services</td>
<td>814-726-2100</td>
</tr>
<tr>
<td>Greene County MH/MR Program</td>
<td>724-852-5276</td>
</tr>
<tr>
<td>Lawrence County MH/MR Program</td>
<td>724-658-2538</td>
</tr>
<tr>
<td>McKean County Human Services</td>
<td>814-887-3350</td>
</tr>
<tr>
<td>Mercer County MH/MR Program</td>
<td>724-662-1550</td>
</tr>
<tr>
<td>Potter County MH/MR Program</td>
<td>814-544-7315</td>
</tr>
<tr>
<td>Venango County MH/MR/D&amp;A Admin.</td>
<td>814-432-9753</td>
</tr>
<tr>
<td>Washington County MH/MR Program</td>
<td>724-228-6832</td>
</tr>
<tr>
<td>Westmoreland County MH/MR Program</td>
<td>724-830-3617</td>
</tr>
</tbody>
</table>


**CENTRAL REGION  717-772-6507**

<table>
<thead>
<tr>
<th>Office</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bedford-Somerset Office of MH/MR</td>
<td>814-443-4891</td>
</tr>
<tr>
<td>Blair County Office of MH/MR</td>
<td>814-693-3023</td>
</tr>
<tr>
<td>Cambria County MH/MR Program</td>
<td>814-534-2600</td>
</tr>
<tr>
<td>Centre County MH/MR Program</td>
<td>814-355-6782</td>
</tr>
<tr>
<td>Columbia-Montour-Snyder-Union MH/MR Program</td>
<td>570-275-5422</td>
</tr>
<tr>
<td>Cumberland-Perry MH/MR Program</td>
<td>717-240-6325</td>
</tr>
<tr>
<td>Dauphin County MH/MR Program</td>
<td>717-780-7050</td>
</tr>
<tr>
<td>Franklin-Fulton MH/MR Program</td>
<td>717-709-4321</td>
</tr>
<tr>
<td>Appendix a: forms</td>
<td></td>
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<tr>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td>Juniata Valley Tri-County MH/MR</td>
<td>Lycoming-Clinton Office of MH/MR</td>
</tr>
<tr>
<td>717-242-6467</td>
<td>570-326-7895</td>
</tr>
<tr>
<td>Lancaster County Office of MH/MR</td>
<td>Northumberland County MH/MR Program</td>
</tr>
<tr>
<td>717-399-7355</td>
<td>570-495-2002</td>
</tr>
<tr>
<td>Lebanon County MH/MR Program</td>
<td>York-Adams MH/MR Program</td>
</tr>
<tr>
<td>717-274-3415</td>
<td>717-771-9618</td>
</tr>
<tr>
<td>For people who live in Blair, Cambria, Centre, Columbia, Montour, Snyder, Union, Cumberland, Perry, Dauphin, Franklin, Fulton, Huntingdon, Mifflin, Juniata, Lancaster, Lebanon, Lycoming, Clinton, Northumberland, Somerset, Bedford, York, Adams Counties call: Central Regional Office of Developmental Programs 717-772-6507</td>
<td></td>
</tr>
<tr>
<td><strong>SOUTHEAST REGION 215-560-6359</strong></td>
<td></td>
</tr>
<tr>
<td>Bucks County Dept. of MH/MR</td>
<td>Montgomery County MH/MR Program</td>
</tr>
<tr>
<td>215-442-0760</td>
<td>610-278-3642</td>
</tr>
<tr>
<td>Chester County MH/MR Program</td>
<td>Philadelphia County Office of MH/MR</td>
</tr>
<tr>
<td>610-344-6265</td>
<td>215-685-5460</td>
</tr>
<tr>
<td>Delaware County Dept. of Human Services</td>
<td></td>
</tr>
<tr>
<td>610-713-2400</td>
<td></td>
</tr>
<tr>
<td>For people who live in Bucks, Chester, Delaware, Montgomery or Philadelphia Counties call: Southeast Regional Office of Developmental Programs 215-560-2242</td>
<td></td>
</tr>
<tr>
<td><strong>NORTHEAST REGION 570-963-4749</strong></td>
<td></td>
</tr>
<tr>
<td>Berks County MH/MR Program</td>
<td>Northampton County MH/MR Dept.</td>
</tr>
<tr>
<td>610-478-3271</td>
<td>610-974-7500</td>
</tr>
<tr>
<td>Bradford-Sullivan MH/MR Program</td>
<td>Schuylkill County MH/MR Program</td>
</tr>
<tr>
<td>570-265-1760</td>
<td>570-621-2890</td>
</tr>
<tr>
<td>Carbon-Monroe-Pike MH/MR Program</td>
<td>Tioga County MH/MR Program</td>
</tr>
<tr>
<td>570-420-1900</td>
<td>570-724-5766</td>
</tr>
<tr>
<td>Lackawanna-Susquehanna MH/MR Program</td>
<td>Wayne County MH/MR Program</td>
</tr>
<tr>
<td>570-346-5741</td>
<td>707-253-9200</td>
</tr>
<tr>
<td>Luzerne-Wyoming Department of MH/MR</td>
<td>610-782-3126</td>
</tr>
<tr>
<td>570-825-9441</td>
<td></td>
</tr>
</tbody>
</table>

**LEGISLATIVE INFORMATION**

___ List the name and number of your State Representative

________________________________________  __________________________________

___ List the name and number of your State Senator

________________________________________  __________________________________

___ List the name and number of your Federal Representative

________________________________________  __________________________________

___ List the name and number of your Federal Senator

________________________________________  __________________________________

___ I've made legislative contact

___ I've joined an ADVOCACY group (Self Advocates United as 1, Speaking for Ourselves, The Arc or local group) to have my voice heard.

