

Understanding the Office of Developmental Programs in Pennsylvania: Intellectual Disability and Autism Services

Copyright © 2013 Vision for Equality, Inc.

Permission to reprint, copy and distribute this work is granted provided that it is reproduced as a whole, distributed at no more than actual cost, and displayed with this copyright notice. Any other reproduction is strictly prohibited.

available in alternate formats upon request

DEDICATION

We dedicate this manual to those who advocate for the rights of people with disabilities and especially to those who wait.



COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF PUBLIC WELFARE

April 4, 2013

Dear Colleagues:

The mission of the Office of Developmental Programs is to support Pennsylvanians with developmental disabilities to achieve greater independence, choice and opportunity in their lives. Our vision is to continuously improve an effective system of accessible services and supports that are flexible, innovative and person-centered. We recognize, at times, our services may appear complicated and difficult to navigate. For this reason, current and accurate information organized in a concise manner can be helpful to the stakeholder community. Appreciating the importance of information, I am pleased to endorse the book *Understanding the Office of Developmental Programs in Pennsylvania: Intellectual Disability and Autism Services*.

This book has been compiled by people who were aware of this need and undertook the challenge of writing it – individuals and families. This has truly been a collaborative effort by people knowledgeable about the services and supports 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 Developmental Disability services, supports and resources in the Commonwealth of Pennsylvania.

Sincerely,

A handwritten signature in cursive script that reads "Fred C. Lokuta".

Fred C. Lokuta
Deputy Secretary

TABLE OF CONTENTS

DEDICATION	II
TABLE OF CONTENTS.....	IV
Written and compiled by	VII
ABOUT THIS MANUAL.....	IX
THE “R” WORD.....	IX
ADVOCACY TIPS	X
INTRODUCTION: OVERVIEW OF THE OFFICE OF DEVELOPMENTAL PROGRAMS INTELLECTUAL DISABILITY SYSTEM	XI
What does the Intellectual Disability System look like?	XII
How does Waiver Funding Flow from the Federal and State Governments to the Individual?	XIII
How does Base Funding Flow from the State Government to the Individual?	XIV
Various Funding Sources	XV
What is the Difference between Waiver Funding and FDSS?	XVI
Waiting List	XVI
CHAPTER 1: ACCESSING THE INTELLECTUAL DISABILITY SYSTEM	1
Registering for Intellectual Disability Services	1
Supports Coordinators: Locate, Coordinate, Monitor	3
Prioritization of Urgency of Need for Services (PUNS) Form	4
SIS and PA Plus	5
The Individual Support Plan (ISP)	7
“How Do I Get Services” Checklist	15
CHAPTER 2: INTELLECTUAL DISABILITY WAIVERS.....	16
How to Choose Home and Community-Based Waiver Services	16
Waiver Capacity Commitment	23
Waiver Service Definitions: Services Available to Individuals in the Consolidated Waiver and the Person/Family Directed Supports (P/FDS) Waiver.....	24
Waiver Service Requests	47
Services Provided by Family Members	47
Travel Policy	49
Waiver Monitoring.....	51
CHAPTER 3: ORGANIZING YOUR SUPPORTS	54
Choosing the Supports I Need.....	54
Financial Management Services (FMS).....	56
Choosing Where You Want to Live.....	58

Employment.....	61
Future Planning (Why Should I Plan for the Future?).....	62
Rates and Provider Payments.....	63
CHAPTER 4: UNDERSTANDING YOUR RIGHTS	66
What to do When You Have a Problem: County Level Dispute Resolution.....	66
What can I do if my County MH/ID Program says I am not eligible for Intellectual Disability Base-funded services...?	67
Appeals for Persons with ID when Home and Community-Based Waiver Services are Denied, Reduced, Suspended or Terminated.....	68
Attachment 1.....	77
Attachment 2.....	78
Attachment 3.....	79
Attachment 4.....	81
CHAPTER 5: QUALITY	82
What is Quality?.....	82
ODP’s Quality Oversight Groups and Quality Leadership Board	82
Administrative Entity Oversight Monitoring Process	83
Independent Monitoring for Quality (IM4Q)	83
Health Care Quality Units (HCQUs)	84
Provider Qualifications and Provider Quality Management Plans	84
Incident Management	85
CHAPTER 6: BUREAU OF AUTISM SERVICES	87
Mission Statement	87
Values.....	87
About the Bureau of Autism Services	87
Services and Supports Available through the Bureau of Autism Services: Adult Autism Waiver (AAW) and Adult Community Autism Program (ACAP)	88
Adult Community Autism Program (ACAP)	93
The Adult Autism Waiver	96
Service Descriptions	98
Can Family Members Provide Services?.....	107
Monitoring Requirements.....	108
Fair Hearing	109
Bureau of Autism Services Training Initiatives	110
Additional Resources Available through the Bureau of Autism Services: ASERT Regional Collaboratives	111

How are the ASERTs Supporting Individuals with ASD in their Regions?	111
CHAPTER 7: TRANSITION FROM SCHOOL TO ADULT SERVICES	116
Transition Checklist	116
RESOURCES.....	120
APPENDIX A: FORMS	127
PUNS Form	128
PUNS Disagreement Form.....	133
Home and Community-Base or ICF/ID Application and Service Delivery Preference Form	135
Fair Hearing Form.....	137
MA 51: Medical Evaluation	139
Waiver Service Request Form.....	140
Individual Support Plan Signature Form	143
Request for Exception to Service	146
APPENDIX B: RESOURCES AND CONTACTS.....	151
Calling Your County and Regional ODP Offices.....	152
Advocacy and Agency Contact.....	159
GLOSSARY OF TERMS.....	167
Acronyms.....	176

ACKNOWLEDGMENTS

This manual could not have been written without the talent, encouragement, and support of Vision for Equality, Inc. who recognized the need to inform people and families, sought the answers and made it happen. We also thank the Disability Rights Network for their continual support and encouragement, and the Department of Public Welfare, Office of Developmental Programs.

Written and compiled by

- ❖ **Sheila Stasko, *Statewide Coordinator, Pennsylvania Waiting List Campaign***
4540 Best Station Road
Slatington, Pa. 18080
267-765-0301
Fax: 610-767-2437
sstasko@pawaitinglistcampaign.org
- ❖ **Lisa A. Tesler, *Vision for EQuality, Inc.***
1414 North Cameron Street, Suite B
Harrisburg, PA 17103
717-233-2424
Fax: 717-233-2449
ltesler@visionforequality.org
- ❖ **Kristin Ahrens, *Institute in Disabilities, Temple University***
1755 N. 13th Street, Suite 411S
Philadelphia, PA 19144
215-204-9543
kahrens@temple.edu
- ❖ **Maureen Devaney, *Co-Executive Director, Vision for Equality, Inc.***
The Cast Iron Building
718 Arch Street, 6th Floor North
Philadelphia, PA 19106
215-923-3349
Fax: 215-923-8075
TTY: 215-923-8898, extension 133
mdevaney@visionforequality.org
www.visionforequality.org
www.pawaitinglistcampaign.org

We thank those who participated in the development of this book for their time, honesty and commitment to make this a working document that will assist people and families across the Commonwealth, especially Jackie Epstein, Director of Communication and Training. Additional information was provided by:

Jeanine Zlockie, Human Services Program Specialist Supervisor, ODP Policy

Jacqueline Epstein, Director of Communication and Training, ODP

Jeanne Parisi, Division Director, ODP Program Initiatives

Erica Wexler, Communication and Training Coordinator, BAS

Angela Fortney, Director of Community Services

Lee Stephens, QI Initiative Program Specialist, ODP

Carmen Donegan, Program Specialist, ODP

Lisa Meyer, ODP Consulting System (OCS) Director

Jill Morrow-Gorton, Medical Director, ODP

Kyla Schultz, ISP Review Lead, ODP

AmyLyn Morocco, ISP Reviewer, ODP

Mark Murphy, Esq., Executive Director, Disability Rights Network

Nathaniel Williams, EdD, MHS, MPA, MBA President/CEO HumanWorks Affiliates, Inc.

Printing this book was made possible by the **Pennsylvania Training Partnership for People with Disabilities and Families**, which is funded by the Pennsylvania Office of Developmental Programs, Department of Public Welfare

ABOUT THIS MANUAL

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 Intellectual Disability 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. There are also chapters 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.

THE “R” WORD

In 2010 President Obama signed “Rosa’s Law” and in 2011 Governor Corbett signed Act 105, the “Words Do Matter” bill, into law. Both of these laws were passed in an effort to remove the “R-Word” from our federal and state laws and, ultimately, to stop the use of the archaic term that has become offensive and hurtful. Both the federal and state laws modernize language by replacing the term “mental retardation” with “intellectual disability.” In line with these changes on the federal and state level, local programs have changed their names and policies, now using the term “intellectual disability.” Throughout this book, we will use the term “intellectual disability.”

ADVOCACY 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 Intellectual Disability 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 limits 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 ID 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 INTELLECTUAL DISABILITY 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 intellectual disability. 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 Intellectual Disability 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. As we write this manual (Winter 2012-13), the Pennsylvania Department of Public Welfare, Office of Developmental Programs just completed a five year waiver renewal and revised state regulations governing the system. The changes will impact procedures on state and local levels. 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 or call 1-888-565-9435.

What does the Intellectual Disability System look like?

The Intellectual Disability (ID) system is part of the Office of Developmental Programs (ODP) within the Pennsylvania Department of Public Welfare (DPW). You will access the ID system through a County Office that is partnered with a Regional Office. Currently there are four Regional Offices within the state of Pennsylvania that partner with forty-eight County Offices.

You will need to register in the county where you live in order to officially become part of the ID system. This will allow you to request services and supports to meet your needs. You can find your County Office in the Blue pages of your phone book or in Appendix B of this manual. It is helpful to note that some County Offices serve more than one county in the ID System. If you are unable to figure out what County Office will be able to help you register, you can call the customer service hotline 1-888-565-9435. If you are unsure if you will qualify for services, please review Chapter 1. If you are still uncertain if you qualify for services in the ID system, your County Office can help you or you can call the customer service hotline. If you are not registered in the system, then you are limiting your access to services and supports in the state of Pennsylvania.

****Please note that you will need to read Chapter 6 to learn more about Autism Services, as it is not part of the county based ID system.**

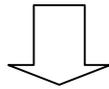
The Office of Developmental Programs (ODP) sets policy and guidelines for the County and Regional Offices to administer and implement ID programs. These policies are published and distributed through Bulletins, Memos, and Informational Packets issued by the State Office. You can access those documents through the Partnership Website, www.TheTrainingPartnership.org, the ODP Consulting System website, www.odpconsulting.net, or by contacting the Partnership 1-866-865-6170.

FUNDING

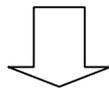
The Office of Developmental Programs is funded through your tax dollars. You will most likely hear discussions about funding in the ID system using the term “Waiver”. The Waiver program, which is most of the funding available in the system, is a combination of federal Medicaid monies and state monies. You may also hear the term “Base” when talking about funding. Base money 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.

How does Waiver Funding Flow from the Federal and State Governments to the Individual?

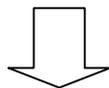
Federal funds from the Centers for Medicare and Medicaid Services (CMS) — also known as Medical Assistance, Access, Waiver Funding, Targeted Service Management. CMS provides funding for health care including long term services and supports for people with disabilities.



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.



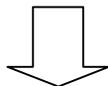
Administrative Entities (AE)/County Programs, County Mental Health/Intellectual Disability (MH/ID) Offices, AE/County Administrators. AE/Counties enroll individuals into the Waiver program and authorize services outlined in Individual Support Plans (ISPs).



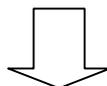
Individuals – Services and Supports for Individuals and Families. Individual Support Plans (ISPs) are developed to outline services needed. An individual chooses who will provide the services and a budget is created. Once the plan is authorized by the AE/County, the providers of waiver services bill 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/Intellectual Disability (MH/ID) Offices, AE/County Administrators. AE/Counties enroll individuals into the Intellectual Disability 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 or by looking on-line:
http://www.portal.state.pa.us/portal/server.pt/community/vocational_rehabilitation/10356/ovr_office_directory/606620. 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.
- **Ticket to Work** – Social Security's Ticket to Work Program is free, voluntary and available to most people who receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits. Eligible beneficiaries may choose to assign their "Ticket" to an Employment Network (EN) of their choice or to OVR. The "Ticket" helps people get employment services and supports necessary to achieve a work goal.
- **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 Base Funding** – This is state funding from the PA Office of Developmental Programs that is given to the counties. This funding is becoming more limited as states turn to federal dollars to support community programs. Some counties Base Funding is a part of a larger Block Grant for Human Services. Request information from your Supports Coordinator about what funds are available.
- **State Family Driven Support Services 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.
- **Person/Family Directed Supports Waiver** – See section on *P/FDS Waiver*, page 20.
- **Consolidated Waiver** – See section on *Consolidated Waiver*, page 20.

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.

Waiting List

The Waiting List is comprised of individuals who are qualified and eligible to receive services and supports through the Office of Developmental Programs waivers, however, due to insufficient resources, the state cannot currently meet their needs. When a person applies for services and is deemed eligible, they may be placed on the waiting list for services until funding becomes available to enroll them into a waiver program. The state Office of Developmental programs allocates waiver capacity to Counties/AEs each year. The waiver capacity is the maximum number of people that can be served that year. A person on the waiting list can only enroll into services when capacity becomes available. Individuals on the waiting list are placed in a category of need, Emergency, Critical or Planning, depending on their specific situation and the person with the most urgent need will have priority for enrollment. The determination of category of need is part of the PUNS process, which is discussed in Chapter 1.

At the time of publication (January 2013), there are approximately 15,000 people waiting for supports and services. About 4,000 people are in emergency situations and need services immediately to maintain their health and safety in the community.

The Pennsylvania Waiting List Campaign is a grassroots organization of individuals and families of people with intellectual disabilities and autism. The waiting list campaign shares information about the struggles of individuals waiting for services and advocates with government officials and policy makers to provide the funding and resources to end the wait. For information about PA Waiting List Campaign, visit www.pawaitinglistcampaign.org or www.visionforequality.org or find our contact information in the resource section.

CHAPTER 1: ACCESSING THE INTELLECTUAL DISABILITY SYSTEM

This chapter is an overview of how to register for services through your County Intellectual Disability Office. It covers eligibility criteria, a checklist for you to use as you go through the process and information about the role of your Supports Coordinator.

This chapter also covers the Prioritization of Urgency of Need for Services (PUNS), the Supports Intensity Scale (SIS)[™] assessment, and the Individual Support Planning (ISP) process.

Registering for Intellectual Disability Services

WHY DO I NEED TO REGISTER FOR INTELLECTUAL DISABILITY 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 Intellectual Disability system.

HOW DO I REGISTER WITH THE COUNTY INTELLECTUAL DISABILITY OFFICE?

There are several simple steps you need to take in order to register with the Intellectual Disability system:

1. Begin by looking in the Appendix for the *Advocacy and Agency Contacts* section of this manual and find your County Intellectual Disability Program listing and phone number. The Blue Pages of your telephone book also lists your County Program under Human Services or Intellectual Disability Services. You may call the ODP Customer Services line at 1-888-565-9435 if you are unable to locate the County phone number.
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

[™] Supports Intensity Scale 2004 AAIDD

- Proof of Address (for example, utility bill, lease, etc.)
- MA Card (if you have one – also referred to as Medicaid, Access Card, Medical Assistance), other insurance cards
- Assessments, Evaluations, Psychological evaluation (if you have one)
- Legal guardian or custodial papers (if this applies to you)

The County Intellectual Disability 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 INTELLECTUAL DISABILITY SERVICES?

The essential feature of an intellectual disability 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 an intellectual disability 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 Intellectual Disability 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 Intellectual Disability Service system, and has no prior records of testing. Clinical judgment may be used to determine whether the age of onset of an intellectual disability 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 ODP 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

When you register for Intellectual Disability (ID) services through your County ID Program you will be assigned a Supports Coordinator. Your Supports Coordinator is someone with whom you should be able to discuss your life and goals freely.

A Supports Coordinator is responsible for making sure all steps leading to applying for and receiving Intellectual Disability 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 desired outcomes in 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 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 (SCO) 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. 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 (ODP), commissioned Temple University's Institute on Disabilities, University Center for Excellence in Developmental Disabilities, to conduct a standardized survey of people waiting for services and supports in Pennsylvania. The Institute on Disabilities, 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 show 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 Administrative Entities (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.
- 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.

- 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. If you do not receive a copy of the HCSIS PUNS form in the mail within 3 weeks, contact your Supports Coordinator.
- 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.
- 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 the top priority when funding becomes available.
- Refer to the *Appendix A: 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.

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 roughly 20 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 Intensity Scale 2004 AAIDD

supports needed to help you live independently. Topics covered include home and community living, lifelong learning, and employment, to name a few.

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.

ASSESSORS

ODP wanted assessments to be conflict-free so an independent contractor administers assessments. 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 the agency that does the assessments 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 the assessor, 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.

The Individual Support Plan (ISP)

The Individual Support Plan (ISP) is a planning document that is used to support an individual's everyday life – a life in which you live, work, play and worship in the community of your choice. It is used by the Office of Developmental Programs (ODP) to identify the services and supports you need. It reflects your vision for the future and provides details of how to support you in reaching that vision. Your ISP should be all about you and written in a way that lets others know what supports you need at home and in the community.

The ISP meeting is facilitated by the Supports Coordinator (SC) and based upon input from the ISP Team (“the Team”). All the people on your Team should be supportive of you and your vision. The Supports Coordinator will enter the ISP into HCSIS (Home and Community Service Information System) when the information is complete. HCSIS is a web-based system that Pennsylvania uses for storing and tracking information within ODP.

THE ISP TEAM

The ISP Team includes the individual for whom the plan is being written— you and your Supports Coordinator. The program specialist of each licensed service provider involved in your life must be present (as per current regulation). Licensed service providers in Pennsylvania include Community Homes (group homes), Family Living Homes and Day Programs (Adult and Vocational Facilities).

Anyone who is important to you and knows you well may be on your Team and at your meeting. This includes family members; friends; your guardian, surrogate, or advocate; and school district employees involved in providing support. Unpaid and caring people are essential, too, because Team members should represent all aspects of your life.

If you choose not to attend the ISP meeting, your Supports Coordinator should review your ISP with you after the meeting to ensure you agree with its content and outcomes. You will be asked to sign the signature form at this time. If you disagree with the content of the ISP, there is a place on the signature form where you sign and indicate that you have an objection to the content.

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?

- Think about who is on your team. Is your team prepared to help you with the desired outcomes listed on the ISP by doing what they said they would do? Are there other people you should invite to join your team?
- What do you want to make sure gets addressed at your ISP meeting? Are there areas in your life that are problematic and you want the teams help to figure out and support you with a solution?

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.

Your ISP must be reviewed and updated once a year. But, because an ISP is designed specifically for you, it can be changed more often as changes occur in your life.

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.

Questions Related to Individual Preferences

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.

Areas to Address Related to 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 arm's 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 arm's 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 arm's 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.

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.

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.

SERVICE AND SUPPORTS: DEVELOPING OUTCOMES IN YOUR ISP

Your Team uses outcomes to determine the services and/or supports you need to achieve and maintain a life that balances what is important to you and what is important for you. Your health and safety must always be addressed throughout this process. Outcomes supported by ODP funding must be within the context of your health and safety and with the assurance of your continued life in the community. All outcomes should be documented whether or not they are supported by ODP funding.

An outcome is a desired final result. *Outcomes reflect what will exist as a RESULT of the specific actions taken or the support received.* Outcomes represent what is important to you, what you want to happen, what you would like to maintain based upon your assessed needs and things you would like to change. Information gathered during the ISP meeting about things that could make a difference in your life and meet your assessed needs is used in developing outcomes. Any barriers and obstacles that might affect success in meeting outcomes,

especially if these obstacles impact health and welfare, should be addressed. Outcomes are written in plain language.

Together, you and your ISP Team develop outcomes to reflect what is important to you and for you and how the desired results will make a difference in your life. Outcomes should build on the information and assessments that the ISP Team gathers during the planning process and reflect a shared commitment to action.

Writing an Outcome Statement

Outcome statements use information from previous sections of the ISP. Outcome statements use phrases such as “in order to” and “so that” because they are helpful in connecting how the outcome will make a difference for the person.

Typically an outcome will use the person’s name followed by the action and the reason for the action. An example is:

“Kate participates in the church bell group in order to enjoy music and socialize with friends in the community.”

“*Kate participates*” – the person and the action that is expected

“in order to enjoy music and socialize with friends in the community” – why the action is important to or for the person.

