Gold Book

Understanding the Office of Developmental Programs

3rd edition
July 2023

Supporting People with Intellectual and Developmental Disabilities, Complex Medical Conditions, Autism, and Their Families

pennsylvania
DEPARTMENT OF HUMAN SERVICES

DEDICATION

This book is dedicated to people with disabilities and their families and the advocates, allies, and supporters who make Everyday Lives possible for ALL people in Pennsylvania.

This book could not have been created without the talent, encouragement and support of Vision for Equality, Inc. who recognize the need to inform people and families, sought the answers, and made it happen. We thank the Office of Developmental Programs for their continual support to self-advocates and families.

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The Mission of the Office of Developmental Programs (ODP) is to support Pennsylvanians with developmental disabilities and their families to achieve greater independence, choice, and opportunity in their lives. The office seeks to continuously improve an effective system of accessible services and supports that are flexible, innovative, and person-centered.

MISSION

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May 18, 2023

Dear Individuals and Families:

It is with tremendous pleasure I write this introductory letter to the Gold Book: Understanding the Office of Developmental Programs. As one of the authors of the last version of the Gold Book, which was published 10 years ago, I know how incredibly valuable this long-awaited update is for individuals and families who are navigating service systems.

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 can be complicated and difficult to navigate. For this reason, we have organized information to be more accessible and helpful for individuals and families.

This book has been compiled in part by people who were aware of this need and undertook the challenge of writing it – individuals and families. I wish to acknowledge Disability Rights Network of Pennsylvania, the Pennsylvania Family Network, and Self-Advocates United as 1 for their contributions.

In the following pages you will find information to help guide you through the intellectual disability and autism services, supports, and resources in the Commonwealth of Pennsylvania.

Sincerely,

Kristin Ahrens
Deputy Secretary

About this Book

The service system that is supported by the Office of Developmental Programs is varied and vast. For those new to the system this can be overwhelming. For individuals and families new to the system or for anyone interested in navigating ODP, this book is intended to be a guide to the system. The information contained in this publication was gathered from a variety of sources. It has been compiled and related in what we hope is a readable and helpful format.

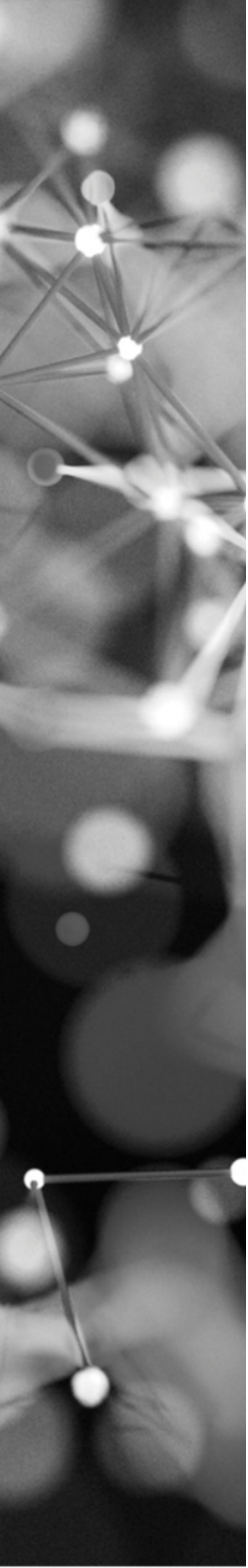
Throughout the document we often use the word "you," directly addressing people who need or are receiving service. But the document is also intended to be a resource for families, Supports Coordinators and anyone who supports an individual with disabilities. This book is for you.

There are several terms that appear throughout this book, and you may use the glossary to understand them. One term which is very important is "person-centered." The concept is simply that what is important to the person who is receiving services is always first.

To implement person-centered practices, we must recognize that family is an integral part of everyone's everyday life. We are born into families, and we also choose those we consider family. Families are the foundation of our early development and often our achievements as adults.

If people with disabilities are to enjoy the everyday life that all citizens enjoy, families will play a key role which begins in childhood with a positive and promising vision for their child, families can facilitate their son's or daughter's full inclusion in school and the community and ensure their child has the experiences and opportunities needed to learn and grow to adulthood. Families are strong and resourceful but also need assistance. They need information, advocacy skills, and connections to other families. The realization of Everyday Lives is dependent on the service system successfully partnering with families to achieve the hopes and dreams of their family members.

This Gold Book is intended to assist people with intellectual disabilities, developmental disabilities, and autism, along with their families and those who provide support, to better understand what services and supports are available and how to access them.