To locate Pennsylvania State legislators visit: [www.legis.state.pa.us](http://www.legis.state.pa.us)
Or contact the League of Women Voters 800-692-7281

**Other Organizations:**

- The Arc USA: [www.thearc.org](http://www.thearc.org)
- The Arc PA: [www.thearcpa.org](http://www.thearcpa.org)
- Self-Advocates United as 1: [www.sau1.org](http://www.sau1.org)
- Speaking for Ourselves: [www.speaking.org](http://www.speaking.org)
- Disability Rights Network of PA: [www.drnpa.org](http://www.drnpa.org)
- Education Law Center: [www.elc-pa.org](http://www.elc-pa.org)
- Vision For Equality: [www.visionforequality.org](http://www.visionforequality.org)
- Pennsylvania Waiting List Campaign: [www.pawaitinglistcampaign.org](http://www.pawaitinglistcampaign.org)
The Arc of Pennsylvania is a statewide non-profit organization that provides advocacy and resources for citizens with intellectual and developmental disabilities and their families. It is affiliated with The Arc of the United States and 36 local chapters of The Arc covering 52 counties across Pennsylvania.

The Arc of Pennsylvania’s mission is to work to include all children and adults with intellectual and developmental disabilities in every community. People with intellectual and developmental disabilities have the right to live everyday lives, which means among other things living in the community, going to school in regular classrooms in their neighborhood schools with their peers without disabilities, working, playing, shopping, attending religious service, and developing relationships with people of their own choosing.

The Arc of Pennsylvania was founded in 1949 by a group of parents who wanted more for their children with intellectual disabilities than a life in a segregated, isolated institution. Sixty years later, it is one of the strongest grassroots family-driven advocacy organizations in the Commonwealth. The Arc of Pennsylvania places emphasis on its responsibility to advocacy. Advocacy includes both systems advocacy and individual advocacy. The Arc of Pennsylvania focuses on systems advocacy and governmental affairs, demonstrating leadership and guidance among all advocacy organizations.

Over its 60-year history, the accomplishments of The Arc of PA include the PARC Consent Decree, which resulted in the first-ever right to a free and appropriate public education in the least restrictive environment for children with intellectual disabilities. This landmark decision led to the federal Individuals with Disabilities Education Act (IDEA). In addition, The Arc of Pennsylvania was a significant contributor to the movement to close state institutions and support people with disabilities in their own communities. In recent years, The Arc of PA has led efforts to advocate for high-quality community-based supports and services, inclusive
education, funding to end waiting lists for services, and stronger laws to protect people vulnerable to abuse.

**COMMONWEALTH INFORMATION CENTER (CIC)**

402A Finance Building  
Harrisburg, PA 17125  
Toll Free: 800-932-0784  
Phone: 717-787-2121  
TDD/TTY: 800-324-8040

CIC operators answer questions and provide vital information to Commonwealth constituents and employees. They also record opinions, comments and complaints, which are forwarded to the appropriate Commonwealth agencies and/or the Governor’s Office. The Commonwealth Information Center (CIC) provides directory assistance and information services for the Commonwealth. The CIC maintains several data banks which include telephone listings for Commonwealth employees, departments, commissions, offices and bureaus. The CIC also maintains listings of referral numbers and agency help lines.

**DISABILITIES LAW PROJECT**

Chestnut Street, Suite 400  
The Philadelphia Building  
Philadelphia, PA 19107  
Phone: 215-238-8070  
TTD: 215-789-2498  
TTD: 412-467-8940  
Fax: 215-772-312  
Email: dlp.phila@dlp-pa.org  
Website: [www.dlp-pa.org](http://www.dlp-pa.org)

AND

429 Fourth Avenue  
1901 Law & Finance Building  
Pittsburgh, PA 15219  
Phone: 412-391-5225 Fax: 412-391-4496

The Disabilities Law Project (DLP) is a non-profit Pennsylvania law firm that provides free legal assistance to people with disabilities, their families, and their organizations. DLP’s main purpose is to advocate for the civil rights of persons with mental and physical disabilities, especially their right to live as integral parts of their communities. DLP works to ensure that people with disabilities have equal and unhindered access to employment, transportation, public accommodations, and government services; to enforce their rights to vocational, habilitative, post-secondary educational, health, and other services; and to protect them from
abuse and neglect. DLP identifies systemic issues that are important to people with disabilities and seeks necessary reform through litigation, administrative advocacy, and public education.