Another example of an outcome statement:

Matthew’s Team knows that finding a job, being part of a team, providing a service for other people and following a routine are important to him. Several Team members have expressed concern that working in a store could be too physically demanding for Matthew due to his physical disability. They write an outcome that states:

”Matthew volunteers at the Salvation Army store so that he can decide whether retail work is something he can do.”

This outcome will guide the Team to the services and supports Matthew will need in order to move towards his dream of getting a job.

How do Outcome Statements Lead to Services and Supports?

Services and supports can be directly tied to one (or more) outcome(s) and should promote the outcome(s). “**Outcome Actions**” is another term for identifying the supports and services you need to live an Everyday Life.

Continuing with Matthew’s example above, Matthew needs transportation to get to his volunteer work. The services and supports to meet that outcome might include a paid service such as bus fare and support to learn how to use the bus system. If buses are not available where Matthew lives, he might have to rely on a natural support such as a friend or a family member or a paid support person. In either case, transportation must be addressed in his ISP.

The Service Summary of the ISP will list the frequency and duration of the service(s) you need, the cost of each service, who is paying for it and who is providing the service.

Your Approval of the Plan: The ISP Signature Form

The ISP Signature Form (DP 1032) is a Department approved form that you are required to complete and sign **at the end** of your ISP meeting. Signing the DP 1032 says that you were in attendance at the ISP meeting and you are in agreement with all information that was discussed, the content of the ISP and information that was changed as a result of your meeting. If you disagree with the content of the ISP, there is a place on the Signature Form where you would sign and indicate that you have an objection. The AE/County has the responsibility to try to resolve the objections that are raised. This resolution process should not delay authorization of other services in your plan.

What if I have a Waiver and Disagree with Something in the ISP?

If you have a waiver and request a change to an existing waiver service, an ISP modification, or a new service or support that an ISP Team cannot agree on, that Team member must complete a Waiver Service Request form (DP 1022). Your Supports Coordinator will help fill out the form. Your Supports Coordinator must submit this form to the Administrative Entity (AE)/County within 10 days and the AE/County must give you a written approval or denial of your request within 20 calendar days of when they receive the form.

If the AE/County approves the request in full, a critical revision to the ISP is completed, the plan is approved and the change is authorized. The requested service(s) should start within 30 calendar days of that written approval. If the AE/County partially approves the request, then partial or time-limited services will be approved through a critical revision of the ISP.

If the AE/County denies the request, the AE/County will send you an explanation of why this request was denied at least 10 calendar days from date of written notice. You have the right to file an appeal and request a fair hearing. The AE/County must receive the appeal request within 30 calendar days of the date on the notification of denial.

For further information on appeals and a fair hearing, refer to *Chapter 4: Understanding Your Rights*.

“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 ID diagnosis prior to age 22).
- I received a copy of the Certification of Need for ICF/ID Level of Care (DP250) form that was filled out by the Qualified Intellectual Disability Professional (QIDP) stating that I meet the criteria for Waiver.
- I completed an Individual Support Plan (ISP) with my Supports Coordinator.
- My Individual Support Plan (ISP) was approved and authorized and I received a copy.

CHAPTER 2: INTELLECTUAL DISABILITY WAIVERS

This Chapter is a detailed description of the two waivers available for people with Intellectual Disability. It covers the application process, eligibility criteria and determination, the enrollment process, definitions for the services available and mandatory monitoring of waiver services.

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 Intellectual Disability 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 Intellectual Disability [ICF/ID] 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.

If you are enrolled in ID services through your county, but don’t have your Medical Assistance (MA) Card, the county can help you apply through the County Assistance Office. You must have an MA Card to receive Waiver services.

SERVICE DELIVERY PREFERENCE

The majority of Intellectual Disability 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 Intellectual Disability services. They are:

- **Intermediate Care Facilities for Persons with Intellectual Disability (ICF/ID):** ICF/ID funding supports state-operated institutions and private ICFs/ID. ICF/ID services are an entitlement for eligible persons and cannot be capped or subject to waiting lists.
- **Home and Community-Based Waivers:** Waivers generally support people 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 intellectual disability. These two waivers are known as the (1) Consolidated Waiver and (2) Person/Family Directed Supports Waiver.

Anyone who is eligible for Intellectual Disability services and enrolled in Medical Assistance (MA Card) must be provided with the opportunity to identify their preference in service delivery.

If you are determined eligible for ICF/ID Level of Care, you can choose between ICF/ID and home and community-based waiver 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 in services. Your ability to communicate a preference may be assessed by a Qualified Intellectual Disability Professional (QIDP) through a face-to-face meeting. The QIDP can help you determine your preference at this time, if appropriate. Your choice in services is determined by signing a Home and Community-Based or ICF/ID Application and Service Delivery Preference form (DP 457) which indicates your choice of Home and Community-Based Services or ICF/ID 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.

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.

ELIGIBILITY DETAILS

“ICF/ID Level of Care” means that you need the same level of care as someone who would otherwise receive services in an institution. To qualify for an ID waiver you must meet this level of care.

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

- Have a diagnosis of intellectual disability
- Require active treatment
- Be recommended for an ICF/ID level of care based on a medical evaluation

ICF/ID 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: ID Diagnosis

A determination of a diagnosis of intellectual disability 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:

- Performance that is more than two standard deviations below the mean of a standardized general intelligence test;
- OR
- 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 Intellectual Disability Professional (QIDP) 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:

- Significant limitations in meeting the standards of maturation, learning, individual independence, and/or social responsibility for his or her age and cultural group
- OR
- 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

You meet the criteria for needing active treatment only when a Qualified Intellectual Disability Professional (QIDP) reviews your social, psychological, and medical history and determines you will benefit from activities, experiences or therapies that may assist you in functioning at your greatest physical, intellectual, social, or vocational potential. The QIDP can also certify the need for active treatment if it will prevent a loss of skills. Active treatment basically means that the person needs at least one on-going waiver service. To see a detailed explanation about what qualifies as a need for active treatment see the *“Individual Eligibility for Medicaid Waiver Services Bulletin 00-08-04.”*

Level of Care: Medical Evaluation

A current medical evaluation either approved by the Department of Public Welfare (Form MA-51) or completed by a licensed physician, physician's assistant, or nurse practitioner must be completed. The evaluation must be current (within the last 365 days), detail any current medical conditions, and indicate you are being recommended for ICF/ID level of care.

QUALIFIED INTELLECTUAL DISABILITY PROFESSIONAL (QIDP) DETERMINATION

The QIDP will review the your social, psychological, and medical history. This review shall consist of:

1. Notes, observations and reports from educational facilities, human service agencies, hospitals and other reliable sources. The review shall be done in conjunction with your support team.
2. A current medical evaluation which indicates you are being recommended for ICF/ID level of care.

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

Level of Care: Annual Re-Certification

All individuals enrolled in a Waiver require annual re-determination of need for an ICF/ID level of care to continue to qualify for services funded under the Waivers.

Certification of the individual's intellectual disability and need for active treatment, as well as subsequent re-certification information can be found in two ODP Bulletins "*Need for ICF/ID Level of Care Bulletin 00-02-13*" and "*Individual Eligibility for Medicaid Waiver Services Bulletin 00-08-04*."

The AE/County Program is responsible to re-certify need for an ICF/ID level of care based on the evaluation and certification of a QIDP. The first re-determination of need for an ICF/ID 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.

WAIVER DETAILS

There are two Medicaid Waivers administered by the Pennsylvania Office of Developmental Programs for Pennsylvanians with intellectual disability. Approximately 95% of all funding for the Pennsylvania Intellectual Disability system is now Waiver funding. Waiver is a Medicaid funding source for many of the supports and services available through the Intellectual Disability 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 Intellectual Disability 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 PERSON/FAMILY DIRECTED SUPPORT (P/FDS) WAIVERS:

- The Administrative Entity (AE)/County Program gives priority 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 find this form in *Appendix A*.
- You can only be enrolled in one Waiver at a time.
- If the services you need exceed the cap 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 and receive funding for programs, supports, and services anywhere in the State.

THE MAIN DIFFERENCE BETWEEN THE CONSOLIDATED WAIVER AND THE PERSON/FAMILY DIRECTED SUPPORT (P/FDS) 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/ID, and there are some limits for certain services.
- The P/FDS Waiver is currently capped at \$30,000 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 P/FDS Waiver that cost more than a total of \$30,000 (with the exception of Supports Coordination services).

- Additionally, the Consolidated Waiver includes Unlicensed and 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 2013, this amount is \$2,130 per month.

IS IT POSSIBLE TO LOSE MY WAIVER AFTER I AM ENROLLED?

Yes, it is possible to lose your Waiver after you are enrolled. You must continue to meet all of the following criteria:

Eligibility for Intellectual Disability Services

- **Intermediate Care Facility for People with Intellectual Disability (ICF/ID) Eligibility** – This means that you need the same level of care as someone who would otherwise receive services in an institution. You must also continue to need “Active Treatment.” This means that you need at least one on-going service that is covered under the Waiver.
- **Financial Eligibility** – There are income and asset limitations to qualify for a Waiver. If you are working, be sure to remember those limits. Contact your Benefits Planning Program [formerly Work Incentive Planning Assistance Program (WIPA)] if you anticipate increases in wages. This contact information can be found in *Appendix B*.

The County Assistance Office (CAO) does an annual financial eligibility re-determination that covers both your Medical Assistance and Waiver. They will look at your income and any assets you have and make sure that you still qualify. Annually, the AE/County will ask you to have a medical evaluation by your physician regarding your disability to ensure that you still meet the Intellectual Disabilities and ICF/ID eligibility standards. The MA-51 Medical Evaluation form (see *Appendix A*) can be filled out by your physician to document that you continue to meet the ICF/ID eligibility standard.

Waiver Capacity Commitment

Each year the Office of Developmental Programs tells each Administrative Entity/County how many Person/Family Directed and Consolidated waivers they have. This is called the AE/County's "Waiver Capacity Commitment." Sometimes this waiver capacity allows for a small number of new people to receive services. In years where there have been large Waiting List initiatives by the Governor, there are larger numbers of new people offered waiver services. Taking into account their waiver capacity, AEs/Counties decide who gets offered waivers based on urgency of need and availability of services to meet those needs. Waiver opportunities may also become available within the county as individuals are dis-enrolled from the waiver through movement out of state, placement in a nursing home, etc.

The waiver capacity commitment for each Waiver cannot be shifted or combined from one Waiver to another Waiver and is not interchangeable. It is the responsibility of the AE to perform administrative functions for the Waivers and manage enrollment. The number provided for each waiver capacity commitment cannot be exceeded or modified without the approval of ODP. It is the responsibility of ODP to manage total waiver capacity statewide.

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 Consolidated Waiver and the Person/Family Directed Supports (P/FDS) Waiver

WAIVER-FUNDED SUPPORTS COORDINATION

The following definition for Supports Coordination applies only to Supports Coordination services funded through the Consolidated and P/FDS Waivers.

Supports Coordination 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, as well as the documentation of the 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 participants' 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;
- Locate resources for 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 the use of 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 to exercise their 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, as well as the documentation of the 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 ISP planning with providers of service to ensure consistency of services;
- Coordinate with other entities, resources and programs as necessary to ensure all areas of the participant's needs are addressed;
- Contact with family, friends, and other community members to facilitate coordination of the participant's natural support network;
- Facilitate the resolution of barriers to service delivery; 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 or her family, to ensure services are implemented as per the ISP. Activities included under the monitoring function include all of the following, as well as the documentation of the activities:

- Monitor the health and welfare of participants through regular contacts at the minimum frequency outlined the Waiver;
- Monitor ISP implementation through monitoring visits with the participant, at the minimum frequency outlined in Appendix D-2-a of the Waiver;
- Visit with the participant's family, when applicable, and providers of service for monitoring of health and welfare and ISP implementation;

- Respond to and assess emergency situations and incidents and assure that appropriate actions are taken to protect the health and welfare of participants;
- Review participant progress on outcomes and initiate ISP team discussions or meetings when services are not achieving desired outcomes;
- 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 identified in the ISP;
- Work with the authorizing entity regarding the authorization of services on an ongoing basis and when issues are identified regarding requested 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 individual, preparing survey information, and follow up activities ("closing the loop") and other activities as identified by ODP.

Supports Coordination also includes providing information and assistance to help with transition to the community or participant-direction. Activities include all of the following, in addition to the documentation of activities:

- Provide information on participant-direction, including the potential benefits and risks and standard ODP information 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.

RESIDENTIAL HOME AND COMMUNITY HABILITATION – LICENSED HOMES

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

These are direct (face-to-face) and indirect services provided to participants who live in licensed provider owned, rented/leased, or operated (i.e. licensed Family Living homes) residential settings. Residential Habilitation Services are provided to protect the health and welfare of participants who reside at the residential setting by assisting them in acquiring, retaining, and improving self-help, 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, personal adjustment, relationship development, socialization, and use of community resources. Residential Habilitation may be provided up to 24 hours a day based on the needs of the participant receiving services. This service also includes transportation services that are necessary to enable the participant to access services and resources outlined in the ISP, including transportation to and from day or employment services. The Residential Habilitation provider is not responsible for transportation services for which another provider is responsible.

LIMITATIONS ON SERVICE

- Licensed residential habilitation is only available for individuals who are receiving Consolidated Waiver.
- Prior to Residential Habilitation Services being authorized, the SC and ISP team and AE must utilize the ODP Residential Habilitation Service criteria (This criterion is in the Chapter 51 Regulations).
- If you receive Residential Habilitation Services you cannot use the following Waiver services: Companion, Transportation², Homemaker/Chore, Supports Broker, Specialized Supplies and Home and Vehicle Accessibility Adaptations. The only exception is that Home and Vehicle Accessibility Adaptations may be authorized for individuals residing in licensed and unlicensed family living homes when the home or vehicle being adapted and utilized by the individual is not owned, rented or leased by the family living provider agency.
- The licensed residential provider is not responsible for transportation to community activities for which another provider is responsible.
- Licensed Residential Habilitation may not include other home and community services, for example, physical therapy or nursing. These other services must be included separately on the individual's ISP.

UNLICENSED RESIDENTIAL HABILITATION

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

These are direct (face-to-face) and indirect services provided to participants who live in provider owned, rented/leased, or operated (i.e. Family Living homes) residential settings. Unlicensed Residential Habilitation Services are provided to protect the health and welfare of participants who reside at the residential setting by assisting them in acquiring, retaining, and improving self-help, socialization, and adaptive skills necessary to reside successfully in home

² If you use Residential Habilitation, your transportation is included in the Residential Habilitation so you can not use Transportation as a separate service in the Waiver

and community-based settings. Services consist of support in the general areas of self-care, communication, fine and gross motor skills, mobility, personal adjustment, relationship development, socialization, and use of community resources.

Unlicensed Residential Habilitation may be provided to participants who live in provider-owned, rented, leased or operated family living homes, if:

- Three or fewer individuals with an intellectual disability 18 years of age or older live in the home. The individuals need a yearly average of 30 hours or less of direct staff contact per week per home; or
- In Family Living Homes, one or two individuals with an intellectual disability 18 years of age or older live in the home. The individuals need a yearly average of 30 hours or less of direct training and assistance per week per home from the Family Living Provider agency.

HOME AND COMMUNITY HABILITATION (UNLICENSED)

This is a direct service (face-to-face) provided in home and community settings to assist participants 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, personal adjustment, relationship development, socialization, and use of community resources. When services are provided by agency-based providers, this service also includes transportation services necessary to enable the participant to participate in the Home and Community Habilitation Service, in accordance with the participant's ISP. Through the provision of this service participants will acquire, maintain, or improve skills necessary for participants to live in the community, to live more independently, or to be more productive and participatory in community life.

Participants receiving Residential Habilitation Services may elect to receive Home and Community Habilitation Services as an alternative to a licensed Day Habilitation or Prevocational Services. Under these circumstances the Home and Community Habilitation Service must occur anytime during the hours of 8:00 am – 5:00 pm, Monday through Friday.

Home and Community Habilitation Services may provide the following supports to meet participants' habilitative outcomes as documented in the ISP:

1. Support that enables the participant to access and use community resources such as instruction in using transportation, translation and communication assistance related to a habilitative outcome, and services to assist the participant in shopping and other necessary activities of community life.

2. Support that assists the participant 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.
3. Support that enables a participant to participate in community projects, associations, groups, and functions, such as support that assists a participant to participate in a volunteer association or a community work project.
4. Support that enables a participant to visit with friends and family in the community.
5. Support that enables a participant to participate in public and private boards, advisory groups, and commissions.
6. Support that enables the participant to exercise rights as a citizen, such as assistance in exercising civic responsibilities.
7. Support provided during overnight hours when the participant needs the habilitation service to protect their health and welfare. The staff providing the Home and Community Habilitation Service must be awake. If the participant only needs supervision during overnight hours, the appropriate service is Companion Services.

COMPANION SERVICES

Companion services are provided to participants living in private homes for the limited purposes of providing supervision and assistance that is focused solely on the health and safety of the *adult* participant with intellectual disabilities. This service is not available to participants who are residing in Unlicensed or Licensed Residential Habilitation settings.

Companion Services are used in lieu of Home and Community Habilitation Services to protect the health and welfare of the participant when a habilitative outcome is not appropriate or feasible (i.e. when the participant 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 participant with intellectual disabilities. For example, a companion can be used during overnight hours for a participant 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 participants during socialization or non-habilitative activities when necessary to ensure the participant's safety. Companions may supervise and provide 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 (with the exception of Supports Coordination). When services are provided by agency-based providers, this service also includes transportation services necessary to enable the participant to participate in the Companion Service, in accordance with the participant's ISP. This service is

not available to participants when a legally responsible person is required to provide supervision or assistance or when the service is a covered service under the MA State Plan.

RESPITE SERVICES

Respite Services are direct services that are provided to supervise and support participants living in private homes on a short-term basis due to the absence or need for relief of those persons normally providing care.

There are two types of Respite: 24-hour respite and 15-minute respite.

- 24-hour respite is provided for periods of more than 16 hours, and is billed using a daily unit. The limit on 24-hour Respite is 30 days per person per year.
- 15-minute respite is provided for periods of 16 hours or less, and is billed using a 15-minute unit. The limit on 15-minute Respite is 480 units (15 minutes) or 120 hours per person per year.

If you need more Respite than what is allowed with these limits, talk with your Supports Coordinator. There is a standard ODP exception process and these limits may be extended based on need. The Supports Coordinator will complete the Request for Exception to Established Limits form (DP 1023). You can find this form in *Appendix A* of this book.

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

- Participant's private home or place of residence located in Pennsylvania.
- Unlicensed home of a provider or a private home that is located in Pennsylvania or a contiguous state.
- Other community settings such as camp where the setting meets applicable state or local codes and the provider of service meets the provider qualifications established by the Department.
- Licensed Family Living Home or Licensed Community Home located in Pennsylvania
- Licensed Child Residential Service Home or Licensed Community Residential Rehabilitation Services for the Mentally Ill Home located in Pennsylvania.
- During temporary travel, this service may be provided in Pennsylvania or other locations as per the ODP travel policy.

OTHER LIMITATIONS ON SERVICE

- Only people who live in private homes can use Respite. The only exception is for an emergency circumstance approved by ODP for participants who receive Residential Habilitation Services.
- Respite services may not be provided in Nursing Homes, Hospitals, Personal Care Homes or ICFs/ID.

- 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.

During Respite Services you can receive supporting for involvement in activities in the community. During 24-hour Respite Services you can still participate in your Day and Employment services.

Room and board costs may only be included when the Respite Service is provided in a facility that is approved (licensed or accredited) by the state. Room and board costs may be included solely for Respite in a licensed residential setting or Respite in camp settings that are licensed or accredited.

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 participant or the family member(s) or friend(s) with whom the participant resides to maintain their primary private home. Homemaker Services must be provided by a qualified homemaker and may include cleaning and laundry, meal preparation, and other general household care.

This service can only be provided in the following situations:

- 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.

- Neither the participant, 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 the provision.

Chore services consist of services needed to maintain the home in a clean, sanitary, and safe condition. 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 participant's home is not allowed in this service. This service must be delivered in Pennsylvania in the participant's private home.

This service is limited to 40 hours per participant per fiscal year when the participant or family member(s) or friend(s) with whom the participant resides is temporarily unable to perform and financially provide for the homemaker/chore functions. A person is considered temporarily unable when the condition or situation that prevents them from performing and financially providing for the homemaker/chore functions is expected to improve. There is no limit when the participant lives independently or with family member(s) or friend(s) who are permanently unable to perform and financially provide for the homemaker/chore functions.

A person is considered permanently unable when the condition or situation that prevents them from 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 perform and financially provide for the homemaker/chore functions. The ISP team's determination should be documented in the ISP.