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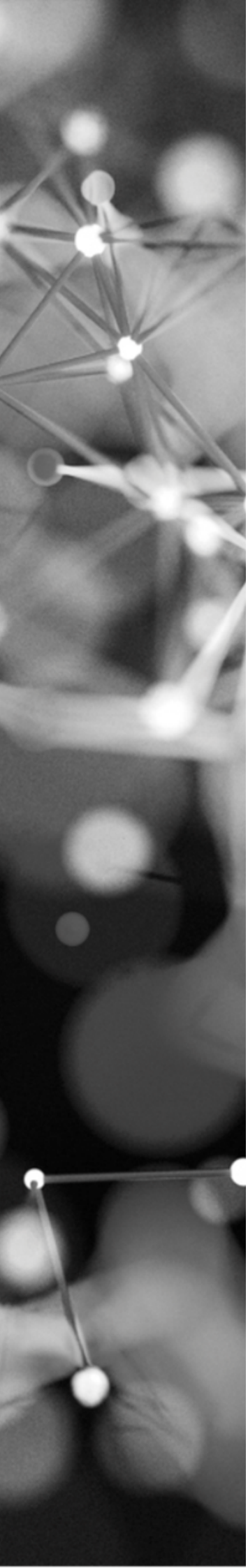

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Chapter 1

Everyday Lives and the LifeCourse Framework

WELCOME

This first chapter describes the foundation for the ODP services system: Everyday Lives, a set of values and beliefs that guide the design of the service system, and the LifeCourse Framework, an approach and set of tools to help people achieve an everyday life. The idea that everyone is entitled to an everyday life is the basis of everything in our service system.

An everyday life is about opportunities, relationships, rights, and responsibilities. It is about being a member of the community, having a valued role, and having one's rights as a citizen fully respected. Understanding this concept will help you to understand the service system and how it is constructed. How we live our lives is often described as "walking along the path of life." If you were to draw a picture of how your life started and where it is now, you might draw a picture of yourself on a winding path. That path may also be called a course. The path of your life is your life's course. The LifeCourse Framework uses this idea to help you look at your life, examine what you need to make your life more fulfilling, and provide you with tools for achieving whatever you want in life.

What is Everyday Lives?

Everyday Lives is the name of a 1991 publication developed by a group of people convened by the state office that is today known as the Office of Developmental Programs. Self-advocates, families, advocates, providers and county and state government representatives collaborated over several months to develop a vision for people with disabilities in our state. This vision included a set of values that have guided the service system in Pennsylvania since that time. Everyday Lives communicates the belief that, no matter who we are, we all have the same rights and should have the same opportunities to live the life we choose. It makes clear that services provided to people in the Commonwealth must be founded on that belief.

This is only the ***beginning.***

Your life, your decisions, your plans for the future: these are all important factors in ensuring that you are being treated the way you want and deserve to be treated, and in ensuring that you are receiving all the services and supports you need to help you live your life.

What follows is material directly from the Office of Developmental Programs' Everyday Lives and The Lifecourse Nexus, sponsored by the University of Missouri Kansas City, Institute for Human Development University Centers for Excellence in Developmental Disabilities

In 2016, The Office of Developmental Programs convened people with disabilities families, advocates, providers and county and state government representatives to take a fresh look at Everyday Lives. Again, after several months of collaboration, the publication was updated with 1) values statements for individuals, 2) values statements for families, and 3) 14 specific recommendations developed.

Everyday Lives: Values in Action opens with the following message:

"Our goal should be clear. We are seeking nothing less than a life surrounded by the richness and diversity of community. A collective life. A common life. An everyday life. A powerful life that gains its joy from the creativity and connectedness that comes when we join in association as citizens to create an inclusive world."
– John McKnight, Emeritus Professor at Northwestern University

Everyday Lives Value Statements for Individuals

Everyday Lives in Action: What is Important to **People with Disabilities**	
CONTROL: I have control over all areas of my life. My family and supporters know these are my decisions and work with me to achieve greater control.	RELATIONSHIPS: I decide who is in my life: friends, family, partners, neighbors, pets, and others in the community.
CHOICE: I decide everything about my life. My family, supporters, and community help me learn about opportunities and together we make them happen.	RESPONSIBILITY: I am dependable and honor my commitments. I keep my word. My family and supporters are honest and fair and keep their word.
FREEDOM: I have the same rights as all other members of the community, and I can fully use them. My family, supporters, and community respect my rights.	PARTNERSHIP: I need people in my life who will honor my life's journey. My family, supporters, and community work together with me to form connections.
STABILITY: Changes to my life are made only with my permission and input. My family, supporters, and community do "nothing about me without me."	EMPLOYMENT/MEANINGFUL CONTRIBUTION: I want to work at a job with good wages and benefits, start my own business, or volunteer.