**Disability Rights Network of Pennsylvania**

1414 Cameron St., Suite C  
Harrisburg, PA 17103  
Toll Free: 800-692-7443  
Email: intake@drnpa.org  
Website: www.drnpa.org

Disability Rights Network of Pennsylvania (DRNPA) is a federally funded, non-profit agency responsible for providing protection and advocacy services to people with disabilities. If you are experiencing discrimination related to your disability or have any questions regarding the rights and services related to your disability, please contact DRNPA using the contact information above.

**Education Law Center**

The Philadelphia Building  
1315 Walnut Street, Suite 400  
Philadelphia, PA 19107  
Phone: 215-238-6970  
Fax: 215-772-3126  
Email: elc@elc-pa.or

AND

702 Law & Finance Building  
429 Fourth Avenue  
Pittsburgh, PA 15219  
Phone: 412-258-2120  
Fax: 412-391-4496

The Education Law Center-PA (ELC-PA) is a non-profit legal advocacy organization dedicated to insuring that all of Pennsylvania's children have access to a quality public education. Their main office is in Philadelphia, with a branch office in Pittsburgh.

ELC-PA staff members:

- Advise families, advocates, and others on how to enforce students’ legal rights;
- Develop materials for use by parents, advocates, and students;
- Conduct workshops and training programs for parents and professionals;
- Provide consultation to private and public attorneys;
- Analyze important state and national proposals in the education and child welfare fields; and
- Represent parents and children in lawsuits that seek important reforms.
Appendix B: Resources and Contacts

Anyone can call ELC-PA and receive free advice or written information about problems involving the public school system in Pennsylvania. They do not handle cases involving kids placed by their parents in private schools, home schooling, or gifted children. There are publications on ELC’s website on many topics at www.elc-pa.org.

**MENTORS FOR SELF DETERMINATION (M4SD)**

1414 North Cameron Street, Suite B  
Harrisburg, PA 17103  
Phone: 814-547-1577  
or 724-813-5702  
Fax: 814-382-7735 or 724-932-1041

Mentors for Self Determination is a statewide organization for people with developmental disabilities and their families. Its mission is to provide education and information about the mental retardation system based on the principles of Self Determination, Person Centered Thinking and Positive Approaches. Mentors accomplish this through self advocates and family members MENTORING other self advocates and family members and the people that support them in living an EVERYDAY LIFE.

**OFFICE OF VOCATIONAL REHABILITATION (OVR)**

Phone (Central Office): 800-442-6351  
Website: http://www.dli.state.pa.us

**An Overview of OVR Individualized Services**

An OVR Counselor can assist you in planning your job search. You will receive ideas, practice, and advice on finding job leads, filling out job applications, getting interviews for a job, and how to interview for a job. Your counselor may also give you job leads or contact employers to explain available tax credits and other hiring incentives. The more contacts with employers you make, the better your chances are of finding a job. Your Counselor can help you explore employment trends, your capabilities, and possible job accommodations, so that you are better prepared to make informed vocational decisions and effectively look for a job.

**ELIGIBILITY REQUIREMENTS**

You will be eligible for OVR services if (1) you have a disability; that is a physical, mental, or emotional impairment which results in a substantial impediment to employment, (2) you can benefit in terms of an employment outcome from services provided, and (3) Vocational Rehabilitation services are required for you to prepare for, enter, engage in, or retain gainful employment.

**ON-THE-JOB TRAINING**

Many jobs require on-site training. Many people learn a job better and faster when they work in a real job situation. Depending on the job and the time it takes to train a new employee, OVR
can reimburse employers for a percentage of the weekly wage for a specified period of time. Both the percentage and the time are negotiable. The employer is responsible for providing the trainer.

Job Coaching is also available for individuals needing intensive on-site job training. Individuals needing this service require more extensive training time or assistance than an employer is able to provide. OVR can hire a Job Coach who does the actual skill training rather than the employer. The Coach works alongside the employee until the employee learns the job to the employer’s and employee’s satisfaction. Job Coaches provide follow-up support to both the employee and the employer.

These training programs enable employers to acquire trained, skilled employees capable of satisfying the specific needs of their business. The employee has the added advantage of earning wages while undergoing training.

**PARENT EDUCATION NETWORK (PEN)**
Toll Free: 800-522-5827
www.parentednet.org

Parent Education Network (PEN) is a statewide coalition in Pennsylvania of parents of children representing a range of disabilities and ages. PEN believes strongly that knowledgeable, skillful parents can impact effectively on early intervention, special education, and adult services for their child with disabilities. PEN’s Parent Training Projects promote mutual respect between parents and professionals for the knowledge, skills, and abilities each contributes to develop appropriate educational and service delivery outcomes for the child and adult with disabilities. PEN’s services are available to parents and professionals.