This service is not available to participants residing in agency-owned, rented, leased, or operated 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

Licensed Day Habilitation is a direct service (face-to-face) that consists 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 Habilitation provider is not, however, responsible for transportation to and from a participant's home.

PREVOCATIONAL SERVICES

This service is provided to assist participants in developing skills necessary for placement into competitive employment. Prevocational Services focus on the development of competitive worker traits through the use of work as the primary training method. The service may be provided as:

- Occupational training which 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.
- Work related evaluation which involves the use of planned activities, systematic observation, and testing to accomplish a formal assessment of the participant, including identification of service needs, potential for employment, and identification of employment objectives.

Participants receiving Prevocational Services must have an outcome for employment included in their ISP. The service must be reviewed at least every 6 months or more frequently as needed to assess the need for the service and progress on the employment outcome. The

service also includes transportation that is an integral component of the service, for example, transportation to a work activity. The Prevocational provider is not, however, responsible for transportation to and from a participant's home.

SUPPORTED EMPLOYMENT SERVICES

Supported Employment Services are direct and indirect services that are provided in a variety of community employment work sites with co-workers who do not have disabilities for the purposes of finding and supporting participants in competitive jobs of their choice. Supported Employment Services enable participants to receive paid employment at minimum wage or higher from the employer. This service is provided to participants who, because of their disabilities, need additional support to perform in a work setting. Supported Employment Services include activities such as supervision and training needed by the participant in order to obtain and sustain paid work. Payment will be made only for the supervision, and training required by the participants 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. Waiver does not pay for participant's wages earned for working on the job site. 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 a participant; assistance in beginning a business; and outreach with prospective employers on behalf of the participant including consultation on tax advantages and other benefits.

Job support consists of training the participant receiving the service on job assignments, periodic follow-up and/or ongoing support with participants and their employers. The service must be necessary for participants 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 participants 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 participant's co-workers that will enable peer support.

Ongoing use of the service is limited to support for participants 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 6 months by the ISP team, to assess whether the service is assisting the participant with the outcome of finding community employment. If the service is not assisting the participant 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 participant's needs. The provision of job support services must be evaluated at least annually, as part of the ISP process, to determine whether the participant 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 participants in transitioning to integrated, competitive employment through work that occurs in a location other than a Prevocational or Day Habilitation facility. Transitional work service options include mobile work force, work station in industry, affirmative industry, and enclave.

- 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.
- A **Work Station in Industry** involves individual or group training of participants 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 participant(s) demonstrates job expertise and meets established production rates.
- **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** is a business model where disabled participants are employed by a business/industry to perform specific job functions while working alongside non-disabled workers.

The goal for this service is competitive employment. Participants receiving this service must have an employment outcome included in their ISP. 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 a participant's home, unless the provider is designated as the transportation provider in the participant's ISP. In this case, the transportation service must be billed as a discrete service. This service can be delivered in Pennsylvania and in states contiguous to Pennsylvania.

Transitional Work Services may not be provided until your Supports Coordinator has verified that the services are not available to you under the Rehabilitation Act of 1973 or IDEA. When Transitional Work Services are provided alone or in conjunction with Prevocational, Licensed Day Habilitation or Supported Employment services, the total number of hours for these services (whether utilized alone or in conjunction with one another) cannot exceed 40 hours (160 15-minute units) per participant per calendar week based on a 52-week year

Transitional Work Services may not be provided at the same time as any of the following: Companion Services, the direct portion of Supported Employment, Licensed Day Habilitation, Prevocational Services and Home and Community Habilitation Services.

TRANSPORTATION SERVICES

Transportation is a direct service that enables participants to access services and activities specified in their approved ISP. This service does not include transportation that is an integral part of the provision of another Waiver service, nor does it include transportation associated with Residential Habilitation Services, as transportation is included as part of these other Waiver services.

Transportation services consist of:

1. **Transportation (Mile)** This transportation service is delivered by providers, family members, and other licensed drivers. Transportation Mile is used to reimburse the owner of the vehicle or other qualified licensed driver who transports the participant to and from services and resources specified in the participant's ISP. The unit of service is one mile. Mileage will be paid round trip. A round trip is defined as from the point of first pickup to the service destination and the return distance to the point of origin.

When transportation is provided to more than one participant at a time, the provider will divide the shared miles equitably among the participants to whom transportation is provided. The provider is required (or it is the legal employer's responsibility under the VF/EA model) to track mileage, allocate a portion to each participant and provide that information to the Supports Coordinator for inclusion in the participant's ISP.

2. **Public Transportation** Public transportation services are provided to or purchased for participants 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 participants as a cost-effective means of accessing services and activities.
3. **Transportation – Trip** This service is transportation provided to participants for which costs are determined on a per trip basis. A trip is either transportation to a service from a participant's private home or from the service to the participant's home. Taking a participant to a service and returning the participant to his/her home is considered two trips or two

units of service. Trip distances are defined by ODP through the use of zones. Zones are defined as follows: Zone 1 — greater than 0 and up to 20 miles; Zone 2 — greater than 20 and up to 40 miles; and Zone 3 — greater than 40 and up to 60 miles. Providers that transport more than 6 participants are required to have an aide on the vehicle. If a provider transports 6 or fewer participants, the provider has the discretion to determine if an aide is required. The determination must be based upon the needs of the participants, the provider's ability to ensure the health and welfare of participants and be consistent with ODP requirements for safe transportation.

This service can be delivered in Pennsylvania and in states contiguous to Pennsylvania. During temporary travel, this service may be provided in Pennsylvania or other locations as per the ODP travel policy.

EDUCATION SUPPORT SERVICES

Education 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 support to the participant to participate in an apprenticeship program. The Waivers can cover this service only if you are not eligible to receive them through IDEA or Office of Vocational Rehabilitation (OVR).

Education Support Services consist of special education and related services as defined in Sections (16) and (17) of the Individuals with Disabilities Education Act (IDEA) to the extent that they are not available under a program funded by IDEA or available for funding by the Office of Vocational Rehabilitation (OVR). Participants authorized for Education Support Services must have an employment outcome or an outcome related to skill attainment or development which is documented in the ISP and is related to the Education Support Service need.

SPECIALIZED SUPPLIES

Specialized Supplies consist of incontinence supplies that are medically necessary and are not a covered service through the MA State Plan, Medicare or private insurance. Services must be provided under the MA State Plan, Medicare and/or private insurance plans until the plan limitations have been reached.

LIMITATIONS

- Supplies are limited to diapers, incontinence pads, cleansing wipes, underpads, and vinyl or latex gloves.
- Maximum cost \$500 per participant per fiscal year.
- This service is not available to participants who reside in licensed or unlicensed residential habilitation settings.

During temporary travel, this service may be provided in Pennsylvania or other locations as per the ODP travel policy.

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.
- **Occupational therapy** by a registered occupational therapist based on a prescription for a specific therapy program by a physician.
- **Speech/language therapy** provided by an American Speech-Language-Hearing Association (ASHA) certified and state licensed speech-language pathologist. This service requires an evaluation 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 participants in the acquisition, retention, or improvement of skills necessary for the participant to live and work in the community, and must be attached to a participant's outcome as documented in his or her ISP. Training caretakers and development of a home program for caretakers to implement the recommendations of the therapist are included in the provision of Therapy services.

The need for the service must be documented by a professional as noted above for each service and must be evaluated at least annually, or more frequently if needed, as part of the ISP process. This evaluation must review whether the participant continues to require the current level of authorized services and that the service continues to result in positive outcomes for the participant. It is recognized, however, that long-term Therapy Services may be necessary due to a participant's extraordinary medical or behavioral conditions. The need for long-term Therapy Services must be documented in the participant's ISP.

Therapy Services may only be funded through the Waiver if there is documentation that the service is medically necessary and not covered through the MA State Plan which includes EPSDT, Medicare and/or private insurance. Therapy Services must be provided under the MA State Plan including EPSDT, Medicare and/or private insurance plans until the plan limitations have been reached and documentation is secured by the SC.

PHYSICAL THERAPY

The Physical Therapy Practice Act (63 P.S. §1301 et seq.) defines physical therapy as follows:

“...means the evaluation and treatment of any person by the utilization of the effective properties of physical measures such as mechanical stimulation, heat, cold, light, air, water, electricity, sound, massage, mobilization, and the use of therapeutic exercises and rehabilitative procedures including training in functional activities, with or without assistive devices, for the purpose of limiting or preventing disability and alleviating or correcting any physical or mental conditions, and the performance of tests and measurements as an aid in diagnosis or evaluation of function.”

OCCUPATIONAL THERAPY

The Occupational Therapy Practice Act (63 P.S. §1501 et seq.) defines occupational therapy as follows: “The evaluation of learning and performance skills and the analysis, selection and adaptation of activities for an individual whose abilities to cope with the activities of daily living, to perform tasks normally performed at a given stage of development and to perform essential vocational tasks which are threatened or impaired by that person’s developmental deficiencies, aging process, environmental deprivation or physical, psychological, injury or illness, through specific techniques which include: (1) Planning and implementing activity programs to improve sensory and motor functioning at the level of performance for the individual’s stage of development; (2) Teaching skills, behaviors and attitudes crucial to the individual’s independent, productive and satisfying social functioning; (3) The design, fabrication and application of splints, not to include prosthetic or orthotic devices, and the adaptation of equipment necessary to assist patients in adjusting to a potential or actual impairment and instructing in the use of such devices and equipment; and (4) Analyzing, selecting and adapting activities to maintain the individual’s optimal performance of tasks to prevent disability.”

SPEECH AND LANGUAGE THERAPY

Services provided by a licensed and American Speech-Language-Hearing Association (ASHA) certified speech-language pathologist including the evaluation, counseling, habilitation and rehabilitation of participants whose communicative disorders involve the functioning of speech, voice or language, including the prevention, identification, examination, diagnosis and treatment of conditions of the human speech-language system, and including the examination for, and adapting and use of augmentative and alternative communication strategies, including, assistive devices and assistive technology.

BEHAVIOR THERAPY

The treatment, by psychological means, of the problem of an emotional nature in which a licensed psychologist or psychiatrist deliberately establishes a professional relationship with a

participant, in an attempt to alleviate or ameliorate the emotional distress disturbances, reverse or change maladaptive patterns of behavioral challenges, and promote positive personality growth and development. Such therapy must take place at the psychologist or psychiatrist's office and may take the form of either individual therapy with the participant and the psychologist or psychiatrist, or group therapy with the participant and other individuals receiving therapy that is supervised and directed by the psychologist or psychiatrist.

VISUAL/MOBILITY THERAPY

This therapy is for participants who are blind or have visual impairments. The provision of therapy is for the purpose of increasing participants' travel skills and/or access to items used in activities of daily living. This service may include evaluation and assessment of participants and the environments in which they interact, direct service (face-to-face) to participants, and training of support individuals. The provision of this service may result in recommendations for adapting environments or purchasing assistive technology.

This service can be delivered in Pennsylvania and in states contiguous to Pennsylvania. During temporary travel, this service may be provided in Pennsylvania or other locations as per the ODP travel policy.

NURSING SERVICES

49 Pa. Code Chapter 21 (State Board of Nursing) provides the following service definition for the practice of professional nursing: "Diagnosing and treating human responses to actual or potential health problems through such services 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."

This service can be delivered in Pennsylvania and in states contiguous to Pennsylvania. During temporary travel, this service may be provided in Pennsylvania or other locations as per the ODP travel policy.

Nursing Services may only be funded through the Waiver if there is documentation that the service is medically necessary and not covered through the Medical Assistance (MA) State Plan which includes Early Periodic Screening and Diagnostic Testing (EPSDT), Medicare and/or private insurance. Nursing Services must be provided under the MA State Plan including EPSDT, Medicare and/or private insurance plans until the plan limitations have been reached and documentation is secured by the Supports Coordinator.

BEHAVIORAL SUPPORT

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

The service is performed by an individual with a Master's Degree in Human Services (or a closely related field) or an individual under the supervision of a professional who is licensed or has a Master's 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, staff and caretakers;
- 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 participant's home or service location, 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. This service can be delivered in Pennsylvania and in states contiguous to Pennsylvania. During temporary travel, this service may be provided in Pennsylvania or other locations as per the ODP travel policy.

HOME ACCESSIBILITY ADAPTATIONS

Home accessibility adaptations consist of certain modifications to the private home of the participant (including homes owned or leased by parents/relatives with whom the participant resides and family living homes that are privately owned, rented, or leased by the host family) which are necessary due to the participant's disability, to ensure the health, security of, and accessibility for the participant, or which enable the participant to function with greater independence in the home. This service may only be used to adapt the participant's primary residence and may not be used to adapt homes that are owned, rented, leased, or operated by providers except when there is a needed adaptation for participants residing in a Family Living setting and the life sharing host home is owned, rented or leased by the host and not the Family Living Provider Agency.

Home modifications must have utility primarily for the participant 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. Adaptations that add to the total square footage of the home are excluded from this benefit. The only exception to this is adaptations to existing bathrooms that are necessary to complete the adaptation (e.g., necessary to configure a bathroom to accommodate a wheelchair).

Modifications to a household subject to funding under the Waivers are limited to the following:

- 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 someone 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 participant during emergencies, when approved by the ODP Regional Office.

- Swing clear and expandable offset door hinges.
- Flush entries and leveled thresholds.
- Plexiglas windows for participants with behavioral issues as noted in the participant'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 modifications shall meet the applicable standards of manufacture, design, and installation. Modifications shall be specific to the participant's needs and 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 participant are excluded.

All adaptations to the household shall be provided in accordance with applicable building codes. This service must be delivered in Pennsylvania.

OTHER LIMITATIONS ON SERVICE

- Maximum \$20,000 per participant during a 10-year period. The 10-year period begins with the first utilization of authorized Home Accessibility Adaptations. A new \$20,000 limit can be applied when the participant moves to a new home. In situations of joint custody (as determined by an official court order) or other situations where a participant 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.
- Building a new room is excluded.
- Durable medical equipment is excluded.
- Home accessibility adaptations are limited to individuals residing in private homes (including homes owned or leased by parents/relatives with whom the individual resides and family living homes that are privately owned, rented, or leased by the host family).

VEHICLE ACCESSIBILITY ADAPTATIONS

Vehicle accessibility adaptations consist of certain modifications to the vehicle that the participant uses as his or her primary means of transportation to meet his or her needs. The modifications must be necessary due to the participant's disability. The vehicle that is adapted

may be owned by the participant, a family member with whom the participant lives, or a non-relative who provides primary support to the participant and is not a paid provider agency of services. This service may also be used to adapt a privately owned vehicle of a life sharing host when the vehicle is not owned by the Family Living provider agency.

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 waiver cannot be used to purchase vehicles for waiver recipients, 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 accessibility adaptations. In order to fund these types of adaptations, a clear breakdown of purchase price versus adaptation is required.

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

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

Maximum state and federal funding participation is limited to \$10,000 per participant during a 5-year period. The 5-year period begins with the first utilization of authorized Vehicle Accessibility Adaptations.

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 a participant's functioning.

Assistive technology services include direct support to a participant 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 participant;
- Selecting, fitting, customizing, adapting, maintaining, repairing, or replacing assistive technology devices;
- Training for the participant, or where appropriate, the participant'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 for the proper functioning of assistive technology devices, such as replacement batteries and materials necessary to adapt low-tech devices. This includes applications for electronic devices not available through the Waiver that assist participants with a need identified through the evaluation described below.

All items shall meet the applicable standards of manufacture, design, and installation. Items shall be specific to the participant's needs and not be a device or equipment that benefits the public at large, staff, significant others, or family members. Although Waiver funds cannot be used to purchase items such as iPads, iPods or personal computers, applications to such items that assist participants with a need identified through the evaluation described below are eligible for Waiver funding through this service.

Items reimbursed with Waiver funds shall be in addition to any medical supplies provided under the MA State Plan and shall exclude those items not of direct medical or remedial benefit to the participant. If the participant receives Behavioral Therapy or Behavioral Support Services, the assistive technology must be consistent with the participant's behavior support plan. Assistive technology devices must be recommended by an independent evaluation of the participant'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.

Assistive technology may only be funded through the Waiver if there is documentation that the service is medically necessary and not covered through the MA State Plan which includes EPSDT, Medicare and/or private insurance. Assistive Technology must be provided under the MA State Plan including EPSDT, Medicare and/or private insurance plans until the plan limitations have been reached and documentation is secured by the Supports Coordinator. Durable medical equipment, as defined by 55 Pa. Code Chapter 1123 and the MA State Plan, is excluded.

Assistive technology has a lifetime limit of \$10,000 per participant except when the limit is extended by ODP using the standard ODP exception process (form DP 1023)

SUPPORTS BROKER SERVICES

The Supports Broker service is available to people who self-direct their services. The Supports Broker service is designed to assist participants or their designated surrogate with employer-related functions in order to be successful in self-directing some or all needed services.

This service is limited to the following list of activities:

- Explaining and providing support in completing employer-or managing employer related paperwork.
- Participating in Financial Management Services (FMS) orientation and other necessary trainings and interactions with the FMS provider.
- Developing effective recruiting and hiring techniques.
- Determining pay rates for workers.
- Providing or arranging for worker training.
- Developing worker schedules.
- Developing, implementing and modifying a back-up plan for services, staffing for emergencies and/or worker absences.
- Scheduling paid and unpaid supports.
- Developing effective management and supervision techniques such as conflict resolution.
- Developing proper procedures for termination of workers in the VF/EA FMS option or communication with the Agency With Choice regarding the desire for removal of the workers from working with the participant in the AWC FMS option.
- Reviewing of workplace safety issues and strategies for effective management of workplace injury prevention.
- Assisting the participant or their designated surrogate in understanding and/or fulfilling the responsibilities outlined in the Common Law Employer Agreement form and the Managing Employer Agreement form.
- Facilitating a support group that helps to meet the participant's self-direction needs. These support groups are separate and apart from the ISP team meetings arranged and facilitated by the Supports Coordinator.
- Expanding and coordinating informal, unpaid resources and networks within the community to support success with participant-direction.
- Identifying areas of support that will promote success with self-direction and independence and share the information with the team and Supports Coordinator for inclusion in the ISPs.
- Identifying and communicating any proposed modifications to the participant's ISP.
- Advising and assisting with the development of procedures to monitor expenditures and utilization of services.
- Complying with the standards, regulations, policies and the waiver requirements related to self-direction.
- Advising in problem-solving, decision-making, and achieving desired personal and assessed outcomes related to the participant-directed services.

- When applicable, securing a new surrogate and responding to notices for corrective action from the FMS, SC, AE or ODP.

All functions performed by a Supports Broker must be related to the personal and assessed outcomes related to the participant-directed services in the ISP. Supports Brokers must work collaboratively with the participant's Supports Coordinator and team. Supports Brokers may not replace the role of, or perform the functions of a Supports Coordinator. The role of the Supports Coordinator continues to involve providing the primary functions of locating, coordinating, and monitoring of waiver services; while the Supports Broker assists participants or their designated surrogate with assistance with the above noted functions.

This service is limited to a maximum of 1040 (15-minute) units (260 hours or about 5 hours per week) per person per fiscal year. This service is limited to participants who are self-directing their services through an AWC or VF/EA.

Waiver Service Requests

If you request a new service or a change in services and are told that it cannot be included in your ISP because your ISP team does not agree that you need the change in services or the new service, your Supports Coordinator (SC) can assist you in filling out the Waiver Service Request form (DP 1022). The form can be found in *Appendix A* of this book.

The Waiver Service Request form is a formal request in which you will state what service you need, how much of it you need, and why you need it. Your SC should submit this form to the AE/County program within 10 days and the AE/County program should give you a formal approval or denial of your request within 20 calendar days of when they receive the form.

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 intellectual disability:

- 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 intellectual disability
- Adult grandchild of a grandparent with intellectual disability

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 the approved Waivers.

Waiver services that relatives or legal guardians can provide are limited to the following: Home and Community Habilitation (Unlicensed), Supported Employment 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 or legal guardians, who function as the employer or managing employer through an FMS, may not provide Supports Broker services to the individual who they are employer or managing employer for. 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 caregiver.

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 the approved Waivers.

Services that legally responsible individuals can provide are limited to the following: Home and Community Habilitation (Unlicensed), Supported Employment, Transportation (Mile) and Supports Broker Services. Legally responsible individuals, who function as the employer or managing employer through an FMS, may not provide Supports Broker services to the individual who they are employer or managing employer for.