**PARENT TO PARENT OF PENNSYLVANIA**
Linking families of children and adults with disabilities or special needs
Toll Free: 888-727-2706
www.parenttoparent.org

Parent to Parent of Pennsylvania links parents and family members of children and adults with disabilities or special needs on a one-to-one basis according to conditions or concerns. Parent to Parent of PA can match for the following conditions or concerns: Physical disabilities, developmental disabilities, special health care needs, behavioral/mental health concerns, foster care or adoption and educational issues…*please note list is not inclusive.*

**PENNSYLVANIA COUNCIL ON INDEPENDENT LIVING**
200 Locust Street
Suite 200
Harrisburg, PA 17101
Voice and TTY: 717-920-0530
The Pennsylvania Council on Independent Living (PCIL) exists to promote the development and expansion of a statewide network of consumer-directed Centers for Independent Living (CILs) which operate consistently within the Independent Living Philosophy, that is, to engage in collective systems change, to promote the availability of Independent Living options to persons regardless of their disability, and to outreach to those unserved and underserved. PCIL strives to enhance the capacity of its network of CILs by providing mutual technical assistance and support to its members.

**Pennsylvania Health Law Project (PHLP)**

**Philadelphia Office**
The Corn Exchange  
123 Chestnut St., Suite 40  
Philadelphia, PA 19106  
Phone: 215-625-3663  
Fax: 215-625-3879  
Website: [http://www.phlp.org](http://www.phlp.org)  
Email: [staff@phlp.org](mailto:staff@phlp.org)

**Harrisburg Office**
1414 N. Cameron Street, Suite B  
Harrisburg, PA 17103  
Phone: 717-236-6310  
Fax: 717-236-6311

**Pittsburgh Office**
650 Smithfield Street, Suite 2130  
Pittsburgh, PA 15222  
Phone: 412-434-5779  
Fax: 412-434-0128

PHLP provides free legal services and advocacy to Pennsylvanians having trouble accessing publicly funded health care coverage or services. For assistance, call our helpline at 800-274-3258 or 866-236-6310 (TTY).

**Pennsylvania Training Partnership for People with Disabilities and Families (The Partnership)**

Toll Free: 866-865-6170  
Fax: 215-204-6336  
http://www.TheTrainingPartnership.org

The Partnership believes knowledge is power. Knowledge of the systems that serve people with disabilities allows people to move through systems more easily, to use systems more fully, and to change systems more effectively. For the first time, The Partnership makes available training and technical assistance, developed and provided by people with disabilities and families. The training is coordinated statewide yet regionally-responsive; person-centered and culturally competent; attentive to capacity-building and supportive of leadership development.

The Partnership is a collaboration of Achieva, the Institute on Disabilities at Temple University, Mentors for Self-Determination, Self-Advocates United as 1, and Vision for Equality. Together
the Partners provide training, technical assistance, mentoring, and leadership development across the Commonwealth. Some training topics offered by the Partnership are: *Mental Retardation System Basics, What is a Mental Retardation Waiver and How Do I Get One?, Developing a Good ISP, Self-Advocacy, and My Choice, My Direction: Participant-Directed Services.*

**Pennsylvania Waiting List Campaign**

4540 Best Station Road  
Slattington PA 18080  
Toll Free: 877-372-WAIT  
Phone/Fax: 610-767-2437  
Website: [www.pawaitinglistcampaign.org](http://www.pawaitinglistcampaign.org)

The mission of the Pennsylvania Waiting List Campaign is to end waiting lists for people who need community services and supports. The Pennsylvania Waiting List Movement is comprised of people with disabilities, their families, caregivers, advocates and agencies. Their advocacy and educational efforts resulted in the state creating, developing and funding a Five-Year Plan to address waiting lists. Their goal is to give people the tools they need so they can secure and use community services that are needed.

**Self Advocates United as 1**

8 Hutcheson Way  
Greenville PA 16125  
Toll Free Message Line: 877-304-7730  
Email: klenkner@sau1.org  
Website: [www.sau1.org](http://www.sau1.org)

Self Advocates United as 1 (SAU1) is a statewide grassroots advocacy group, fully led by people with disabilities. SAU1’s Mission is to support the self advocacy of people with disabilities and family members for positive impact in our communities and in people’s lives. SAU1 envisions a world where individuals with developmental disabilities and their families are united to share knowledge, empower others, and use their voices to transform their lives and communities. SAU1 members serve on statewide and local boards and advisory groups to represent and spread awareness of the needs of people with disabilities and are active in advocacy at local and statewide levels. SAU1 welcomes new voting members (people with disabilities) and non-voting members (people interested in advocacy, family members, etc).

**Speaking for Ourselves**

714 Market Street, Suite 326  
Philadelphia, PA 19106  
Phone: 800-867-3330  
215-923-8600
The Mission of Speaking For Ourselves is for developmentally disabled people to find a voice for themselves, teach the public about the needs, wishes and potential of people with disabilities, speak out on important issues, and support each other through sharing, leadership development, helping and encouraging each other.