Travel Policy

The following services may occur during temporary travel (as defined below):

- Home and Community Habilitation (Unlicensed)
- Residential Habilitation (licensed and unlicensed)

- Nursing
- Therapy
- Supports Coordination
- Supports Broker
- Behavioral Support
- Companion
- Transportation mile and public

These services may be provided anywhere during temporary travel. During the temporary travel period, qualified agency and individual providers that render these services must be located in Pennsylvania or in states that are contiguous to Pennsylvania. Provider agency staff or contracted personnel must be residents of Pennsylvania or residents of states contiguous to Pennsylvania. For services that are participant-directed, the qualified SSW or qualified individual that renders the service while traveling must be a resident of Pennsylvania or residents of states that are contiguous to Pennsylvania. The physical location of the public transportation company that sells public transportation services is not required to be located in Pennsylvania or in a state contiguous to Pennsylvania, however, the provider of the public transportation service that holds the signed MA agreement with ODP must be physically located in PA or states contiguous to PA.

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 provision of home and community-based services during travel is limited to no more than 30 calendar days per fiscal year.
- 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.
- The waiver will not fund the travel costs of either the individual or the agency or individual provider travel costs.
- The individual is responsible to fund their own travel costs through private or non-system funds.
- Travel costs for agency and individual provider staff or contracted personnel, may be funded through private funds of family members of the individual receiving services or non-intellectual disability system funds generated through fundraising efforts or other means.

- For services that are participant-directed, the qualified SSW or individual's travel costs, may be paid for by the individual out of their own personal funds. If the individual decides to pay for the travel costs, there must be documented team consensus that this was the voluntary and willful decision of the individual.
- An individual cannot exceed the authorized units for a service while on temporary travel.
- All service and program requirements, such as provider qualification criteria and documentation of services, apply during the period of travel.

The location for temporary travel is not limited to PA. Temporary travel can occur anywhere as long as the individual's health and welfare can be met during the temporary travel.

AEs shall ensure that this travel policy is explained to all individuals in the waiver 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.

Waiver Monitoring

Supports Coordination for Waiver monitored services is paid for in the Pennsylvania Intellectual Disability 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. Deviations to this monitoring schedule must be prior approved by ODP.
- 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
- 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.
- Deviations in monitoring frequency and location must be prior approved by ODP. Discuss with your Supports Coordinator.

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 Intellectual Disability 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/ID 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
<https://www.hcsis.state.pa.us/hcsis-ssd/pgm/asp/prhom.asp>
- Ask your Supports Coordinator.
- Ask other families and friends.

If you receive money from the County MH/ID 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*. 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.

- 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:
 - 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. 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.).

Financial Management Services (FMS)

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 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.

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

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 or www.odpconsulting.net.

There are two models of FMS in place in the Pennsylvania's Intellectual Disability 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. You are the “Employer of Record.” 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.
 - As of January 1, 2013 Public Partnerships, LLC (PPL) is contracted with the Commonwealth as the statewide VF/EA. More information on PPL can be found on their website:
<https://www.publicpartnerships.com//programs/Pennsylvania/PADPWODP/index.asp>
 - You can also contact them at 1-877-634-6805
2. **Agency with Choice (AWC) FMS.** In this model the AWC FMS is the legal employer/“Employer of Record.” 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

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 options available for receiving support where you live 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 living in your family or own home and owning your own home.

When you are making your final decision about where to live it is important to keep in mind that each option might meet your social, physical and emotional needs in a different way. Your role in this process is to find the "best" home for your life right now and to keep in mind that as your needs change, your home might have to change as well.

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

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. Your Supports Coordinator can assist you in visiting homes.

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

Lifesharing, 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.

Lifesharing (Licensed and Unlicensed) can be funded as Residential Habilitation through the Consolidated Waiver. Base funding, if available, can also be used to fund Lifesharing for non-waiver participants.

Beginning in January 2006, ODP instructed AE/Counties 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/ID or other residential service options. At this time, there are about 1500 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.

There is a Lifesharing Coalition which can be helpful to families who want to understand how Lifesharing works. Contact persons for the Coalition are:

Central Region	Sarah Shaw, Skills of Central PA 814-272-0341 x 217	James Malesky 717-635-2711
Northeast Region	Christine Diehl 610-435-1561 x 2240	Joe Karpinskie 717-274-5170
Southeast Region	Jim Boyle, Catholic Social Services 484-908-6583	Stephanie Brown, KenCrest 610-487-1582 x 2520
Western Region	Carrie Kontis 814-878-4043	

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:

Central Region	717-772-6507
Northeast Region	570-963-4749
Southeast Region	215-560-2242
Western Region	412-565-5144

Bulletin Reference for Lifesharing Issues

Subject	Bulletin #	Effective Date
Lifesharing Through Family Living	00-05-04	8/8/2005

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.

Employment

Beginning in January 2006, the Office of Developmental Programs (ODP) instructed AE/Counties to institute standard practices to promote employment through the Individual Support Plan 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.

AE/Counties 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

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:

Central Region	717-772-6507
Northeast Region	570-963-4749
Southeast Region	215-560-2242
Western Region	412-565-5144

EMPLOYMENT AND MY BENEFITS

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.

Until June 2012 the Federal government had funded various agencies in Pennsylvania to provide Work Incentives Planning and Assistance (WIPA) to SSI and SSDI recipients who want to work. Two of the agencies (listed below) that provided benefits counseling through the WIPAs continue to provide benefits counseling and planning but are now called "Benefits

Planning Programs.” Benefits counselors stationed across the state are available to provide consultations to individuals and families in determining how work will affect their Social Security, Medical Assistance and other benefits. Contact numbers are as follows:

Statewide	AHEDD 866-902-4333 x 191
Central Region	Goodwill 610-777-7875 x 2038

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. ODP has as another Waiting List initiative aimed at High School graduates for the 2012-13 fiscal year.

Bulletin References for Employment Issues

SUBJECT	BULLETIN #	EFFECTIVE DATE
ODP Policy on Employment	00-05-07	12/20/2005
Employment for Individuals in ICFs/ID	00-06-08	4/5/2006
Medical Assistance for Workers with Disabilities in the Community Intellectual Disability Program	00-03-23	11/25/2003

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 Intellectual Disability 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 including 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:

1. An organization can hire staff you refer to them. The organization is called an Agency with Choice FMS and is the “Employer of Record”.
2. 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.

Rates and Provider Payments

ODP has moved from “program funding” of services to paying for services that are delivered. Providers bill the state for the services they perform for individuals and are paid based on the rates developed for all services by the Office of Developmental Programs.

TYPES OF RATES FOR ODP SERVICES AND SUPPORTS

Cost-Based

Cost-base rates are used for residential services like group homes and transportation trip services. ODP has worked for years with providers to establish these rates. It is a complicated methodology that looks at historical costs, market studies and other factors. Providers submit cost information and ODP experts review and establish the cost-based rate for each service and provider. You can ask your Supports Coordinator to share rates for residential and

transportation trip services with you. You can also view residential service rates in the Services and Supports Directory: <https://www.hcsis.state.pa.us/hcsis-ssd/pgm/asp/prhom.asp>

MA Fee Schedule

Most services in ODP are paid on an MA Fee Schedule. Over the last few years ODP has been shifting payment types to what is called “Medical Assistance (MA) Fee Schedule Rates.” This means a set rate for a service for any provider of that service. These rates do vary by geographic location to account for cost-of-living differences. For example, we know that cost-of-living is higher in Philadelphia County than in Potter County. Rates reflect this.

Medical Assistance Fee Schedule rates are developed using a market-based approach. ODP reviewed the service definitions allowable costs that were reasonable, necessary and related to the delivery of the service. The things ODP looked at in calculating these rates were things like wages for staff, employee-related expenses, administration-related expenses. The rates that were developed by the Department should fund services at a level sufficient to make sure that providers are available for each service in each area of the state.

You can ask your Supports Coordinator for the current MA Fee Rates for Services or find them on the ODP website:

<http://www.dpw.state.pa.us/provider/doingbusinesswithdpw/developmentalprograms/feeschedulerrates/index.htm>

Participant-Directed Services (PDS) Wage Ranges

For people who direct their own services, using Financial Management Services, employees have wages within a range determined by ODP. Ranges are set by 3 cost-of-living areas of the state. Rates reflect wages paid and costs for taxes, worker’s compensation and benefits.

Your Supports Coordinator and Financial Management Service provider can share the wage ranges with you. You can also find the ranges on-line on The Partnership website:

<http://www.temple.edu/thetrainingpartnership/resources/pds/>

Vendor

ODP reimburses vendors based on the cost charged to the general public for the good or service. Services reimbursed under the vendor approach are: Home and Vehicle Accessibility Adaptations, Assistive Technology, Specialized Supplies, Education Support, Public Transportation and Respite Camp.

Regardless of the rate setting methodology, 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, 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.

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.

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 INTELLECTUAL DISABILITY 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 openly 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/Intellectual Disability (MH/ID) office.

If you are not sure your SC or Administrative Entity (AE)/County Program are following the rules, you can call the Intellectual Disabilities Customer Service Line operated by the Office of Developmental Programs (ODP) customer service line at (888-565-9435) (voice) or 866-388-1114 (TTY) 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 ID 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. If you need an advocate refer to the *Agencies* section of *Appendix B*. A number of advocacy organizations are listed.
- 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/ID Program says I am not eligible for Intellectual Disability Base-funded services or denies, reduces, suspends or terminates my Base-funded services?

If you apply for Base-funded Intellectual Disability services in your County and are told you are not eligible, you have the right to disagree with that decision and to have it reviewed under Pennsylvania’s “Local Agency Law.” Similarly, if your County determined that you are eligible for Base-funded services, but denied your request for services or reduced, suspended, or terminated the Base-funded services you had been receiving, you can have the decision reviewed under the Local Agency Law.

Under the Local Agency Law, each County Program must have a clearly defined, written policy and procedure for this appeals process. You can ask your County Program for a copy of the policy and procedure.

The process under the Local Agency Law should include the following steps:

- The County Program must provide you a timely, written notice of the decision that explains why it determined that you are not eligible for Base-funded services. The written notice should explain the appeal process. If you have been told in person or over the phone that you are not eligible for Base-funded services, you should request that information in writing.
- If you had been receiving services that are reduced, suspended, or terminated, you can have a meeting with the County Program, your Supports Coordinator, and providers, as appropriate, to discuss and attempt to resolve the issue.
- The 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.
- The reviewer will issue a written decision within 30 days of the date of the hearing that explains the reasons for the decision.
- If you are not satisfied with the reviewer’s decision, you can file an appeal in your County’s Court of Common Pleas.

- Unlike Waiver recipients, the County Program and/or provider can deny, suspend, reduce, or terminate Base-funded services due to lack of money. If you have been receiving Base-funded services and the County suspends, reduces, or terminates them, you are not entitled to have those services remain in place while you appeal the decision through the Local Agency Law. However, you should request that the services continue until resolution of any appeal.

Appeals for Persons with ID 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 intellectual disability 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 administrative appeal to DPW 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 an impartial 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 intellectual disability, you do not need an ICF/ID 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 simply challenges a delay in access to services because you are 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 Waiver 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. Also, an appeal is unlikely to succeed if you seek services that are not available under a Waiver or an amount of services that is not available under the Waiver. 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 should receive a written notice for any of the decisions listed above. The notice will explain the reasons for the decision and your appeal rights. If you are told in person or by phone about a decision, you should insist on a written notice.

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

You will not be permitted to appeal changes that are authorized by changes in state or federal law or changes to the Waiver that are approved by the federal government. For instance, if the federal government allows DPW to stop providing a particular Waiver service or to limit the amount of the service, you cannot appeal that decision.

WHEN MUST YOU FILE YOUR APPEAL?

Timelines are extremely important in the appeals process. If you do not comply with the deadlines for filing appeals, your appeal may be dismissed or you will lose “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 within 10 calendar days of the mailing date of the written notice. Keep the envelope with the notice you received that shows the postmark.
- **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. Keep the envelope with the notice you received that shows the postmark.
- **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 the decision involves services that were reduced or terminated, your services will be reinstated retroactively to the date they were reduced or terminated pending a ruling on the 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 AE/County. You can also request the form from your Supports Coordinator or AE/County Program. You must complete the information on the form, including the following:

- **State 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 an intellectual disability; 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 Homemaker/Chore services, etc.
- State 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, Plymouth, and Reading.**
- **State 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 an intellectual disability) 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 written notice with the decision that you are appealing. See *Attachment 2* for a sample cover letter.

You must send your completed DP458 and any cover letter to your AE/County Program, which will forward your appeal to the appropriate DPW offices generally within 3 working days.

WILL THERE ALWAYS BE A HEARING?

There are two processes that may avoid the need for a hearing: (1) service reviews, and (2) pre-hearing conferences.

After an appeal is filed, the Regional Office of DPW's Office of Developmental Programs (ODP) will conduct a "**service review**" if the appeal involves the denial, reduction, suspension, or termination of Waiver services by the AE/County Program. 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.

Service reviews allow ODP an opportunity to correct errors before the matter proceeds to a hearing. If the Regional ODP Office requires that a service be provided to the individual, the AE/County Program 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.

You also can request a “**pre-hearing conference**” with the AE/County Program. The pre-hearing conference is optional and you do not have to request one. The pre-hearing conference is to discuss the appeal issue, give additional information if appropriate, and attempt to resolve the dispute. You are not required to change your position at a pre-hearing conference. Even if you choose to request a pre-hearing conference, you should still file the appeal form (DP 458) no later than 30 days of the mailing date and within 10 days of the mailing date if you want to maintain your current services pending appeal.

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.

If you are appealing a decision that you are not eligible for Waiver services, you will need to present evidence that addresses your eligibility. Depending on the reason for the decision, this may require you to establish that you have an intellectual disability, that you need habilitation services, or that you meet the financial criteria for the Waiver.

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

- You are in the Waiver.
- 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 current Waiver and Service Definitions from the ISP

Manual, 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. An affidavit is a sworn statement in writing made especially under oath.

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 Program; 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 Program. 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 Program will present its evidence and witnesses first.
 - *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.
 - *Questions* – You have the right to ask questions of the witnesses presented by the AE/County Program 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 Program 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/Chore 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 Program can seek further extensions from the ODP Regional Office.

The AE/County Program also may request reconsideration from the Secretary of Public Welfare. A request for reconsideration will stop implementation of the decision.

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 AE/County 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

December 1, 2012

ID Coordinator/Director

Address of AE/County Program

Re: John Doe's Request for Services Under the Person/Family Directed Support Waiver

Dear ID Coordinator/Director:

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

- Overnight respite care for 7 days to allow his parents to travel.
- A 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 December 21, 2012, 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)

Attachment 2

SAMPLE COVER LETTER WITH REQUEST FOR A HEARING

December 1, 2012

ID Coordinator/Director

Address of AE/County Program

Re: John Doe's Appeal and Request for Fair Hearing

Dear ID Coordinator/Director:

I am writing to appeal the denial dated November 26, 2012. In that written notice, you say that Mr. Doe's Behavior Therapy services will be reduced to one hour per week from the three hours per week that currently are authorized. I am writing to appeal that decision, to request a fair hearing, and to request that the three hours per week of Behavior Therapy 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)**

Attachment 3

SAMPLE RECORDS REQUEST

December 1, 2012

BY REGISTERED MAIL

ID Coordinator/Director

Address of AE/County Program

Re: Request for Records and Other Information from the AE/County ID Program

Dear ID Coordinator/Director:

Pursuant to 55 Pa. Code § 275.3(a)(3), please immediately provide me with copies of the following items 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/ID 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 ID 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 ID 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 Program will present at the hearing on this matter.
11. Any and all documents or other evidence which the **[name of county]** AE/County Program 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 ID services, denials of ID 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,

Attachment 4

SAMPLE REQUEST FOR INTERIM ASSISTANCE

December 1, 2012

ID Coordinator/Director

Address of AE/County Program

Re: John Doe's Request for Interim Assistance

Dear ID Coordinator/Director:

As you know, John Doe appealed his denial of Behavior Therapy services under the Consolidated 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 hours per week of Behavior Therapy services.

Thank you for your attention to this request.

Sincerely,

cc: **ODP Regional Office**
 Supports Coordinator

CHAPTER 5: QUALITY

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

What is Quality?

For a person who uses the service system, quality can be defined as a self-determined life that is fulfilling. Quality may mean that your services and supports meet your needs, and the people helping you and providing you with services and supports are able to support you in a way that allows you to live the life that you want. You are in charge of the services and supports that are purchased on your behalf. You can choose the providers that provide your services. You can recruit, hire, or fire qualified support services workers if you choose to use participant-directed services. 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.

For the service system, there are many things in place to try to ensure quality. The Office of Developmental Programs (ODP) has a comprehensive quality management strategy to promote quality at every level of the service system. Some of the major components of ODP's approach to quality management are:

- ODP's Quality Oversight Groups and Quality Leadership Board
- Administrative Entity (AE) Oversight Monitoring Process
- Independent Monitoring for Quality (IM4Q)
- Health Care Quality Units (HCQUs)
- Provider Qualifications and Provider Quality Management
- Incident Management System

ODP's Quality Oversight Groups and Quality Leadership Board

ODP has developed Quality Oversight Groups in each of its four Regional Offices and a Community Services Quality Oversight Group to review data that have been collected in areas such as provider standards, health and welfare, services planning and delivery, and choice of alternatives (between institutional and community-based settings). These groups review data and make recommendations to ODP's Quality Leadership Board. Health and safety of individuals is given highest priority. The data that these groups use comes from AE, regional and statewide reports and Independent Monitoring for Quality (IM4Q). IM4Q is a statewide method that the State has adopted to independently review quality of life issues for people in the ID system.

Administrative Entity Oversight Monitoring Process

ODP has ultimate responsibility for the operation of the waivers. ODP uses Administrative Entities to administer the waiver programs on a local level. ODP reviews the work of the Administrative Entities using a standardized process. This process is *AE Oversight Monitoring*, (*AEOM*). The purpose of the AEOM is to ensure compliance with Departmental policies, regulations, rules, and waiver requirements related to these delegated functions.

Each Administrative Entity is reviewed by an ODP Central Office team that studies samples of ISPs, PUNS data, monitoring and service notes and a Regional Office AE Oversight Team that conducts visits to AEs to review required documentation of records and training onsite. ODP monitors a new sample of AE records and conducts reviews of each AE onsite every year. If problematic areas are found in the review, a Final Report will identify those areas and the AE is required to complete a Corrective Action Plan to address the findings in the AE Oversight Monitoring Final Report. ODP must then review and approve the plan.

Independent Monitoring for Quality (IM4Q)

In 1997, ODP's Multi-Year Plan presented eight recommendations for change and improvement in the Pennsylvania Intellectual Disability 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.

Currently, over 6,000 IM4Q interviews are conducted annually across the state. Considerations based on these interviews are shared with Administrative Entities (AEs)/Counties, 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 summary results from these interviews are used by the ODP and AEs to continuously improve services and supports 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 AE/County has a designated IM4Q Coordinator who can be contacted for additional information, including AE/County 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 is:

Central Region	717-772-6507
Northeast Region	570-963-4749
Southeast Region	215-560-2242
Western Region	412-565-5144

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.

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 intellectual disability. The organizations provide training and technical assistance to community support providers and medical providers to help both systems serve people with ID and other health conditions. The HCQUs also provide training and technical assistance to counties, ID 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. Results are reviewed at the provider, county, and regional levels to inform quality improvement initiatives.

Provider Qualifications and Provider Quality Management Plans

Providers of services in the Intellectual Disability system must meet specific qualifications for each of the services they provide. These qualifications are outlined in the Waivers. Some of the most basic qualifications for all providers are: 18 years of age or older; background checks; valid driver's license and valid insurance(s). The list of specific qualifications for each service can be found in the Waivers. Your Supports Coordinator can also provide them for you. Providers must requalify every two years by demonstrating that they continue to meet ODP's standards specific to the services they provide.

ODP uses Provider Quality Management Plans as a way of measuring and influencing the quality of services. Providers must develop Quality Management Plans that address areas that ODP has identified as priorities. Some of these areas are:

- Following incident management policies and procedures
- Improving participant satisfaction with services
- Increasing the number of people employed
- Increasing the number of people who use lifesharing
- Reducing the number of restraints used
- Ensuring that each individual is supported in the use of an effective communication strategy.
- Diverting individuals from admission to State Centers and State Hospitals.

ODP evaluates Provider Quality Management Plans through a Provider Monitoring process that is conducted at least every two years. ODP also collects and analyzes data on the areas identified as priorities to determine if progress is being made. This data is used by ODP to celebrate success and to make decisions about future quality improvement initiatives.

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 Intellectual Disabilities 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 ODP Incident Management Bulletin Number 6000-04-01. You can find this bulletin on the Partnership website www.thetrainingpartnership.org.

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 Line Number at 888-565-9435

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. In the event of death of a person living in a residential setting, the family will be notified by the Supports Coordinator or provider.

The providers must report suspected or alleged abuse immediately. When you are only receiving Supports Coordination services, the Supports Coordinator will report incidents of suspected abuse and neglect 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 autism **throughout the life span**
 - Support those living with autism **across the spectrum**
 - Support families
 - Every person living with autism can have an improved quality of life given the right supports delivered by trained staff
 - Increased independence and self-sufficiency
 - Explore innovative models
-

About the Bureau of Autism Services

In 2009, the Bureau of Autism Services released the *Pennsylvania Autism Census Study*.^{*} According to the study, in 2005 there were close to 20,000 Pennsylvanians diagnosed with autism who were receiving services. Because this study only captured children and adults who had a diagnosis and were receiving services at that time, this number is a drastic underestimate of how many families and individuals in the Commonwealth are living with autism. Given trends, that number was estimated to have reached closer to 30,000 Pennsylvanians with autism in 2010.

The report also illustrates a significant increase in the number of **adults** with autism in Pennsylvania. It is estimated that there are currently 3,825 adults with autism in the Commonwealth, and that this number will grow to more than 10,000 adults with autism by 2014. By 2020, Pennsylvania's adult ASD population will reach almost 20,000, which is roughly equal to Pennsylvania's entire ASD population, adults and children, in 2005.

^{*}Pennsylvania Autism Census Report, available by visiting www.autisminpa.org or calling 866-539-7689

The increase in Pennsylvania's numbers is supported by national trends. A [2007 study](#) (PDF download)**from the federal Centers for Disease Control and Prevention, also referred to as the CDC, indicates that one in 150 children have some form of autism. In 2012 the CDC released an estimate suggesting that autism is about 25% more common than previously thought. Furthermore, the U.S. Census Bureau released a report in July 2012 indicating that the number of people with disabilities in general is on the rise. The federal agency found that 56.7 million people had a disability in 2010, an increase of 2.2 million since 2005. (<http://www.census.gov/prod/2012pubs/p70-131.pdf>)

The increase emphasizes the need for collaborative planning in order to respond to the complex needs of the thousands of children with autism who are transitioning into adulthood, and the thousands more who will be transitioning in the future. In July 2003, the Pennsylvania Autism Task Force was convened by the Pennsylvania Department of Public Welfare in response to growing difficulties in meeting the complex needs of individuals with autism in Pennsylvania. This Task Force was comprised of over 250 family members, advocates, medical and health care professionals, clinicians, researchers, educators, agency and legislative staff, administrators and provider professionals. It 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 in early 2007 was transformed into the Bureau of Autism Services, housed within the Office of Developmental Programs, has helped the Department of Public Welfare take great strides towards this goal.

Services and Supports Available through the Bureau of Autism Services: Adult Autism Waiver (AAW) and Adult Community Autism Program (ACAP)

BAS ADULT AUTISM PROGRAMS

Many people with autism are served by the Office of Developmental Program's intellectual disability programs. They are eligible for those programs because they have an intellectual disability as well as a diagnosis of autism. However, only a portion of individuals with autism also have a co-occurring intellectual disability. As a result, many individuals with autism do not meet the IQ eligibility criteria for intellectual disability programs. Therefore, it is important to offer services that don't require IQ as an eligibility factor.

** Morbidity and Mortality Weekly Report, Vol. 56, February 9, 2007

One of the primary goals of the Bureau of Autism Services (BAS) has been to develop autism-specific programs for adults with Autism Spectrum Disorders (ASD) not served by any system, the third recommendation of the Autism Task Force (DPW, 2004). Pennsylvania is leading the nation in the development and administration of autism-specific services for adults. The Commonwealth offers two program options for adults with ASD: the Adult Autism Waiver (AAW) and the Adult Community Autism Program (ACAP).

The Adult Autism Waiver was created because the 2003 Autism Task Force recommended the establishment of a waiver that was similar in structure to existing Pennsylvania waivers, such as ODP's Consolidated and PFDS waivers. In an effort to explore trends in innovative service models, the Bureau also created a second model that is very different in structure from traditional Home and Community Based Services waivers. This model was named the Adult Community Autism Program, typically referred to as ACAP.

Like the Consolidated and Person/Family Directed Supports Waivers in the Office of Developmental Programs, the Adult Autism Waiver and the Adult Community Autism Program are funded through a combination of state monies and federal monies.

HOW ARE THE BAS ADULT PROGRAMS SIMILAR TO EACH OTHER?

Both programs are designed to help adults with autism live in their communities in the way that they want to, based on their identified needs. The goals of the two adult autism programs are to:

- Increase a person's ability to care for him or herself
- Decrease family and caregiver stress
- Enhance the quality of life for both the person and the family
- Provide specialized supports to adults with autism based on their needs
- Help adults with autism meet their desired employment outcomes
- Support adults so that they can have more involvement in community activities; and
- Decrease the incidence of crisis episodes and psychiatric hospitalizations

Meeting these goals can also result in fewer episodes of law enforcement involvement, emergency room care, chemical restraints, and homelessness.

There are some additional shared features of the AAW and ACAP:

- 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 before and after enrolling to provide services

- Clinical and technical assistance available to enrolled providers
- Service planning and measures of success based on individual goals
- Services based upon proven approaches to help individuals realize their goals

There are also some shared **eligibility factors** for the two Bureau of Autism Services programs. For example, individuals served must live in Pennsylvania, and be age 21 or older, at the time of enrollment. They must have a diagnosis of an autism spectrum disorder (ASD). They must also meet Medical Assistance income eligibility, which is determined by the County Assistance Office. Additionally, they must meet federal functional eligibility.

Functional eligibility means that an individual must have substantial functional limitations that are likely to continue indefinitely in three or more of the major life activities listed below:

- Self-care
- Understanding and use of receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living

Please note that there are **additional eligibility factors** unique to each program, which can be found by visiting www.autisminpa.org and are also listed later in this chapter.

HOW ARE THE BAS ADULT PROGRAMS DIFFERENT FROM EACH OTHER?

In addition to the similarities between the two adult programs administered by the Bureau of Autism Services, there are also some differences between them.

The **Adult Autism Waiver** is a traditional Home and Community Based Services (HCBS) waiver designed to provide long-term services and supports for community living, tailored to the specific needs of adults with an ASD. Priority is given to adults not receiving ongoing state or federally funded services. Additionally, the Adult Autism Waiver is available statewide, and provides participants with a choice of an enrolled provider for each service. Residential services are an option if a need is determined through assessment.

The Adult Autism Waiver does not include physical health services. Participants in the waiver continue to get medical insurance from outside the waiver. For example, an individual may receive medical services through private insurance, Medicaid, Access Plus, or HealthChoices. The waiver is an additional set of services, outside of a person's medical insurance, and enrolling in the waiver has no effect on a person's insurance.

ACAP is not a waiver. It is a managed care program that is an integrated model of care reflecting trends being seen in service delivery systems. ACAP is currently available in a

limited number of counties, with services provided by one primary provider, and their network of providers, including primary care physicians and dentists. It provides physician, behavioral, and community services through an integrated approach to create a coordinated system of supports.

The chart below summarizes the distinguishing features of each program as of 2012. It is important to note that this overview reflects the structure of the programs as they were initially designed, and that one of the fundamental values incorporated into their design is the ability for their structures to evolve over time.

ADULT AUTISM WAIVER	ADULT COMMUNITY AUTISM PROGRAM
<ul style="list-style-type: none"> • Available statewide • Priority given to individuals not receiving ongoing state/federally funded services • Physical health services not included as a waiver service; participants retain existing medical insurance • Choice of an enrolled provider for each service • Does allow for residential 24/7 care if a need is determined through assessment 	<ul style="list-style-type: none"> • Available in a limited number of counties: Dauphin, Cumberland, Lancaster, and Chester • Becomes the participant's health plan • Integrated physical/behavioral health and community services • Keystone Autism Services (KAS) provides most services, and oversees a network of providers for other services (e.g. primary care physicians, dentists) • At intake, participant cannot require 16 or more hours of awake support

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 ACAP, 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 programs and is assessed each year.

CAN SOMEONE WITH A DIAGNOSIS OF AN INTELLECTUAL DISABILITY ENROLL IN THE ADULT AUTISM WAIVER OR ACAP?

Yes, as long as they meet all the eligibility criteria for that program.

IF I AM FOUND ELIGIBLE FOR THE ADULT AUTISM WAIVER OR 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.

HOW DO I APPLY FOR THE ADULT AUTISM WAIVER OR ACAP?

All application requests must be made through the Bureau of Autism Services' toll free number: **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 note the following about the Bureau of Autism Services application process:

- **Requests for applications are processed in the order they are received.** Applications will not be sent until the capacity to support additional participants is available. *Capacity* means the number of individuals that can be served at any one time. Once either program is able to begin accepting additional applications, requests for applications for that program will be processed in the order they were received.

If you think you may be eligible, or know someone who might be, you are strongly encouraged to request an application as soon as possible.

- **Individuals can request an application for both programs at the same time.** If you think you meet eligibility for both, you can decide which one is a better fit before enrolling in one of them.
- **Individuals can request an application at any time, regardless of age.** Applications received within 90 days of the applicant turning 21 will meet the age criteria; an individual will not be enrolled until they are 21 or older.
- Individuals on wait lists for other programs can request an application for these programs without losing their placement on the wait list.

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

OTHER FREQUENTLY ASKED QUESTIONS ABOUT EACH PROGRAM

In the next section you can find responses to some frequently asked questions about the Adult Autism Waiver (AAW) and the Adult Community Autism Program (ACAP). If you can't find the information you are looking for here, you can find more information by visiting www.autisminpa.org or emailing DPW-AutismOffice@pa.gov or calling **866-539-7689**.

For ACAP-specific questions, 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](http://KeystoneAutismServices-AdultCommunityAutismProgram) or www.keystoneautism.org

Adult Community Autism Program (ACAP)

Pennsylvania's Adult Community Autism Program (ACAP) is a managed care program that is an integrated model of care reflecting trends being seen in service delivery systems. ACAP is currently available in a limited number of counties, with services provided by one primary provider, and their network of providers, including primary care physicians and dentists. It provides physician, behavioral, and community services through an integrated approach to create a coordinated system of supports.

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 also provide most of the services. Currently, ACAP is available 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
- Have substantial functional limitations that are likely to continue indefinitely in three or more of the following major life activities: self-care; understanding and use of receptive and expressive language; learning; mobility; self-direction; capacity for independent living

- 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
- Not be enrolled in the Health Insurance Premium Payment (HIPP) Program 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 his or her 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 PROVIDED THROUGH 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 non-ACAP services that are covered under Medical Assistance fee-for-service include: 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 traditional Home and Community Based Services (HCBS) Medicaid waiver designed to provide long-term services and supports for community living, tailored to the specific needs of adults with an ASD. Priority is given to adults not receiving ongoing state or federally funded services. Additionally, the Adult Autism Waiver is available statewide, and provides participants with a choice of an enrolled provider for each service. Residential services are an option if a need is determined through assessment.

The Adult Autism Waiver does not include physical health services. Participants in the waiver continue to get medical insurance from outside the waiver. For example, an individual may receive medical services through private insurance, Medicaid, Access Plus, or HealthChoices. The waiver is an additional set of services, outside of a person's medical insurance, and enrolling in the waiver has no effect on a person's insurance.

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
 - Retts Disorder

Financial eligibility:

- Must meet Medicaid Medical Assistance resource and income limits for waiver programs in Pennsylvania, which is determined by the County Assistance Office
- 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:
 - Self-care
 - Understanding and use of receptive and expressive language

- Learning
- Mobility
- Self-direction
- Capacity for independent living

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 program 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 by visiting www.autisminpa.org

SERVICES PROVIDED THROUGH THE ADULT AUTISM WAIVER INCLUDE:

SUPPORTS COORDINATION (CASE MANAGEMENT)	HABILITATION	OTHER SERVICES	EXTENDED STATE PLAN SERVICES
Community Transition Services	Community Inclusion	Respite	Occupational Therapy
	Behavioral Specialist Services	Assistive Technology	Speech/Language Therapy
	Residential Habilitation	Job Assessment and Finding	Counseling
	Day Habilitation	Environmental Modifications	
	Supported Employment	Nutritional Counseling	
	Transitional Work Services	Temporary Crisis Services	
		Family Counseling	
		Family Training	

Waiver Services are designed to enable participants to transition from a more restricted environment to a less restrictive environment. Examples include:

- Day Habilitation to more Community Inclusion
- Transitional Work Services to Supported Employment
- Residential Habilitation to more Community Inclusion
- Volunteer employment to more competitive employment

Service Descriptions

The service definitions below are listed alphabetically, and provide a summarized explanation of all the services available through the Adult Autism Waiver (AAW). For a set of complete

definitions, and to access the most current *AAW Supports & Services Directory (SSD)*, 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.

Examples of assistive technology available through this service 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 a 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 MODIFICATIONS

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.

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 paid 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 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: on-site provider reviews, quarterly service reviews by Supports Coordinators, and BAS oversight of provider qualifications (including training). A sample of participants is interviewed annually to determine whether they are receiving the services in their Individual Supports Plan (ISP), if they are happy with those services, and if they are treated well by their providers. BAS also checks to make sure participants are healthy and safe. Family input is an important part of the quality monitoring strategy.

Adult Community Autism Program

Monitoring of the program is an ongoing process throughout the year and includes the following: an on-site Annual Agreement review of the ACAP provider, participant interviews, an annual quality review by an outside agency, quality performance outcome measures, and BAS oversight of provider qualifications (including training). Participants are interviewed to determine whether they are receiving the services in their Individual Service Plan (ISP), if they are happy with those services, and if they are treated well by their providers. BAS also checks to make sure participants are healthy and safe. Family input is an important part of the quality monitoring strategy.

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;
- 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 Intellectual Disability (ICF/ID) 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.

Bureau of Autism Services Training Initiatives

The Bureau of Autism Services recognizes the need for qualified, trained professionals to evaluate, treat, educate and provide services to individuals with autism across the spectrum and the lifespan. In response to this need, BAS has made training a priority across all initiatives.

BAS provides ongoing live and web-based autism-specific training opportunities for a wide variety of audiences. Training topics are developed based on research-based best practices and emerging needs. Adult Autism Waiver and Adult Community Autism Program providers must complete autism training prior to enrolling as providers, and then complete additional training before providing specific services. Both required and supplemental training opportunities continue as the providers work with BAS program participants.

The Bureau of Autism Services also offers a number of live training conferences and workshops. For example, each year BAS hosts the *PA Autism Training Conference (PATC)*, with multiple sessions providing emerging trends and practical strategies to help professionals acquire the necessary skills to support individuals with autism and their families. Sessions are presented by both national and local experts and include a wide breadth of topics including: employment, housing, evidence-based interventions, community inclusion, justice intersections, sexuality, emerging genetic research, anxiety and depression, self-advocacy, and supporting siblings. The conference has been designed to complement the annual National Autism Conference hosted by the Pennsylvania Department of Education. PATC builds upon PaTTAN's support of early childhood and school-aged children by providing additional considerations for the lifespan, with a concentrated focus on proven and emerging best practices for individuals from transition age through adulthood.

In addition to the annual conference, BAS has developed a cache of statewide trainers to conduct the Bureau of Autism Services Functional Behavior Assessment (FBA) training, using a combination of interactive activities, facilitated DVD instruction and data analysis. In an effort to create consistent system-wide standards, the BAS FBA training has been designated as a requirement for professionals providing behavior specialist services within the Adult Autism Waiver, ACAP and the children's service delivery system.

Many BAS trainings are available through virtual forums. The BAS online training system is a free comprehensive resource center designed to enable professionals and families to access trainings, documents, and other resources in one convenient location. For example, many of the required trainings for providers are housed online, and select sessions from live trainings are recorded each year and posted, along with the session materials, as a resource. A series of community DVDs is also available online and through state libraries.

Additional Resources Available through the Bureau of Autism Services: ASERT Regional Collaboratives

AUTISM SERVICES, EDUCATION, RESOURCES & TRAINING COLLABORATIVES (ASERT)

The **ASERT** (Autism Services, Education, Resources, and Training) collaboratives are a key component of the Bureau of Autism Services' strategy for supporting individuals with autism and their families throughout the Commonwealth. Each ASERT collaborative is a partnership of medical centers, centers of autism research and services, universities and other providers of services involved in the treatment and care of adults and children with autism. The ASERTs have been designed to bring together resources locally, regionally, and statewide.

Each ASERT collaborative is charged with addressing the needs of their entire region, including the needs of the most rural regions of the state and the most underserved populations. Families and individuals living with autism often find themselves isolated in general. Geographic or cultural conditions can further compound a sense of isolation. For example, according to the United States Census Bureau, 48 of Pennsylvania's 67 counties are considered to be rural. Many rural families do not have access to information or quality services and supports that would help them in meeting their needs or the needs of their family member living with autism. It is the Bureau of Autism Services' vision that the ASERTs will connect existing resources and pockets of expertise, and address the regional gaps in effective services and supports.

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

The ASERT Mission is 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.

As part of our effort to improve care and quality of life for individuals with Autism Spectrum Disorders (ASD) living in Pennsylvania, the Bureau of Autism Services sponsored an in-depth assessment to answer the question: "How are the current public systems meeting the needs of individuals with autism and their families?"

The survey has been a key task of the ASERT collaboratives and has been led by University of Pennsylvania School of Medicine, Center for Mental Health Policy and Services Research and the Center for Autism Research at The Children's Hospital of Philadelphia.

Eight reports have been published detailing the findings and recommendations from the Pennsylvania Autism Needs Assessment survey. Topics include:

1. Statewide Summary

2. Service Needs
3. Barriers & Limitations to Accessing Services
4. Unwanted Outcomes: Police Contact & Emergency Hospital Care
5. Getting a Diagnosis & Follow-up Care
6. Employment Challenges
7. Family Impact
8. Report Recommendations

The reports, plus additional reports released after the time of this book's publication, can be viewed by visiting the ASERT website: www.paautism.org/asert

Based on the *PA Autism Needs Assessment* findings, the ASERT collaboratives are focusing on three major areas: **Clinical Services, Outreach & Resources, and Education & Training**. Below are examples of some of the ASERT projects within these areas.

CLINICAL SERVICES

Adult Diagnostic and Assessment Clinics

This project involves developing and/or expanding autism diagnosis and assessment clinics specifically targeting the older adolescent/adult population. There will be a focus on more in-depth assessment of mental health co-morbidities (e.g., anxiety, depression, personality) and neuropsychological factors (e.g., executive functioning, memory, learning, attention). An increase in accurate identification of ASD for young adults and adults will lead to better treatment outcomes. *(All regions)*

Autism Life Care Model (ALCM)

Autism Life Care Model (ALCM) emphasizes comprehensive, evidence-based care approached in a systematic manner throughout an individual's lifetime. The goal is to create a comprehensive system of care to support an individual, his/her family, and the community throughout critical phases of development, beginning with the transition to adulthood. An additional goal is to ensure that individual and family needs are thoroughly considered in a coordinated manner and that necessary services and training are in place to meet these needs. *(Central Region)*

Life Coach for Adults with Autism Spectrum Disorder

Life Coaches are professionals who guide adults with ASD through the complex social, academic and employment environments in their community. Each Life Coach will develop individualized life plans based on exploratory interviews with the individuals culminating in a life map and action plans to accomplish the person's personal and professional goals. Based on the results of exploratory interviews and other diagnostic testing the Life Coach will help the

individual access existing community resources as warranted, i.e., the Office of Vocational Rehabilitation, Adult Basic Education and/or other academic endeavors, Social Security, Office of Disabilities, Housing Authority, etc. (*Western Region*)

Positive Behavior Intervention Support Service (PBIS) Call Line

This project involves the development of an on-call service that business and employers can utilize if they have questions or need assistance in supporting their employee with ASD. Having clinicians and service providers available to assist in situations where an individual may have difficulty communicating with peers and supervisors can dramatically increase an individual's ability to live life as independently as possible. Ten businesses will complete an employer training and be provided with ongoing support. A data base of commonly reported challenges and solutions will be developed and maintained, with that information guiding future modifications to employer trainings. (*Eastern Region*)

Telemedicine Consultation to Rural Areas

The goal of this project is to use mobile technology and telemedicine to develop an Autism Clinical Consultation Team for statewide-consultations. This project will develop and test technology applications for providing remote, synchronous audio and video consultations on unique and challenging ASD cases. The consultations will bring together key individuals in a person's life with their current treating professionals. This remote access is expected to improve communication and participation by all members of the intervention team. This project will increase the capacity of rural areas to provide treatment and intervention to adults with ASD where they live. (*Western Region*)

OUTREACH AND RESOURCES

Pennsylvania Autism Census Update

The Pennsylvania Autism Census Project, released in 2009, documented the growth in and statewide profile of individuals living with ASD. Efforts to identify individuals with ASD throughout Pennsylvania for the Pennsylvania Autism Needs Assessment preliminarily indicate that the prevalence of ASD is higher than the Pennsylvania Autism Census Project initially projected it would be. This project, the Pennsylvania Autism Census Update, will use secondary data to document the existing prevalence of ASD in Pennsylvania and produce a release of results for wide dispersion across the Commonwealth.