**UCP (UNITED CEREBRAL PALSY) OF PENNSYLVANIA**

908 North Second Street  
Harrisburg, PA, 17102  
Toll Free: 866-761-6129  
Phone: 717-441-6049  
Fax: 717-236-2046  
Email: info@ucpofpa.org info@ucp.org  
Website: [www.upc.org/ucpf_local.cfm/130](http://www.upc.org/ucpf_local.cfm/130)

For 50 years, UCP (a.k.a. United Cerebral Palsy) has been committed to change and progress for persons with disabilities. The national organization and its nationwide network of 111 affiliates in 39 states strive to ensure the inclusion of persons with disabilities in every facet of society—from the Web to the workplace, from the classroom to the community. As one of the largest health charities in America, UCP’s mission is to advance the independence, productivity, and full citizenship of people with cerebral palsy and other disabilities through our commitment to the principles of independence, inclusion, and self-determination.

UCP strives to build a better world for tomorrow—today. The national office, located in Washington, DC, provides key services for its affiliates. UCP’s national office also serves people with disabilities and others through the development of forward-thinking programs, an information and referral service, legislative advocacy, technology initiatives and research. Direct service provision for people with disabilities and their families is offered through UCP affiliates, represented in 39 states across the U.S. UCP affiliates serve more than 30,000 children and adults with disabilities and their families every day through programs such as therapy, assistive technology training, early intervention programs, individual and family support, social and recreation programs, community living, state and local referrals, employment assistance and advocacy. Each affiliate offers a range of services tailored to its community’s needs. UCP is the leading source of information on cerebral palsy and is a pivotal advocate for the rights of persons with any disability. In fact, 65% of people served by UCP have disabilities other than cerebral palsy.
**VISION FOR EQUALITY, INC.**

**Philadelphia Office**
718 Arch Street, 6N
Philadelphia, PA 19106
Phone: 215-923-3349
Website: www.visionforequality.org

**Harrisburg Office**
1414 North Cameron Street
Harrisburg, PA 17103
Phone: 717-233-2424

Vision for Equality is a unique organization founded for and by people with developmental disabilities and their families. It is an independent, non-profit 501 (c) (3) Corporation that was established in July 1996. Vision for Equality is an agency committed to people with disabilities and family members of people with disabilities. The mission statement of this organization demonstrates core organizational values that celebrate the life and importance of people with disabilities. Vision for Equality seeks to support people to make independent choices, and to bring people to greater empowerment by promoting services that highlight accountability, quality, and access for all. In its work, Vision strives toward standards that emphasize the importance of services to people with disabilities that are person-centered and outcomes based. At the present time the organization has six major program areas: Embreeville Consumer and Family Satisfaction Teams, Court-related and General Advocacy, Training Department, The Pennsylvania Waiting List Campaign including Community Education Service, an Independent Monitoring for Quality Project (IM4Q), and HIV/AIDS Trainin
GLOSSARY OF TERMS

Abbreviated ISP
Shortened version of the ISP used for people who receive under $2,000 in non-waiver services. The minimum screens must be completed: Demographics, Outcome Summary, Outcome Actions, Services and Supports Directory (Provider, Vendor, and/or FMS) and Service details.

ACCESS Card
Medicaid recipients present this card to doctors and health care professionals to verify their eligibility for medical services covered by Medicaid.

Administrative Entity (AE)
An AE is typically a County MH/MR Program that holds an agreement with the Department of Public Welfare to perform waiver-related activities and functions delegated by the Department. The role of the AE is to implement the waiver program(s) and other duties set forth in the Operating Agreement, adhere to all ODP policies and procedures and Departmental regulations and decisions, and provide fiscal and administrative services. An AE can also be a non-governmental entity that holds a contract with the Department to perform the waiver-related activities and functions.

Area Agencies on Aging (AAA)
There are 52 Area Agencies on Aging, covering all 67 counties. They are the local representatives for the Pennsylvania Department of Aging; they administer various programs and services available to older Pennsylvanians.

Attendant Care
Provides in-home personal assistance services, such as help with bathing, dressing, meal preparation, and housekeeping. These services differ from traditional homemaker and chore services in that they recognize the consumer’s right to make decisions regarding the level and intensity of care; provide hands-on personal care services; and are available at any time depending on the consumer’s needs.

Bureau of Hearings and Appeals (BHA)
Departmental office that conducts formal appeals and hearings. The BHA receives notice of appeal from the Administrative Entity (AE). In the service review process, the BHA receives ODP’s service review determination to inform the fair hearing proceedings.

Case Management
See Supports Coordinator.
Centers for Medicare and Medicaid Services (CMS)
Federal agency in the Department of Health and Human Services that oversees the Medicaid, Medicare, and State Children’s Health Insurance programs.

Community Residential Facility
A licensed personal care home, domiciliary care home or community home for persons with mental retardation, or other related conditions.

Community Resources
Educational, recreational, civic, and other public services, buildings and agencies available to the general public.

County Assistance Offices (CAO)
The 105 County Assistance Offices, which cover all 67 counties, administer Department of Public Welfare assistance programs, including food stamps, Medicaid, and cash assistance.

Facility
A building where programs or services take place.

Fair Hearing and Appeal
The right to have a hearing before the Department of Public Welfare, Bureau of Hearing and Appeals when the individual is: 1) Not offered the choice between an ICF/MR and waiver services, 2) Denied the service option of choice, 3) Denied the choice of a willing, qualified waiver provider, and 4) Home- and community-based services received are reduced, terminated, or suspended without consent.