Statewide Toll-free Number and Website

Through the toll-free number, Individuals, professionals and families will be able to contact a live person and access resources available by region and statewide. The website will be a premier resource for families, providers, and self-advocates, and will allow them to access a broad array of information to help meet the needs of those living with or serving people with autism, via the Internet. The ASERT Statewide Website will be an integral to ASERT's effort to

broaden outreach to individuals with and/or affected by autism. In addition to hosting an online resource database, the website will also offer multiple applications, including online versions of autism screening tools. *(All regions – led by Central)*

EDUCATION AND TRAINING

Adult and Adolescent Multimedia Social Skills

This project is developing a social skills intervention aimed at young adults (ages 21-30) with ASD. It has direct skills instruction paired with generalization experiences in community settings. Video modeling will be utilized for skills instructions and self-evaluation. It will be developed in a modular format so that appropriate skills building can be paired with the individual's areas of need and their social goals.

For adolescents (ages 13-17) with ASD, the current project will focus on developing training materials for professionals to deliver this intervention, which has been effective in improving social fluency for individuals with high social anxiety. *(Central Region)*

Employment and College Preparation Programs for Adults Living with ASD

Existing employment and college preparation programs across the country will be identified that are models of excellence. These programs will be documented for potential implementation in Pennsylvania. Dissemination strategies will be developed for the programs documented, specifically via training for the employment programs and via consortium building for the college preparatory programs. *(Eastern Region)*

Family Education and Skill Building: Parents, Caregivers, Siblings

Support services and trainings for parents/caregivers and siblings will be developed. The program emphasizes skills building and education in addition to the traditional functions of a support group. Outcome measures will be designed to measure impact of this programming. *(Central Region)*

Hospital Care Training

The goal of this project is to create trainings for hospital service specialty (imaging, phlebotomy, and dental) providers around caring for individuals with autism *(Eastern Region)*

Juvenile Justice Deterrent Program for ASD

Due to the unique social and communication challenges, individuals with ASD might also be at risk of committing socially inappropriate actions that reach the level of illegal, offending behaviors. For example, the social deficits associated with autism may impact psychosexual development to a degree where inappropriate pursuits, interests, or touching may result in an act that is unlawful. Communication deficits may also impact expressed anger to a degree where violent and aggressive behaviors rather than more appropriate verbal exchanges result. While the acts themselves may be unlawful, the intent driving the act may not be similar to

antisocial attitudes commonly found in offender populations. The goal of this project is to design a training and a manual including best practices for individuals with autism who have interaction with the legal system. The training will target all members of the justice system to include attorneys, judges and probation officers, etc. (*Western Region*)

Psychopharmacology Guidelines Group

The goal of this project is to bring together experts in psychopharmacology practices in Pennsylvania to generate a set of guidelines for the care of individuals with autism, focused on adolescents/adults and those in restrictive settings. These guidelines will be developed and disseminated for the use of psychopharmacology in individuals with autism. (*Eastern Region*)

Residency Training

There has proven to be a need for psychiatrists to provide consultation and treatment in cases of both children and adults with ASD. Through this project, a continued and expanded residency experience for MD's in training will be developed. This will include both face-to-face instruction and clinical supervision on an inpatient program. (*Central and Western Regions*)

Statewide Emergency Responders Training

The aim of this project is to provide training videos and courses for Statewide EMS first responders and emergency room technicians, in collaboration with Indiana University of Pennsylvania. These trainings will demonstrate how the characteristics and needs of persons with autism influence interactions during emergency situations. (*Western Region*)

Training Webinars

Webinars will be provided across the state for training in co-morbid disorders in ASD, adult autism diagnoses, early diagnosis and warning signs, and co-occurring medical conditions, in collaboration with University of Pittsburgh School of Rehabilitation Science and Technology. (*Western Region*)

To learn more about ASERT initiatives in your region, or to review the complete series of *PA Autism Needs Assessment* reports, visit www.paautism.org/asert or www.autisminpa.org or call the ASERT Resource Center toll-free in PA: 877-231-4244.

CHAPTER 7: TRANSITION FROM SCHOOL TO ADULT SERVICES

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/ID 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/ID 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

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: 267-765-0301

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

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> 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> 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, 866-830-7327 TTY.

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 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/ or call 717-783-0629.

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

ODP provides individuals with intellectual disability 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/ 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/ 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/ 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. 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.

Benefits Planning Programs

AHEDD (STATEWIDE)		
CENTRAL PA	EASTERN PA	WESTERN PA
John Miller 3300 Trindle Rd. Camp Hill, PA 17011 866-902-4333 X 90192 john.miller@ahedd.org	Michele Boardman 115 West Avenue, Suite 303 Jenkintown, PA 19046 866-902-4333 X 54018 michele.boardman@ahedd.org	Joy Smith PO Box L Irwin, PA 15642 866-902-4333 X 62001 joy.smith@ahedd.org
GOODWILL INDUSTRIES OF CENTRAL PA (SERVES CENTRAL PA ONLY)		
Corey Nelson 1150 Goodwill Drive Harrisburg, PA 17105 866-541-7005 CNelson@yourgoodwill.org		

Transition Resources

Transition Services:

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

When Youth with Special Health Care Needs Transition to Adulthood:

<http://cms-kids.com/> Transition Planning and Resource Guide

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>

Students with Disabilities Preparing for Postsecondary Education:

Know Your Rights and Responsibilities: www.ed.gov/about/offices/list/ocr/transition.html

Wright’s Law: <http://wrightslaw.com/>

National Down Syndrome Society–Students with Down Syndrome: <http://www.ndss.org/>

The Pennsylvania Department of Health Transition Health Care Checklist:

www.health.state.pa.us/transitionchecklist

Community for transition issues: www.sharedwork.org/

Transition and Self Advocacy

Speaking for Ourselves: <http://www.speaking.org/index.html>

Self Advocates United as 1 (SAU1): <http://www.sau1.org/>

Employment Sites

Works for Me: 1-877-268-9894 www.worksforme-pa.org

Vocational Assessments: www.nichcy.org/pubs/outprint/ts6.pdf

www.ric.edu/uap/publications/VocAssess02.pdf

School to Work Act and IDEA: www.vcase.org/Pieces/EquiWork.pdf

Free consulting designed to increase the employability of people with disabilities:

www.jan.wvu.edu/

Office of Vocational Rehabilitation:

www.dli.state.pa.us/landi/cwp/view.asp?a=128&Q=168255

Working Order – Supports entrepreneurs who have a disability:

<http://72.32.194.107/Services/EmploymentTraining/WorkingOrder/tabid/3082/Default.aspx>

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.kidstogether.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;
www.amazon.com/s/ref=nb_ss_gw/103-8537961-7872647?url=search-alias=aps&field-keywords=transitioning+students+with+disabilities

Assistive Technology Resources

AGENCY/WEBSITE	ADDRESS/PHONE/FAX	CONTACT/EMAIL/COUNTIES
Pennsylvania's Initiative on Assistive Technology (PIAT) Institute on Disabilities http://disabilities.temple.edu	Student Center/Suite 411S 1755 N.13th St. Philadelphia, PA 19122 800-204-PIAT(7428) Voice/TTY (in-state only); 215- 204-9371 Fax	Sandi McNally smcnally@temple.edu
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	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	Roseanna Wayne roseanna@crinet.org Clarion, Crawford, Erie, Forest, Mercer, Venango, Warren
Three Rivers Center for Independent Living	900 Rebecca Avenue Pittsburgh, PA 15221	Kevin Huwe khuwe@trcil.org Allegheny, Armstrong, Beaver,

AGENCY/WEBSITE	ADDRESS/PHONE/FAX	CONTACT/EMAIL/COUNTIES
http://www.trcil.org	800-633-4588 toll-free 412-371-7700, X 111 Voice 412-371-6230 TTY 412-371-9430 Fax	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	Dawn Park liftin@liftcil.org 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	Jackie Wardle jwardle@ucpcentralpa.org Adams, Cumberland, Dauphin, Franklin, Fulton, Huntington, 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	Carol Sneath carols@udservices.org 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	Karen Swimley kswimley@cilncp.org Centre, Clinton, Columbia, Lycoming, Montour, Northumberland, Tioga,
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	Linda Mesavage ucptech@yahoo.com 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	Donya Bernier donya@tripil.com Bedford, Blair, Cambria, Fayette, Greene, Somerset, Washington

APPENDIX A: FORMS

Prioritization of Urgency of Need for Services (PUNS), Home and Community Based or ICF/ID Application Service Delivery Preference Form (DP 457), Fair Hearing Request Form (DP 458), MA 51: Medical Evaluation, Waiver Service Request Form (DP 1022), ISP Signature Form (DP 1032) and Request for Exception to Established Limits Form (DP 1023)

(These forms can also be found at

www.temple.edu/thetrainingpartnership/resources/odpForms.shtml)

PUNS Form

INSERT CONSUMER NAME HERE

CONFIDENTIAL

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

Moved to another county

Comes off waiting list—all needs met

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)

Change of supports needed (more or less) – unchanged category

Died

Annual update (no change in supports needed)

Participant Information:

(Signature may be found on original document)

Name	Role	Date	Signature

INSERT CONSUMER NAME HERE

CONFIDENTIAL

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

Emergency Need (Person needs out-of-home supports immediately)		Yes/No
1	Family/caregiver no longer able to provide care placing the individual's health and/or safety at risk	
2	Death of a caregiver with no other supports available	
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)	
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.))	
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	

Emergency Need (Person needs in-home supports, day supports or other supports immediately)		Yes/No
6	Family/care giver needs immediate support to keep their family member at home (short term – for 90 days or fewer)	
7	Family/caregiver needs immediate support to keep their family member at home (long term)	
8	Individual needs immediate support to stay in their own home/family home (short term – for 90 days or fewer)	
9	Individual needs immediate support to stay in their own home/family home (long term)	
10	Individual needs immediate support to maintain his/her employment situation, obtain follow along supported employment or achieve a post-school employment outcome	

Critical Need (Person needs support within two years)		Yes/No
1	Person has a caregiver age 60+ and will need supports within the next two years	
2	Person has an ill caregiver who will be unable to continue providing care within the next two years	
3	Person has behavior(s) that will warrant additional supports within the next two years	
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	
5	There has been a death or other family crisis (e.g. illness, divorce), requiring additional supports within the next two years	
6	Person has a caregiver who would be unable to work if supports are not provided	
7	Person or caregiver will need an alternative living arrangement within the next two years	
8	Person has graduated or left school in the past 5 years	
9	Person is graduating from high school within the next two years and will need in-home, day or other supports	
10	Person is graduating from high school within the next two years and will need an alternative place to live	
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	
12	Person moved from another county where they were receiving residential, day or in-home supports (non-waiver funds only)	
13	Person is receiving day supports that are inappropriate to meet their needs	

INSERT CONSUMER NAME HERE

CONFIDENTIAL

Critical Need (Person needs support within two years)		Yes/No
14	Person moved from another state where they were receiving residential, day or in-home supports	
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)	
16	Person is losing eligibility for DHS/C&Y supports within the next two years	
17	Person is losing eligibility for EPSDT/BHRS supports within the next two years	
18	Person is losing eligibility for OBRA/Nursing home supports within the next two years	
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	
20	Person is losing eligibility for residential treatment facility within the next two years	
21	Person is losing eligibility for residential supports received in an approved private school within the next two years	
22	Person is leaving jail, prison or other criminal justice setting within the next two years	
23	Individual will need support to stay in his/her own home/family home within the next two years	
24	Person has been identified as ready for discharge within the next two years (from a state hospital, nursing home or other residential setting)	

Planning for Need (Person's need for service is more than two years away but less than five years away)		Yes/No
1	Family/caregiver is or will be 60+ years of age and will need supports in the next 2-5 years	
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)	
3	Known need for supports more than two years away. Specify: _____ Enter Date Needed: (MM/DD/YYYY): / /	
4	Person or family/caregiver will need increased supports in the next 2-5 years.	
5	Person is losing eligibility for C&Y/DHS supports within 2-5 years. Enter Date Needed: (MM/DD/YYYY): / /	
6	Person is losing eligibility for EPSDT/BHRS support (including therapeutic foster care) within 2-5 years. Enter Date Needed: (MM/DD/YYYY): / /	
7	Person is losing eligibility for residential treatment facility supports within 2-5 years. Enter Date Needed: (MM/DD/YYYY): / /	
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): / /	
9	Person will be graduating from high school in the next 2-5 years. Enter Date Needed: (MM/DD/YYYY): / /	
10	Person lives in a residential setting that is more restrictive than what is needed.	

INSERT CONSUMER NAME HERE

CONFIDENTIAL

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).

Individual Supports	MR Supports	Non MR Supports
Respite supports (24 hour)		
Respite supports (<24 hour)		
Occupational therapy		
Physical therapy		
Speech therapy		
Other therapies		
Education		
Post secondary/adult education		
Habilitation		
Assistive technology		
Homemaker/chore supports		
Environmental accessibility (e.g. adaptations to home or vehicle)		
Other individual supports		

Transportation	MR Supports	Non MR Supports
Transportation (including trip/mileage reimbursement, para-transit, etc.)		

Vocational Supports	MR Supports	Non MR Supports
Senior supports		
Community employment (Supported, etc.)		
Pre-Vocational Supports		
Adult Day Supports		
Other day supports (e.g. volunteering, community experience)		

Residential Supports	MR Supports	Non MR Supports
Family living/life sharing		
Foster care (children only)		
Individual home owned/leased by the person with <24 hour staff		
Individual home owned/leased by the person with 24 hour staff		
Agency group home or apartment <24 hour staff		
Agency group home or apartment 24 hour staff		
Nursing home		
Other institution with >15 people		
State center		
Private ICF/MR		
Domiciliary care/personal care boarding home (adult foster care)		
Assisted living		
Transitional housing/respite		
Other residential/housing supports		

INSERT CONSUMER NAME HERE

CONFIDENTIAL

Supports Needed

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

Individual Supports (Date of first request in this category) / / / / / / /
M M D D Y Y Y Y

	Support Needed
Respite supports (24 hour)	
Respite supports (<24 hour)	
Occupational therapy	
Physical therapy	
Speech therapy	
Other therapies	
Post secondary/adult education	
Habilitation	
Assistive technology	
Homemaker/chore supports	
Environmental accessibility (e.g. adaptations to home or vehicle)	
Other individual supports	

Transportation (Date of first request in this category) / / / / / / /
M M D D Y Y Y Y

	Support Needed
Transportation (including trip/mileage reimbursement, para-transit, etc.)	
Other transportation Supports	

Vocational Supports (Date of first request in this category) / / / / / / /
M M D D Y Y Y Y

	Support Needed
Senior supports	
Community employment (supported, etc.)	
Pre-Vocational Supports	
Adult Day Supports	
Other day supports (e.g. volunteering, community experience)	

Residential Supports (Date of first request in this category) / / / / / / /
M M D D Y Y Y Y

	Support Needed
Family living/life sharing	
Individual home owned/leased by the person with <24 hour staff	
Individual home owned/leased by the person with 24 hour staff	
Agency group home or apartment <24 hour staff	
Agency group home or apartment 24 hour staff	
Other residential/housing supports	

PUNS Disagreement Form

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 (P/FDS) 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,

Supports 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

<i>Name and Role</i>	<i>Date</i>	<i>Resolved?</i>
SC: _____	_____	Y <input type="checkbox"/> N <input type="checkbox"/>

If not, why not? _____

SC Supervisor: _____	_____	Y <input type="checkbox"/> N <input type="checkbox"/>
----------------------	-------	---

If not, why not? _____

County/AE Rep: _____	_____	Y <input type="checkbox"/> N <input type="checkbox"/>
----------------------	-------	---

If not, why not? _____

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

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.

Esta solicitud es del Departamento de Bienestar Público, Oficina de Programas de Desarrollo. Si necesita ayuda con el idioma, gratis, llame por favor al 1-888-565-9435.

ព្រមទាំង: គេផ្តល់ជូនការប្រយោជន៍ដោយឥតគិតថ្លៃ បើអ្នកត្រូវការការជំនួយភាសា។ បើអ្នកត្រូវការការជំនួយភាសា ឥតគិតថ្លៃ ទូរស័ព្ទលេខ 1-888-565-9435។

这是公共福利部发展计划办公室提供的申请书。你如果需要语言方面的免费协助，请致电 1-888-565-9435。

Настоящее заявление – от Бюро программ развития Отдела социального обеспечения (Department of Public Welfare). Если вам нужна помощь переводчика, звоните по телефону 1-888-565-9435 (бесплатно).

Mẫu đơn này là của Sở Trợ Cấp Phúc Lợi Công Cộng, Văn Phòng Phát Triển các Chương Trình. Nếu quý vị muốn được trợ giúp về ngôn ngữ, miễn phí, xin gọi số 1-888-565-9435.

HOME AND COMMUNITY-BASED OR ICF/MR APPLICATION AND SERVICE DELIVERY PREFERENCE FORM

I. CONFIRMATION OF UNDERSTANDING

I, _____, have been informed of the following:
(NAME OF INDIVIDUAL)

- 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:
(NAME OF INDIVIDUAL)

- 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.
(NAME OF INDIVIDUAL)
- I, _____, understand that by submission of this application, I can expect a formal assessment of my need for services by the County/Administrative Entity.
(NAME OF INDIVIDUAL)

DP 457 01/08

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:

DP 402 01408

Fair Hearing Form

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).

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.

这是公共福利部发展计划办公室提供的申请书。你如果需要语言方面的免费协助，请致电 1-888-565-9435。

Esta solicitud es del Departamento de Bienestar Público, Oficina de Programas de Desarrollo. Si necesita ayuda con el idioma, gratis, llame por favor al 1-888-565-9435.

Настоящее заявление – от Бюро программ развития Отдела социального обеспечения (Department of Public Welfare). Если вам нужна помощь переводчика, звоните по телефону 1-888-565-9435 (бесплатно).

ពាក្យដាក់សុំ: គេឲ្យដឹងស្តីអំពីការសុំសេវា: ដឹងថា កម្មវិធីសេវាផ្តល់ជូនដល់អ្នកដែលមានបញ្ហាចិត្ត ឬមានបញ្ហា រំលោភបំពានច្បាប់ជាដើម តាមរយៈការសុំសេវាផ្តល់ជូន 1-888-565-9435។

Mẫu đơn này là của Sở Trợ Cấp Phúc Lợi Công Cộng, Văn Phòng Phát Triển các Chương Trình. Nếu quý vị muốn được trợ giúp về ngôn ngữ, miễn phí, xin gọi số 1-888-565-9435.

TO: DEPARTMENT OF PUBLIC WELFARE
BUREAU OF HEARINGS AND APPEALS
(THE COUNTY MH/MR PROGRAM OR ADMINISTRATIVE ENTITY WILL FORWARD THIS APPEAL TO THE APPROPRIATE BUREAU OF HEARINGS AND APPEALS OFFICE LISTED ON PAGE 3)

DATE: _____

FROM: NAME OF APPELLANT: _____ DAY TELEPHONE NUMBER: _____
()
MAILING ADDRESS: _____

SIGNATURES: APPELLANT: _____
WITNESS: (If APPELLANT Makes Mark) _____ WITNESS: (If APPELLANT Makes Mark) _____

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 (If Applicable):	
MAILING ADDRESS:	
DAY TELEPHONE NUMBER: ()	RELATIONSHIP TO INDIVIDUAL:
SIGNATURE OF INDIVIDUAL'S SURROGATE (If Applicable):	

PLEASE INDICATE WHICH TYPE OF HEARING YOU ARE REQUESTING: (See Instructions For More Information)

TELEPHONE HEARING
(Appellant and Administrative Entity or County Program will be at Different Telephone Numbers)
Appellant Number () _____

FACE-TO-FACE HEARING
(All parties involved in the hearing are at one location.)