Family Driven Support Services (FDSS)
State-funded services provided to individuals and families. FDSS funds are limited.

Federal Benefit Rate
The portion of the monthly Supplemental Security Income (SSI) funded by the Social Security Administration.

Federal Financial Participation (FFP)
Federal funds authorized to states to assist in payment for services.

Financial Management Services (FMS)
An organization that provides assistance with employer-related tasks (example, payroll) for people who direct their own qualified support workers. At a minimum, FMSs cut paychecks for an individual’s support providers, take care of paying employment taxes and filing for workers compensation insurance on behalf of a person. Pennsylvania has two FMS models:

• Vendor Fiscal/Employer Agent (VF/EA)
Individuals/families/representatives are able to 1) recruit and hire their qualified support staff, 2) determine staff work schedule(s), 3) determine the tasks to be performed and how and when they are to be performed, 4) orient and train their worker(s), 5) manage the day-to-day activities of their workers, and 6) dismiss workers as necessary. *(You’re the employer, but the VF/EA is the “bookkeeper.”)*

- **Agency With Choice**
  
  Qualified support staff are employed by an agency who works together with the individual/family/representative to 1) recruit qualified support service workers to the agency for hire to support that person, 2) provide and/or participate in training worker(s) to support that person, 3) determine the worker(s)’ work schedule, 4) determine the tasks to be performed and how they are performed, 5) manage the day to day activities of that person’s worker, and (6) dismiss support workers as necessary. *(The agency is the actual employer of record but you have a say in who is hired, staff scheduling and in managing the staff.)*

**Financial Eligibility**

Income and resource limits that have been established in order for people to qualify for Medicaid Waiver services and other MA services.

**Guardian**

A court-appointed person who has the legal responsibility for the care and management of an estate, minor, or person declared incapacitated.

**Health Care Professionals**

Licensed or certified provider of health care services, including physicians, psychologists, therapists, and nurses.

**Home**

Any place a person chooses to live.

**Home and Community Based Services**

Services and supports provided in a home or community location to help persons live as independently as possible. These services include in-home supports, community group homes, transportation, etc.

**Home and Community Services Information System (HCSIS)**

The web-based system that Pennsylvania uses for data entry and tracking of Individual Support Plans, individual (demographic, enrollment, and eligibility) information, Prioritization of Urgency of Need for Services (PUNS), Supports Coordination monitoring and service notes, incident reports and support provider information.

**Hospice**

Programs that provide for the physical and emotional needs of people with terminal illnesses.
Individual Support Plan (ISP)
an integrated planning document reflecting “Person-Centered Planning,” the core values of Everyday Lives and Positive Approaches to result in an enhanced quality of life for everyone who receives mental retardation services and supports in Pennsylvania. The ISP must outline the services and supports that address a waiver participant’s needs.

Informal Support
People who provide supports and are not paid to do so.

Intermediate Care Facility for Persons with Other Related Conditions (ICF/ORC)
A facility that provides health care, rehabilitation, and active treatment services for persons with severe physical developmental delays such as cerebral palsy, muscular dystrophy, epilepsy, or similar conditions diagnosed before the age of 22 and that result in three or more functional limitations of daily living. Services are not designed for persons with mental illness or mental retardation.

Intermediate Care Facility for Persons with Mental Retardation (ICF/MR)
A licensed facility that provides care designed to meet the needs of persons with mental retardation who meet the ICF/MR level of care criteria and who require special health and rehabilitation services.

Long Term Care
Services designed to provide diagnostic, therapeutic, rehabilitative, supportive, or maintenance services for individuals who have chronic functional impairments. Services may be provided in a variety of institutional and non-institutional settings including the home.

Long Term Nursing Facility
An institution to provide nursing home services to residents. The facility may be for-profit, non-profit, hospital-based, or operated by a county. This does not include personal care homes, domiciliary care homes or boarding homes, and also does not include community care that does not operate under a long-term nursing facility license.

Medical Assistance
Health and long-term care services established under the Social Security Act, which a state adopts through its stated Medical Assistance (MA) plan or under an approved Medicaid Waiver.

Medical Assistance (MA) Provider Agreement
All providers, with the exception of unlicensed individuals providing services through a Vendor Fiscal/Employer Agent Financial Management Services, must have a signed Medical Assistance Provider Agreement with the Department of Public Welfare (DPW) in order to receive waiver funding for payment of services. (Unlicensed individuals must have a signed agreement with a VF/EA FMS under contract with the Department in order to receive waiver funds.)
funding for payment of services). The agreement covers things like the provider agrees to follow all waiver rules and regulations, not accept additional payment from recipients and to protect confidentiality.

**Medical Assistance for Workers with Disabilities (MAWD)**
A state Medical Assistance program that encourages people to work. It allows people to maintain a much higher income and resource level than they would under the current MA program.

**Medically Needy**
Eligibility for Medicaid under specific financial requirements that includes income limits after incurred medical expenses have been deducted from the income.

**ODP Quality Leadership Board**
An Office of Developmental Programs internal group of senior managers who oversee ODP Quality Management.

**Operating Agreement**
Contract between the Department of Public Welfare and Administrative Entities (AEs) for functions related to the implementation of the Consolidated and Person/Family Directed Support (P/FDS) Waivers. The agreement reinforces the authority of ODP, and outlines the roles and responsibilities of both the Administrative Entities and ODP. The new agreement also includes steps ODP can take if an Administrative Entity is not fulfilling the contract.

**Oversight**
The watchful care and reporting by a Supports Coordinator, Service Manager, or QMRP for unlicensed providers of service. This also includes ongoing review by ODP of County Programs/AE’s to ensure compliance with applicable policies, procedures, and regulations.

**Person Centered Supports**
A type of service planning that allows the person to develop their own services and supports package to meet their needs, and select their own services and providers.

**Participant Directed Services**
The individual receiving services has the number one role in determining the supports, outcomes, services, and decisions that affect him/her. A person living in his/her own home or family’s home can choose to arrange and manage his/her own services and use Financial Management Services for payroll. He/she may also utilize a Supports Broker for assistance or designate a surrogate to act on their behalf.

**Personal Care Home**
A licensed facility that provides meals, shelter, and personal assistance or supervision for more than 24 consecutive hours for more than three adults who do not require nursing home
care. Personal care homes will accept immobile adults who can be safely evacuated in an emergency.

**Provider Dispute Resolution**

A formal process that providers can use to appeal decisions by the Administrative Entity (AE). Circumstances where the provider could use the formal appeal process are:

- The AE has imposed additional contractual requirements.
- The AE has imposed restrictions or suspension upon the provider.
- The AE has initiated a termination or disqualification action.
- There are violations of 55 Pa. Code 4300 that limit the provider’s ability to provide waiver services.
- The AE has not complied with ODP’s rate setting methodology.

**Provider Qualifications**

The Office of Developmental Programs has a standardized statewide process to qualify waiver providers.

**Qualified Mental Retardation Professional (QMRP)**

The QMRP determines whether a person meets ICF/MR level of care criteria. A QMRP may be any person who has at least one year of experience working with persons with mental retardation or other developmental disabilities and is one of the following: 1) A doctor of medicine or osteopathy, 2) A registered nurse, 3) An individual who holds at least a bachelors degree in a specific professional category.

**Rate Setting**

Rate setting is a standardized method for determining rates that providers can charge for providing waiver services. ODP has developed standards that waiver providers must use in determining the rates for waiver services.

**Regional Program Managers (RPM)**

Oversee regional operations for the Office of Developmental Programs that includes fiscal and program planning, management and oversight of community mental retardation programs.

**Regional Reviewers**

Specific staff members at each ODP Regional Office who are assigned as part of the service review process to review all information regarding an appeal that meets the criteria for a service review. They are the first reviewers in the Service Review process. After reviewing all the information regarding an appeal, the reviewer makes a recommendation to the Regional Program Manager.
Respite
A service that is provided on a short term basis because of the absence or need for relief of the primary caregivers.

Self Determination
A person’s right to determine the course of his/her own life and to make decisions affecting it, along with the responsibilities.

Service Definitions
Descriptions of each service covered under the Consolidated and Person/Family Directed Support Waivers (P/FDS) and through other mental retardation funding. Service definitions provide a standardized definition, unit and billing code for each service. Revisions to the service definitions took effect July 1, 2010.

Service Definition Units
Each waiver service is assigned a billing code number (entered into HCSIS) and amount of time a service must take place to equal one unit. (For example 24 hours of in-home Respite = 1 unit, 15 minutes out-of–home Respite = 1 unit, 15 minutes of 1 to 1 Habilitation = 1 unit). These units allow for standardized billing of Waiver services.

Service Preference
Individuals who are likely to meet the ICF/MR level of care criteria, or their representative, have the right to choose between institutional and home-and-community-based services.

Service Provider
An agency or individual employed to provide a service. In order to provide services through Medicaid Waivers, a provider must be willing and qualified to provide the service.

Service Review
Service Review is a formal process that takes place for Waiver recipients prior to the Fair Hearing process. Service Review is used if Waiver services have been denied, terminated, suspended or reduced. It is a protocol set forth by ODP to ensure consistent application of ODP policies. The service review process does not interfere with the individual/families due process rights.

Services and Support Directory (SSD)
A web-based service directory that contains information about providers of services in Pennsylvania.

SSI Resource Limit
The amount of money or savings a person can have and still be eligible for services under the Waiver. The resource limit is $2,000 for a person and $3,000 for a couple.
Supports Broker
An individual or agency that provides assistance needed for a person to plan, organize, and manage community resources. Some specific functions include: assistance in identifying and sustaining a personal support network of family, friends and associates for the person, assistance in arranging for and effectively managing community resources and informal supports, assistance at meetings to ensure the person’s access to quality community resources, and assistance in identifying and developing community resources to preserve the person’s well-being in the home and community. This waiver service is available to participants directing their own supports.

Supports Coordinator
Formerly known as Case Managers, Supports Coordinators help locate, coordinate, and monitor services and supports for individuals.