TELEPHONE HEARING
(Appellant and the Administrative Entity or County Program will be at the same telephone number)

FACE-TO-FACE HEARING
(Appellant and local 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:

MA 51: Medical Evaluation

MEDICAL EVALUATION <input type="checkbox"/> NEW <input type="checkbox"/> UPDATED																																			
1. MA RECIPIENT NUMBER	2. NAME OF APPLICANT (Last, first, middle initial)	3. SOCIAL SECURITY NO.	4. BIRTHDATE	5. AGE	6. SEX																														
7. ATTENDING PHYSICIAN			8. PHYSICIAN LICENSE NUMBER																																
9. EVALUATION AT (Description and code)		10. For the purpose of determining my need for TITLE XIX INPATIENT CARE, Home and Community Based Services, and if applicable, my need for a shelter deduction, I authorize the release of any medical information by the physician to the County Assistance Office, State Department of Public Welfare or its agents.																																	
01 Hospital 02 NF 03 Personal Care/Dom Care 04 Own House/Apartment 05 Other (Specify) _____		SIGNATURE - APPLICANT OR PERSON ACTING FOR APPLICANT		DATE																															
11. HEIGHT	WEIGHT	BLOOD PRESSURE	TEMPERATURE	PULSE RATE	CARDIAC RHYTHM																														
12. MEDICAL SUMMARY																																			
13. IN EVENT OF AN EMERGENCY THE PATIENT CAN VACATE THE BUILDING			14. PATIENT IS CAPABLE OF ADMINISTERING HIS/HER OWN MEDICATIONS																																
<input type="checkbox"/> 1. Independently <input type="checkbox"/> 2. With Minimal Assistance <input type="checkbox"/> 3. With Total Assistance			<input type="checkbox"/> 1. Self <input type="checkbox"/> 2. Under Supervision <input type="checkbox"/> 3. No																																
15. ICD-9-CM DIAGNOSTIC CODES																																			
<table border="1" style="width: 100%; height: 40px;"> <tr><td> </td><td> </td><td> </td></tr> </table>																																PRIMARY (Principal) _____ SECONDARY _____ TERTIARY _____			
16. PROFESSIONAL AND TECHNICAL CARE NEEDED - CHECK ✓ EACH CATEGORY THAT IS APPLICABLE																																			
<input type="checkbox"/> Physical Therapy		<input type="checkbox"/> Speech Therapy		<input type="checkbox"/> Occupational Therapy																															
<input type="checkbox"/> Special Skin Care		<input type="checkbox"/> Parenteral Fluids		<input type="checkbox"/> Suctioning																															
		<input type="checkbox"/> Inhalation Therapy		<input type="checkbox"/> Special Dressings																															
		<input type="checkbox"/> Other (Specify) _____		<input type="checkbox"/> Irrigations																															
17. PHYSICIAN ORDERS																																			
Medications _____																																			
Treatment _____																																			
Rehabilitative and Restorative Services _____																																			
Therapies _____																																			
Diet _____																																			
Activities _____																																			
Social Services _____																																			
Special Procedures for Health and Safety or to Meet Objectives _____																																			
18. PROGNOSIS - CHECK ✓ ONLY ONE			19. REHABILITATION POTENTIAL - CHECK ✓ ONLY ONE																																
<input type="checkbox"/> 1. Stable <input type="checkbox"/> 2. Improving <input type="checkbox"/> 3. Deteriorating			<input type="checkbox"/> 1. Good <input type="checkbox"/> 2. Limited <input type="checkbox"/> 3. Poor																																
20A. PHYSICIAN'S RECOMMENDATION																																			
To the best of my knowledge, the patient's medical condition and related needs are essentially as indicated above. I recommend that the services and care to meet these needs can be provided at the level of care indicated - check ✓ only one																																			
<input type="checkbox"/> Nursing Facility Clinically Eligible Services to be provided at home or in a nursing facility		<input type="checkbox"/> Personal Care Home Services provided in a Personal Care Home		<input type="checkbox"/> ICFMR Care Services to be provided at home or in an intermediate care facility for the mentally retarded																															
		<input type="checkbox"/> ICFI/CRC Care Services to be provided at home or in an intermediate care facility for consumers with ORCs		<input type="checkbox"/> Inpatient Psychiatric Care																															
				<input type="checkbox"/> Other (Please Specify) _____																															
20B. COMPLETE ONLY IF CONSUMER IS NURSING FACILITY CLINICALLY ELIGIBLE AND WILL BE SERVED IN A NURSING FACILITY.																																			
ON THE BASIS OF PRESENT MEDICAL FINDINGS THE PATIENT MAY EVENTUALLY RETURN HOME OR BE DISCHARGED. <input type="checkbox"/> YES <input type="checkbox"/> NO If Yes, Check ✓ Only One <input type="checkbox"/> 1. Within 180 days <input type="checkbox"/> 2. Over 180 days																																			
20C. PHYSICIAN'S SIGNATURE																																			
_____ PHYSICIAN (PRINTED NAME)		_____ TELEPHONE		_____ PHYSICIAN SIGNATURE																															
				_____ DATE																															
FOR DEPARTMENT USE Medical and other professional personnel of the Medicaid agency or its designee MUST evaluate each applicant's or recipient's need for admission by reviewing and assessing the evaluations required by regulations.																																			
21A. MEDICALLY ELIGIBLE		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Medically Appropriate for Waiver Services		21B. Length of Stay <input type="checkbox"/> Within 180 days <input type="checkbox"/> Over 180 days																															
22 Comments. Attach a separate sheet if additional comments are necessary.																																			
_____ REVIEWER'S SIGNATURE AND TITLE				_____ DATE																															

ORIGINAL TO CAO - RETAIN PHOTOCOPY FOR YOUR FILE

MA 51 - 1/94

Waiver Service Request Form



Office of Developmental Programs Waiver Service Request Form

INSTRUCTIONS FOR COMPLETING THE FORM

PURPOSE: This form should be completed when the following requests did not result in team concurrence: a change to an existing waiver service or a new service request.

PROCEDURES FOR PROCESSING THE WAIVER SERVICE REQUEST FORM (DP 1022)

- The supports coordinator (SC) should clarify the waiver service request with the individual and/or surrogate.
 - What specific new service or change to an additional service is requested by the individual/surrogate?
- The SC should identify what has changed in the individual's life by gathering the necessary information that has prompted this request. Some questions to ask include:
 - Has an assessment been completed to identify the need?
 - Does the service require a physician's order, submission to Medical Assistance (MA) or private insurance and/or an evaluation from a physician/specialist?
 - Was there a change in the individual's physical health or behavioral health?
 - What progress is the individual making towards the desired outcome?
 - Has there been a change with the primary caregiver?
 - Does the individual receive the currently authorized level of services?
 - Does the individual receive the authorized level of services from other service systems (EPSDT, education, children and youth, etc.)?
 - Is the request for the service related to services authorized but not received through other service system (i.e. EPSDT or therapeutic staff support)?
 - Is the requested service related to a specific health or welfare need for the individual/surrogate?
- The SC should explain, in detail, the specific need and how the requested services will support this need.
- If the requested new or additional services require a physician's order, submission to MA or private insurance and/or an evaluation, the 15-calendar day timeline will begin when the additional information is obtained and the formal request can be submitted.
- The SC should complete the DP 1022 with the individual.
- The SC provides a copy of DP 1022 to individual/surrogate before submitting to SC supervisor for review.
- The SC submits DP 1022 to SC supervisor for review.
- The SC supervisor formally submits the DP 1022 to the designated staff person at the administrative entity (AE) within five-calendar days from date of receipt from SC supervisor for approval or disapproval.
- The AE is required to review and respond to the request by approving in full, in part, for a limited time, or denying within 10-calendar days from receipt of the DP 1022.
- If the form is incomplete, the AE shall notify the SC supervisor in writing. The SC supervisor has three-calendar days from date of notification to resubmit the completed form to the AE.
- If, during the review, a "no" response is indicated in any question, the AE will provide instructions to the SC supervisor of what is needed to move forward with the request.
- If additional information cannot be obtained within the 15-calendar day time frame, the AE shall consider this a denial and follow the rest of this procedure.
- The AE will complete, sign and date the form in all applicable sections and mail the completed copy of the DP 1022 to the individual/surrogate that explains the AEs actions within 10-calendar days of receipt of the form.
- If full or partial approval was granted, the AE will communicate the decision to the SC supervisor who submitted the request.
- The requested service should start within 30-calendar days from the authorization date of the service.
- If the AE denies the request, fair hearing and appeal rights will be attached to the completed copy of the DP 1022.



Office of Developmental Programs
Waiver Service Request Form

- The AE must maintain a copy of the DP 1022 and the fair hearing and appeal rights, if applicable, in the individual's file and also send a copy to the SC supervisor who submitted the request.

PROCEDURES IF DP 1022 IS APPROVED IN FULL, IN PART, OR FOR A TIME LIMITED BASIS

- If the AE approves the request in full, in part, or for a time limited basis, the decision should be communicated to the SC supervisor within three-calendar days of approving the request.
- Within five-calendar days of receiving the decision, the SC shall complete a critical revision to the ISP, the SC supervisor submits the ISP to the AE, and the change is authorized by the AE.
- If the change involves a currently authorized service in the HCSIS, the old authorization must be end-dated and a new authorization reflecting the approved change in units must be entered.
- The requested services should start within 30-calendar days of the service authorization.
- If the AE approves the request in part, or for a time limited basis, the basis for this partial or limited approval must be provided.
- The AE must provide due process and fair hearing information when services are approved in part or for a limited time basis.

PROCEDURES IF DP 1022 IS DENIED

- If the AE denies the request, the decision should be communicated to the SC supervisor within three-calendar days of denying the request.
- Within five-calendar days the AE sends a denial letter to the individual/surrogate making the request and the SC supervisor, detailing specifically what is being denied and the basis for the denial. Specific references to the AE operating agreement, the approved Waivers, and/or applicable Office of Developmental Programs (ODP) bulletins must be included in the denial letter. A copy of the individual's fair hearing and appeal rights should be attached.
- If the AE denies an individual/surrogate's request or gives the individual partial or limited approval, the basis for this partial or limited approval must be provided.
- If the individual/surrogate pursues a fair hearing, then the AE will submit a copy of the denial letter with the fair hearing request.

1. INDIVIDUAL'S NAME:		2. SUPPORTS COORDINATOR'S NAME:	
3. SURROGATE'S NAME:		4. RELATIONSHIP TO INDIVIDUAL:	
5. FUNDING (Please check which funding you receive):		<input type="checkbox"/> Consolidated Waiver <input type="checkbox"/> Person/Family Directed Support Waiver	
6. SERVICE CHANGE (Please describe the change in service or new request for a service that is needed at this time and the amount of the service needed. Remember that a service can only be approved if it is required to meet an assessed need of the individual being served. For multiple requests, please attach additional forms.)			
DESCRIBE THE CHANGE IN SERVICE OR NEW REQUEST (Include why these services are necessary to maintain health and welfare and what may have changed in the individual's life to warrant the request):			
SERVICE DEFINITION NAME:		UNITS OF SERVICE NEEDED:	
SIGNATURE (individual/surrogate):			DATE OF REQUEST:



Office of Developmental Programs
Waiver Service Request Form

ADMINISTRATIVE ENTITY REVIEW OF WAIVER SERVICE REQUESTS

The AE completes this section. If a question is marked "no", additional instructions will be given on what information is needed to approve the request, or the reason for denial will be provided.

1. Has an assessment been completed which identifies a need for the requested services?	<input type="checkbox"/> YES	<input type="checkbox"/> NO
2. Do the services require a physician's order, submission to MA or private insurance, and/or an evaluation from a physician/specialist?	<input type="checkbox"/> YES	<input type="checkbox"/> NO
3. Is the requested service eligible under the waiver?	<input type="checkbox"/> YES	<input type="checkbox"/> NO
4. Is the individual eligible for the requested service through the Office of Vocational Rehabilitation, Individuals with Disabilities Education Act or MA/private insurance?	<input type="checkbox"/> YES	<input type="checkbox"/> NO
5. Is the requested service eligible in the location where the service would be provided?	<input type="checkbox"/> YES	<input type="checkbox"/> NO
6. Has the provider signed a Medicaid agreement with the state?	<input type="checkbox"/> YES	<input type="checkbox"/> NO
SIGNATURE	DATE	

ADMINISTRATIVE ENTITY DECISION

SERVICE REQUEST HAS BEEN REVIEWED AND IS (Please check one):			
<input type="checkbox"/> Fully approved	<input type="checkbox"/> Partially approved	<input type="checkbox"/> Approved on a time-limited basis	<input type="checkbox"/> Disapproved
List approved change(s):			
List fully and partially disapproved requests. Clearly state reason(s) for disapproval. Specific references to the current approved waivers and applicable ODP bulletins must be included.			
SIGNATURE (Administrative entity):		DATE:	

Individual Support Plan Signature Form



www.dpw.state.pa.us

INDIVIDUAL SUPPORT PLAN SIGNATURE FORM

PURPOSE: This Office of Developmental Programs Individual Support Plan (ISP) Signature Form (revised 6/2012) is required to be completed during the following:

- Initial ISP meetings
- Annual Review Update meetings
- Team meetings regarding service changes that result in a critical revision to the ISP

INSTRUCTIONS FOR COMPLETING THE ISP SIGNATURE FORM

Page 1: At the conclusion of the meeting, the individual and team members should complete Page 1 of the ISP Signature Form.

- It is essential to have the individual attend his/her own meeting whenever possible. Each person who attended the meeting should sign and date the signature column across from their name and complete the title, agency and relationship to individual sections on the ISP Signature Form. If the individual, surrogate, or any other invited ISP team member chose not to be present, the reason for their absence must be documented on the ISP Signature Form under the column signature/date. The Supports Coordinators, SC's should document the absent team member was invited, but did not attend.
- If an individual is in attendance at the meeting but chooses not to sign the ISP Signature Form, the SC must indicate on the ISP Signature Form that the individual was in attendance at the meeting but chose not to sign on the line designated for the signature of individual.
- If an individual did not attend the meeting, the SC must review the results of the meeting with the individual, and have the individual sign the ISP Signature Form, noting the date that the review was held outside of the ISP meeting.
- If the individual, family member, or any other team member disagrees with the content of the ISP, sign at the designated content objection section at the bottom of page 1.

Page 2: The table below contains detailed information to supplement the questions found on page 2 of this ISP Signature Form.

- Each SC should use this information to thoroughly explain each question to the individual/surrogate prior to indicating the appropriate answer in the check box.
- During the initial ISP and annual update meetings, all questions on page 2 must be answered. During ISP team meetings that result in a critical revision to the ISP due to a service change, complete page 1 and designate on page 2 only that the individual was informed of their due process rights.
- The SC will attach a copy of the completed ISP Signature Form to the ISP and send to all meeting participants as well as other invited meeting participants who could not attend. The SC will only send a copy of the ISP Signature Form to providers who have access to HCSIS as they can obtain the ISP.

QUESTIONS FOUND ON PAGE 2 OF THIS FORM	DESCRIPTION OF WHAT "YES/NO" INDICATES N/A INDICATES THE QUESTION IS NOT APPLICABLE
1. I attended this meeting.	Yes/No indicates whether the individual was present and participated.
2. I agree to comply with all waiver requirements (ie; recertification, eligibility, SC monitoring, SIS).	Yes/No indicates whether the individual agrees/does not agree to comply with the waiver requirements. N/A indicates the individual is not in a waiver.
3. My ISP team and I reviewed the PA Universal Summary Report (Supports Intensity Scale, SIS®, and PA Plus assessment results) during this meeting.	Yes/No indicates whether the PA Universal Summary Report was used during the ISP meeting. N/A indicates that the individual has not had a SIS® and a PA Plus assessment completed.
4. I have been informed of the right to select a qualified and willing provider (including supports coordination organization) at any time.	Yes/No indicates whether the individual has been informed of free choice of all willing and qualified providers.
5. I have selected and agree with the identified services and qualified providers in my ISP.	Yes/No indicates whether the individual agrees/disagrees with the identified services and chosen qualified providers reflected in their current ISP. N/A indicates that the individual currently does not have services.

DP 1032 8/12



INDIVIDUAL SUPPORT PLAN SIGNATURE FORM

Individual's Name: _____

Date: _____

	YES	NO	N/A (not applicable)
1. I attended this meeting.	<input type="checkbox"/>	<input type="checkbox"/>	
2. I agree to comply with waiver requirements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My ISP team and I reviewed the PA Universal Summary Report (SIS™ and PA Plus assessment results) during the ISP meeting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I have been informed of the right to select a qualified and willing provider (including supports coordination organization) at any time.	<input type="checkbox"/>	<input type="checkbox"/>	
5. I have selected and agree with the identified services and qualified providers identified in my ISP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Types of services and available qualified providers have been reviewed.	<input type="checkbox"/>	<input type="checkbox"/>	
7. I have been informed of the right to request a change in my services at any time.	<input type="checkbox"/>	<input type="checkbox"/>	
8. I agree with the outcomes in my ISP.	<input type="checkbox"/>	<input type="checkbox"/>	
9. I have had my Prioritization of Urgency of Need for Services, or PUNS, reviewed and if needed, a PUNS change of status form has been completed and signed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I have been informed about employment service options.	<input type="checkbox"/>	<input type="checkbox"/>	
11. I have been informed about the Financial Management Service, or FMS, option to self-direct.	<input type="checkbox"/>	<input type="checkbox"/>	
12. I have agreed to receive SC services through Targeted Services Management, TSM.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I received information on how to report abuse, neglect, and exploitation from my SC.	<input type="checkbox"/>	<input type="checkbox"/>	
14. If in the Consolidated or P/FDS Waiver, and my approved services are reduced, suspended, denied, or terminated at any time, I have been informed of my due process rights and the Department's fair hearings and appeals process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. If receiving county funded services, I have been informed of my due process rights.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I understand my SC will provide copies of my ISP to the persons, agencies, or both listed on page 1. Providers having HCSIS access shall obtain the ISP electronically.	<input type="checkbox"/>	<input type="checkbox"/>	

Request for Exception to Service



REQUEST FOR EXCEPTION TO ESTABLISHED SERVICE LIMITS OR MAXIMUM NUMBER OF SERVICE UNITS

The Office of Developmental Programs, ODP, recognizes that unique situations may occur that will result in a need to request an exception to the established limits or service conditions as detailed in the approved Waivers. ODP has developed a process to request an exception to the following items:

- Respite services (15 minute and 24 hour)
- Respite in a non-waiver funded licensed residential setting
- Assistive technology lifetime limit

INSTRUCTIONS

All requests for an exception must be made in writing using Form DP 1023 and be submitted by the Supports Coordination Organization, SCO, to the appropriate Administrative Entity, AE. The AE will review the request and forward its recommendation to the appropriate Regional Program Manager, RPM.

1. The SCO will submit the completed DP 1023 to the AE for review and approval or disapproval.
2. The AE will review all requests for an exception within 10 business days of receipt of Form DP 1023 and forward a copy of the exception request and their recommendation to the RPM, with comments explaining the reasons for the recommendation.
3. The ODP RPM will review and either approve, disapprove or indicate whether documentation supports authorization for all requests for exception within 10 business days of receipt of the request. Written notification will be sent to the AE with a copy to the SCO and the ODP Claims Resolution Unit.

The exception request (DP 1023) must contain the following information for assistive technology:

- The proposed item, equipment or product to be acquired.
- Total cost (include work in excess of \$10,000 limit).
- Justification for item, including summary of independent evaluation, documentation that the item is not covered by MA or other insurance, and description of other less costly items considered/used.

The exception request (DP 1023) must contain the following information for respite:

- The proposed number of additional units.
- A detailed description of the circumstances on which the request for exception to the established maximum number of units or service condition is based.
- A justification for increased units based on a review of services previously utilized or the existing approved claims.
- The proposed site location, if a request is submitted for permission to render respite in a non-waiver funded licensed residential setting.
- * If emergency approval of respite was requested and approved, please note and attach documentation of the approval.



REQUEST FOR EXCEPTION TO ESTABLISHED SERVICE LIMITS OR MAXIMUM NUMBER OF SERVICE UNITS

NAME OF INDIVIDUAL FOR WHOM EXCEPTION IS BEING REQUESTED:	MCI NUMBER OF INDIVIDUAL:
PROVIDER NAME:	PROVIDER MPI:
SITE LOCATION:	PROCEDURE CODE/MODIFIER:
NAME OF SCO:	NAME AND EMAIL OF SC COMPLETING REQUEST:

AVAILABLE WAIVER OR FUNDING TYPE:

- Consolidated

 P/FDS

TYPE OF RESPITE EXCEPTION REQUESTED (choose one):

- Waiver-funded 24-hour respite (24-hour respite requested beyond 30 days in a fiscal year for a waiver participant)
- Waiver-funded 15-minute respite (15-minute respite requested beyond 480 units for a waiver participant)
- Location of respite services (request for exception to provide respite in a non-waiver funded residential setting licensed under 55 Pa. Code, Chapter 6400, 6500, 3800, 5310).

NUMBER OF UNITS INITIALLY AUTHORIZED: _____

NUMBER OF ADDITIONAL UNITS BEING PROPOSED: _____

DESCRIBE CIRCUMSTANCES REQUIRING AN EXCEPTION TO THE ESTABLISHED LIMIT OR CONDITION
(Include information about current utilization based on the review of claims, efforts taken to address the situation, time period for desired exception and plans to avoid a recurrence):



REQUEST FOR EXCEPTION TO ESTABLISHED SERVICE LIMITS OR MAXIMUM NUMBER OF SERVICE UNITS

Assistive technology exception to lifetime limit

ASSISTIVE TECHNOLOGY REQUEST (Lifetime limit of \$10,000 per participant)

ITEM, EQUIPMENT OR PRODUCT REQUESTED:	
TOTAL AMOUNT OF ITEM, EQUIPMENT OR PRODUCT REQUESTED:	LIFETIME AMOUNT USED:
ADDITIONAL AMOUNT (beyond \$10,000) REQUESTED:	
SUMMARIZE RESULTS OF INDEPENDENT EVALUATION, INCLUDING THE NAME OF THE ORGANIZATION OR PROFESSIONAL CONDUCTING THE REVIEW (evaluation may be submitted as an attachment):	
PROVIDE OR EXPLAIN DOCUMENTATION OBTAINED TO DETERMINE THAT THE ITEM, EQUIPMENT OR PRODUCT REQUESTED IS NOT COVERED THROUGH THE MA STATE PLAN, MEDICARE AND/OR PRIVATE INSURANCE:	
DESCRIBE CIRCUMSTANCES REQUIRING AN EXCEPTION TO THE ESTABLISHED LIMIT (specify what other less costly alternatives have been considered and used and explain why each was determined not to be an effective option(s)):	



REQUEST FOR EXCEPTION TO ESTABLISHED SERVICE LIMITS OR MAXIMUM NUMBER OF SERVICE UNITS

DATE REQUEST SUBMITTED TO ADMINISTRATIVE ENTITY: _____

ADMINISTRATIVE ENTITY RECOMMENDATION: APPROVED DISAPPROVED

NAME OF AE REPRESENTATIVE	TITLE	DATE SUBMITTED TO ODP REGIONAL OFFICE

REASONS FOR RECOMMENDATION:

ODP REGIONAL OFFICE DETERMINATION FOR:

ASSISTIVE TECHNOLOGY OR RESPITE SERVICE LIMITS:

APPROVED DISAPPROVED

RESPITE IN A NON-WAIVER FUNDED LICENSED RESIDENTIAL SETTING:

- DOCUMENTATION SUPPORTS REQUEST
- ADDITIONAL DOCUMENTATION NEEDED FOR AE AUTHORIZATION

DATE ODP REGIONAL OFFICE DECISION SUBMITTED TO AE, SCO AND ODP CLAIMS RESOLUTION UNIT: _____

ADDITIONAL COMMENTS: SCO AE REGIONAL OFFICE



**REQUEST FOR EXCEPTION TO ESTABLISHED SERVICE
LIMITS OR MAXIMUM NUMBER OF SERVICE UNITS**

ADDITIONAL COMMENTS (continued):

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) 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.gov

Calling Your County and Regional ODP Offices

Sometimes you cannot get the help you need through your local MH/ID 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:

AGENCIES

WESTERN REGION	412-565-5144
Allegheny Co. Dept. of Human Services	412-436-2750
Armstrong-Indiana Behavioral & Developmental Health Program	724-548-3451
Beaver County Behavioral Health	724-847-6225
Butler County MH/EI/ID Program	724-284-5114
Cameron-Elk MH/ID	814-772-8016
Clarion County MH/ID/EI	814-226-6252
Community Connections of Clearfield Jefferson	814-371-5100
Crawford County ID Programs	814-724-8380
Erie County MH/ID	814-451-6860
Fayette County Behavioral Health Administration	724-430-1370
Forest-Warren Human Services	814-726-2100
Greene County Human Services	724-852-5276
Lawrence County Mental Health & Developmental Services	724-658-2538
McKean County MH/ID	814-887-3350
Mercer County MH/DS	724-662-6715
Potter County Human Services	814-544-7315
Venango County Mental Health & Developmental Programs.	814-432-9753
Washington County BH/DS	724-228-6832
Westmoreland County Behavioral Health & Developmental Services	724-830-3617
For people who live in Allegheny, Armstrong, Indiana, Beaver, Butler, Cameron, Elk, McKean, Clarion, Clearfield, Jefferson, Crawford, Erie, Fayette, Forest, Warren, Lawrence, Mercer, Potter, Venango, Washington, Green, Westmoreland Counties call: Western Regional ODP at 412-565-5144.	

CENTRAL REGION	717-772-6507
Bedford-Somerset Office of MH/ID	814-443-4891
Blair County MH/BH/ID Programs	814-693-3023
Cambria County Behavioral Health/ID Programs	814-535-8531
Centre County MH/ID	814-355-6782
CMSU Behavioral & Developmental Services Columbia-Montour-Snyder-Union	570-275-5422
Cumberland-Perry MH/IDD	717-240-6325
Dauphin County MH/ID	717 780-7050
Franklin-Fulton MH/ID/EI	717- 264-5387
Juniata Valley Tri-County Behavior & Developmental Programs	717-242-6467
Lancaster County MH/ID/EI	717-299-8021
Lebanon County MH/ID Program	717-274-3415
Lycoming-Clinton MH/ID	570-326-7895
Northumberland County BH/ID Services	570-495-2003
York-Adams MH/IDD	717-771-9618
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	

SOUTHEAST REGION	215-560-6359
Bucks County Dept. of Mental Health/Developmental Programs	215-444-2800
Chester County Dept. of MH/IDD	610-344-6265
Delaware County BH/ ID Services	610-713-2330
Montgomery County BH/DD	610-278-3642
Philadelphia County Office of Behavioral Health/ Intellectual disAbility Services	215-685-4677
For people who live in Bucks, Chester, Delaware, Montgomery or Philadelphia Counties call: Southeast Regional Office of Developmental Programs 215-560-2242	

NORTHEAST REGION	570-963-4749
Berks County MH/DD	610-478-3271
Bradford-Sullivan MH/ID	570-265-1760
Carbon-Monroe-Pike MH/DS	570-420-1900

NORTHEAST REGION		570-963-4749
Lackawanna-Susquehanna BH/ID/EI Programs		570-346-5741
Luzerne-Wyoming MH/Developmental Services Program		570-825-9441
Northampton County MH/EI/Developmental Programs		610-974-7500
Schuylkill County MH/DS/D&A		570-621-2890
Tioga County Dept. of Human Services		570-724-5766
Wayne County Office of Developmental Programs		570-253-9200
For people who live in Berks, Bradford, Sullivan, Carbon, Monroe, Pike, Lackawanna, Susquehanna, Wayne, Lehigh, Luzerne, Wyoming, Northampton, Schuylkill, or Tioga Counties call: Northeast Regional Office of Developmental Programs 570-963-4749		

AGENCIES WITH CHOICE (AWC)

CENTRAL REGION		
County/Joinder	AWC Address	AWC Contact Information
Centre, CMSU, Cumberland/Perry, Dauphin, Lancaster, Lebanon, Lycoming/Clinton, Northumberland	UCP of Central PA 44 South 38th Street Camp Hill, PA 17011	Tom Bunker 717-737-3477 tbunker@ucpcentralpa.org
Cambria	UCP of Southern Alleghenies Region, Inc. 119 Jari Drive Johnstown, PA. 15904	Mark Malzi 814-262-9600 Ext. 320 mmalzi@alucp.org
York/Adams	The ARC of York County 497 Hill Street York, PA. 17403	Greg Knox/Len Lubinsky 717- 846-6589 gknox@thearcofyorkcounty.org or llubinsky@thearcofyorkcounty.org
Huntington/Mifflin/Juniata	Mifflin-Juniata Special Needs Center Inc. 401 Yale Street Lewistown, PA 17044	Beth Zong 717-248-6261 bzong@mjsnc.org
Bedford/Somerset, Blair	Home Nursing Agency Community Services 154 Lakemont Park Blvd Altoona, PA. 16602	Linda Weber/Lorrie Hetager 814-944-8179 lweber@homenursingagency.com or lheterger@homenursingagency.com
Franklin/Fulton	The ARC of Franklin/Fulton Counties 4351 Philadelphia Avenue Chambersburg, PA 17202	Lorrie Miller 717-264-4390 arc4390@embarqmail.com

NORTHEAST REGION		
County/Joinder	AWC Address	AWC Contact Information
Berks, Schuylkill	Abilities in Motion 416 Blair Ave Reading, PA, 19601	Regina Stewart 610-376-0010 Regina@abilitiesinmotion.org
Bradford/Sullivan, Tioga	Futures Community Support Services Inc. 23 Main Street Towanda, PA, 18848	Debbie Bennett 570-265-3800 dbennett@fcsonline.com
Carbon/Monroe/ Pike-(C/M/P)**	Fitzmaurice Community Services Inc.** 2115 N 5th Street Stroudsburg, PA 18360 AND Human Resources Center Inc.** 294 Bethel School Road Honesdale, PA 18431	Eve Killimett (570)-213-4312 ekillimett@fitzmaurice.org AND Mark Hoover 570-253-3782 mark.hoover@hrcinc.org
Lackawanna/ Susquehanna	Caregivers America, LLC 718 South State Street Clarks Summit, PA, 18411	Paul Batoletti 570-586-6633 paulb@caregiversamerica.com
Lehigh, Northampton	The ARC of Lehigh and Northampton Counties, Inc. 2289 Avenue A Bethlehem, PA 18017	Karen Grady 610-849-8076 kgrady@arcofl-n.org
Luzerne/Wyoming	Wilkes-Barre Behavioral Ventures LLC 562 Wyoming Ave Kingston, PA 18704	Frank Piazza 570-552-3625 fpiazza@wvhcs.org
Wayne	Human Resources Center Inc. 294 Bethel School Road Honesdale, PA 18431	Mark Hoover 570-253-3782 mark.hoover@hrcinc.org
** C/M/P (in the Northeast) had 2 AWC providers prior to July 1,2008 and was therefore permitted to maintain this arrangement. All other AE's have one AWC provider available to serve waiver participants registered with that AE who express an interest in the AWC option to self-direct their services.		

SOUTHEAST REGION		
County/Joinder	AWC Address	AWC Contact Information
Chester, Delaware	The ARC of Chester County 900 Lawrence Drive West Chester, Pennsylvania 19380	Diane Carey, Executive Director 610-696-8090 dcarey@arcofchestercounty.org or kburdeau@arcofchester.county.org
Philadelphia, Bucks	Neighbours, Incorporated <u>Main Office Address:</u> 49 Woodbridge Avenue Highland Park New Jersey 08904 <u>Local Address:</u> P.O.Box 685 Fogelsville, PA 18051	Mark Zandanel, AWC/FMS Director 610-529-8998 markgane@neighbours-inc.com
Montgomery	Jewish Employment and Vocational Services (JEVS) 10431 Academy Road, Suite L Philadelphia, PA 19114	Deborah A. Mahnken 267-298-1325 deborah.mahnken@jevs.org or cristina.padilla@jevs.org

WESTERN REGION		
County/Joinder	AWC Address	AWC Contact Information
Allegheny, Armstrong/Indiana, Lawrence	Passavant Memorial Homes 100 Passavant Way Pittsburgh, PA 15238	Jennifer Hanes 412-820-1010 jhanes@passavant.org
Beaver	Beaver County Rehabilitation Center/BCRC 1517 6th Avenue New Brighton, PA 15066	Kay Podbielski 724-847-1306 kpodbielski@BCRC.NET
Butler	Irene Stacy Community Mental Health Center 112 Hillvue Drive Butler, PA 16001	Pat Sassone 724-287-0791 x2150 psassone@irenestacy.com
Cameron/Elk, Clearfield/Jefferson, Crawford, McKean, Potter, Venango	The ARC of Crawford Inc. 222 Chestnut Street Meadville, PA 16335	Vicki Loper 814-724-7346 vloper@windstream.net
Clarion	Clarion Vocational Services ISO, Inc. 214 S 7th Avenue Clarion, PA 16214	Kathy Glosser 814-226-1076 cvs23@verizon.net or tina_hartle@yahoo.com
Erie	Dr. Gertrude A. Barber In Home Services, Inc.	Pam Baker 814-878-5958

WESTERN REGION		
County/Joinder	AWC Address	AWC Contact Information
	100 Barber Place Erie, PA 16507	PamBaker@BarberInstitute.org
Fayette, Westmoreland	Community Living Care Inc. 115 Vannear Avenue Greensburg, PA 15601	Judy Hoza 724-836-8747 ext 1022 judy.hoza@communitylivingcare.com
Forest/Warre	Community Resources for Independence, Inc. 3410 W 12th Street Erie, PA 16505	Bill Essigmann 814-838-7222 bessigmann@crinet.org
Greene, Washington	UCP of Southwestern PA, Inc. 655 Jefferson Avenue Washington, PA 15301	Jennifer Scott 724-225-8145 jscott@ucpswpa.org
Mercer	MCAR 850 North Hermitage Road Hermitage, PA 16148	Katie Bodien 724-981-2950 x 263 kbodien@mercerarc.org

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

Or contact the League of Women Voters 800-692-7281

OTHER ORGANIZATIONS:

- The Arc USA: www.thearc.org
- The Arc PA: www.thearcpa.org
- Self-Advocates United as 1: www.sau1.org
- Speaking for Ourselves: www.speaking.org
- Disability Rights Network of PA: www.drnpa.org
- Education Law Center: www.elc-pa.org
- Vision For Equality: www.visionforequality.org
- Pennsylvania Waiting List Campaign: www.pawaitinglistcampaign.org

Advocacy and Agency Contact

ACHIEVA

711 Bingham Street / Pittsburgh, PA 1520

tel: 412-995-5000 / 1-888-272-7229 toll-free / website: www.achieva.info

ACHIEVA was founded in 1951 by parents who wanted their children with intellectual and developmental disabilities to have access to the programs and educational opportunities available to other children. Since that time, ACHIEVA has grown to become a leading agency in southwestern Pennsylvania, and in 2013 is supporting more than 14,500 people with disabilities and their families. ACHIEVA has historically been a leader in creating innovative supports and services for children and adults with disabilities. ACHIEVA's programs have been replicated nationally and internationally and currently include:

- Advocacy and Public Awareness
- Lifetime Family Support
- Early Intervention
- Preschool Readiness
- Vocational Supports
- Camp Programs and Recreational Opportunities
- Residential Living Options
- Home Care and Respite Supports
- Older Adult Protective Services.
- Disability Healthcare Initiative
- Special Needs Trusts

The Arc of Pennsylvania

101 South 2nd Street / Suite 8 – Executive House / Harrisburg, PA 17101

tel: 717-234-2621 / 800-692-7258 toll-free / fax: 717-234-2622

website: <http://www.thearcpa.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)

555 Walnut Street / Harrisburg, PA17101

tel: 717-787-2121 / 800-9320784 toll-free / 800-324-8040 TDD/TTY

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.

Disability Rights Network of Pennsylvania

1414 Cameron St., Suite C / Harrisburg, PA 17103

tel: 800-692-7443 toll-free / 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
tel: 215-238-6970 / fax: 215-772-3125

AND

702 Law & Finance Building / 429 Fourth Avenue / Pittsburgh, PA 15219
tel: 412-258-2120 / fax: 412-391-449 / website: www.elc-pa.org

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.

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.

Institute on Disabilities at Temple University

1755 N 13th Street, Suite 411S / Philadelphia, PA 19122

tel: 215-204-1356 Voice / 215-204-1805 TTY

email: iod@temple.edu / website: www.disabilities.temple.edu

The Institute on Disabilities at Temple University is one of the sixty-seven University Centers for Excellence in Developmental Disabilities Education, Research and Service funded by the Administration on Intellectual and Developmental Disabilities, U.S. Department of Health and Human Services. The Institute is a vibrant, diverse organization with more than 40 staff members, including students and is considered a national leader in assistive technology, Disability Studies, justice for people with disabilities, policy analysis, leadership development and inclusive education. Much of our success in reaching the community and our constituents can be attributed to our close partnerships with statewide advocacy and self-advocacy groups, Centers for Independent Living, Pennsylvania's Developmental Disabilities Council, The Disability Rights Network of Pennsylvania, state government, specialized and generic service

providers, the criminal justice system, and universities throughout Pennsylvania. The scope of work and dedication to our constituents continues to grow, touching more people with disabilities, families, communities, students, educators, employers and policy makers. The Institute's more than 20 programs have an impact on people's lives throughout Pennsylvania, nationally and internationally.

Mentors for Self Determination (M4SD)

P.O. Box 429 / Conneaut Lake, PA 16316

tel: 814-547-1577 / fax: 814-382-7735 / website: www.mentors4sd.org

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)

tel: 800-442-6351 central office / 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)

tel: 800-522-5827 toll-free / website: 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

tel: 888-727-2706 toll-free / website: 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

tel: 717-920-0530 Voice/TTY / 866-302-7245 toll-free / fax: 717-920-0532

email: office@pcil.net / website: www.pcil.net

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 Bldg / 123 Chestnut St. Suite 400 / Philadelphia, PA 19106
tel: 215-625-3990 / fax: 215-625-3879

Harrisburg Office

1414 N. Cameron Street, Suite B / Harrisburg, PA 17103
tel: 717-236-6310 / fax: 717-236-6311

Pittsburgh Office

415 East Ohio Street, Suite 325 / Pittsburgh, PA 15212
tel: 412-434-5779 / fax: 412-434-0128 / help line 800-274-3258
website: www.phlp.org / email: staff@phhhlp.org

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)

tel: 866-865-6170 toll-free / fax: 215-204-6336 / website: 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: *What is an Intellectual Disability 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 / Slatington PA 18080
tel: 267-765-0301 toll-free / fax: 610-767-2437 / website: 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

tel message line: 877-304-7730 toll-free / email: klenkner@sau1.org / website: 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

tel: 800-867-3330 / 215-923-8600 / fax: 215-923-8601 / website: www.speaking.org

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)

website: <http://www.ucp.org/findaffiliate>

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

tel; 215-923-3349 / website: www.visionforequality.org

Harrisburg Office

1414 North Cameron Street / Harrisburg, PA 17103|

tel: 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 Training.

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/ID 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 intellectual disability, 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.

Employment Networks (EN) - An Employment Network (EN) is approved by SSA to accept Tickets and provide employment services (vocational rehabilitation, job training, or any other public or private person, agency, or business approved by SSA. Services are provided at no cost.

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/ID 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 intellectual disability 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 intellectual disability.

Intermediate Care Facility for Persons with Intellectual Disability (ICF/ID)

A licensed facility that provides care designed to meet the needs of persons with intellectual disability who meet the ICF/ID 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 licensed 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 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 QIDP 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 Intellectual Disability Professional (QIDP)

The QIDP determines whether a person meets ICF/ID level of care criteria. A QIDP may be any person who has at least one year of experience working with persons with intellectual disability 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 bachelor's 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 intellectual disability 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 intellectual disability 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/ID 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 intellectual disability 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 intellectual disability.

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

AE – Administrative Entity	MAWD – Medical Assistance for Workers with Disabilities
AWC – Agency With Choice	MH/ID – Mental Health/Intellectual Disability
BAS – Bureau of Autism Services	MR – Mental Retardation
BHA – Bureau of Hearings and Appeals	ODP – (PA) Office of Developmental Programs
BSU – Base Service Unit	OVR – Office of Vocational Rehabilitation
CLA – Community Living Arrangement	PAWL – PA Waiting List Campaign
CMS – Centers for Medicare and Medicaid Services	PCP – Person Centered Planning
DLP – Disability Law Project	PDS – Participant-Directed Services
DPW – (PA) Department of Public Welfare (ODP is part of DPW)	P/FDS – Person/Family Directed Support Waiver
DRN – Disability Rights Network	PHLP – Pennsylvania Health Law Project
ELC – Education Law Center	PUNS – Prioritization of Urgency of Need for Services
ELP – Essential Lifestyle Planning	RPM – Regional Program Manager
EPSDT – Early Periodic Screening Diagnosis and Treatment	SC – Supports Coordinator (formerly called a Case Manager)
FDSS – Family Driven Support Services	SCO – Supports Coordination Organization
FMS – Financial Management Services	SIS (SIS-PA+) – Supports Intensity Scale and PA Plus (PA+)
HCQU – Health Care Quality Unit	SSA – Social Security Administration
HCSIS – Home and Community Services Information Systems	SSD – Services and Supports Directory
ICF/ID – Intermediate Care Facility for Persons with Intellectual Disability	SSDI – Social Security Disability Insurance
ICF/ORC – Intermediate Care Facility/Other Related Conditions	SSI – Supplemental Security Income
ID – Intellectual Disability	SSW – Support Service Worker
IM4Q – Independent Monitoring for Quality	TSM – Targeted Service Management
ISP – Individual Support Plan	VF/EA – Vendor Fiscal/Employer Agent
MA – Medical Assistance	