Supports Intensity Scale (SIS) and PA Plus (PA+)
The Supports Intensity Scale (SIS) is an assessment tool that evaluates the practical support requirements of a person with a developmental disability. The SIS is a comprehensive and non-deficit based assessment that evaluates support needs throughout many life areas.

- PA Plus (PA+) - Additional questions that may be created by Pennsylvania as an addendum to the SIS. These additional questions address areas that the SIS itself did not address fully. ODP uses the SIS and PA+ as the standardized needs assessment for the Pennsylvania mental retardation system (for Consolidated and P/FDS Waiver participants ages 16-72).

Supported Employment
Paid employment for persons who need intensive, ongoing support to perform in a work setting, which is not covered under the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act.

Surrogate
An individual selected by the person to represent him/her, or in the case of some persons with a cognitive disability, an individual acting on his/her behalf.

Technology Dependent
A person’s dependence on technology to replace a vital bodily function or to sustain life.

Targeted Service Management (TSM)
Medical Assistance funded case or service management for persons with mental retardation.

Underserved people
People who receive some services, but not all of the services they need.

Unserved people
People who do not receive any of the services they need.
**Waiver Capacity**
The number of Waiver participants, approved by CMS, that can receive services through the Consolidated and Person/Family Directed Support (P/FDS) Waivers. Each Waiver has an approved number of slots that can be increased or decreased through a waiver amendment to CMS. Each Administrative Entity (AE) is notified of the number of Waiver participants to which it can provide administrative services through an annual financial commitment letter. The AE is responsible to ensure health and welfare needs of Waiver participants are fully met before enrolling new applicants (Olmstead Letter #4). If the AE indicates an inability to provide services to the number of waiver participants identified in their financial commitment letter, ODP reserves the right to adjust the assigned Waiver slots and related funding.

**Waiver Capacity Commitment**
The number of participants the Administrative Entity may enroll in a specified Waiver at any given point in time during a fiscal year, as approved by the Department.

**Waiver Capacity Commitment Letter**
A notification that designates the Department’s current approved maximum number of participants within the jurisdiction of the Administrative Entity that may be enrolled in each Waiver at any given point in time. There are two numbers designated in the Waiver Capacity Commitment Letter reflecting the number of Participants that may be enrolled in the Consolidated Waiver and in the Person/Family Directed Support Waiver.
### Acronyms

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<tr>
<th>Acronym</th>
<th>Definition</th>
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<td>2176 Waiver</td>
<td>Consolidated Waiver</td>
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<tr>
<td>AE</td>
<td>Administrative Entity</td>
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<tr>
<td>BAS</td>
<td>Bureau of Autism Services</td>
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<td>BHA</td>
<td>Bureau of Hearings and Appeals</td>
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<td>BSU</td>
<td>Base Service Unit</td>
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<td>CLA</td>
<td>Community Living Arrangement</td>
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<td>CMS</td>
<td>Centers for Medicare and Medicaid Services (Federal Agency formerly known as the Health Care Financing Administration, or HCFA)</td>
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<td>DLP</td>
<td>Disability Law Project</td>
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<td>DPW</td>
<td>(PA) Department of Public Welfare (ODP is part of DPW)</td>
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<tr>
<td>DRN</td>
<td>Disability Rights Network</td>
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<td>ELC</td>
<td>Education Law Center</td>
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<td>ELP</td>
<td>Essential Lifestyle Planning</td>
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<tr>
<td>EPSDT</td>
<td>Early Periodic Screening Diagnosis and Treatment</td>
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<td>FDSS</td>
<td>Family Driven Support Services</td>
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<td>FMS</td>
<td>Financial Management Services</td>
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<td>ISO</td>
<td>Intermediary Service Organization</td>
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<td>ISP</td>
<td>Individual Support Plan</td>
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<td>MA</td>
<td>Medical Assistance</td>
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<td>MAWD</td>
<td>Medical Assistance for Workers with Disabilities</td>
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<td>MR</td>
<td>Mental Retardation</td>
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<td>ODP</td>
<td>(PA) Office of Developmental Programs</td>
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<td>OVR</td>
<td>Office of Vocational Rehabilitation</td>
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<td>PAWL</td>
<td>PA Waiting List Campaign</td>
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<tr>
<td>PCP</td>
<td>Person Centered Planning</td>
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<tr>
<td>P/FDS</td>
<td>Person/Family Directed Support Waiver</td>
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<tr>
<td>PUNS</td>
<td>Prioritization of Urgency of Need for Services</td>
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<tr>
<td>RPM</td>
<td>Regional Program Manager</td>
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<tr>
<td>SC</td>
<td>Supports Coordinator (formerly called a Case Manager)</td>
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<td>SIS (SIS-PA+)</td>
<td>Supports Intensity Scale and PA Plus (PA+)</td>
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<td>SSA</td>
<td>Social Security Administration</td>
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<td>SSD</td>
<td>Services and Supports Directory</td>
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<td>SSI</td>
<td>Supplemental Security Income</td>
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<td>TSM</td>
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