Everyday Lives Value Statements for Individuals

Everyday Lives in Action: What is Important to People with Disabilities	
COMMUNICATION: I am listened to and understood; my input is valued. My family and supporters listen to me and communicate in ways that work for me.	QUALITY: I want my life my way. I, my family, supporters, and the community make sure the services I choose are proved to be of high quality.
HEALTH AND SAFETY: I am healthy and safe in all areas of my life. I, my family, supporters, and community balance health, safety, and risk according to my wants and needs.	SUCCESS: I am the best I can be in the goals that I decide. My family, supporters, and community learn how to support me to achieve my goals.
INDIVIDUALITY: I am respected and valued for who I am. My family, supporters, and community treat me with dignity and support me in a person-centered way.	ADVOCACY: I am the best person to let others know what I want and need. My family, supporters, and community listen and assist me
CONNECTED: I am a full member of my community with respect, dignity, and status. My family, supporters, and community know me as a person, welcome and accept me.	

If people with disabilities are to enjoy the everyday life that all citizens should enjoy, families will play a key role beginning in the earliest years and continuing into adulthood.

Everyday Lives in Action:	What Families Value
THE UNIQUE ROLE OF FAMILY: Families represent the very heart of life throughout the lifespan.	CHOICE AND CONTROL: Families seek freedom, on behalf of their family members, to make responsible and personal choices in all aspects of life.
SUPPORTING FAMILIES THROUGHOUT THE LIFESPAN: Our families must be encouraged and supported early on in their children's lives to hope, dream, and reach for the future.	KNOWLEDGE AND RESOURCES: Families want to feel strong so they can provide for and support their loved ones.
HEALTH AND SAFETY: People should be safe at home, work, school, and in the community.	SIMPLICITY AND FLEXIBILITY: Families value a simplified and transparent system that is easy to access, understand, and navigate.
MENTORING: Families value mentoring as a strong component to informing and supporting families.	QUALITY AND STABILITY: Families value quality supports and services that enable people to live everyday lives.
COMMUNICATION: Good communication involves everyone working toward common goals, respecting one another in partnership.	COLLABORATION: Along with self-advocates, family members must be part of the discussion, planning, and creation of every element of the service system.
RESPECT AND TRUST: Respect must be granted to families, their values and beliefs, homes, and privacy.	OPPORTUNITY FOR INNOVATION: Families support innovative, creative approaches that can be the key to truly person-centered solutions and often offer the most cost-efficient solutions.

14 Recommendations: Everyday Lives Values in Action

For a copy of the most recent report on the 14 Recommendations, which also includes its strategies and performance measures, please see this site: [ISAC Recommendation Report]

1. ASSURE EFFECTIVE COMMUNICATION

Every person has an effective way to communicate to express choice and ensure their health and safety. All forms of communication should consider and include the use of current technology.

2. PROMOTE SELF-DIRECTION, CHOICE, & CONTROL

Personal choice and control over all aspects of life must be supported for everyone. Choice about where to live, whom to live with, what to do for a living, and how to have fun all are key choices in life.

3. INCREASE EMPLOYMENT

Employment is a centerpiece of adulthood and must be available for everyone. The benefits are the same as for people without disabilities: getting a paycheck, meeting new people, building new skills, paying taxes.

4. SUPPORT FAMILIES THROUGHOUT THE LIFESPAN

Families need support to make an everyday life possible. They need information, resources, and training.

5. PROMOTE HEALTH, WELLNESS, AND SAFETY

Promote physical and mental health, wellness, and personal safety for every individual and their family.

6. SUPPORT PEOPLE WITH COMPLEX NEEDS

People with physical and behavioral health needs receive the services and supports they need throughout their lifespans. Opportunities for a full community life are dependent on adequate supports.

7. DEVELOP AND SUPPORT QUALIFIED STAFF

People receiving services benefit when staff who support them are well trained. Values, ethics, and person-centered decision-making can be learned and used in daily practice through mentorship and training.

8. SIMPLIFY THE SYSTEM

The system of supports and funding of those supports must be as straightforward and uncomplicated as possible. This will allow for greater understanding and use of the system by individuals needing and receiving supports and their families.

9. IMPROVE QUALITY

We must plan and deliver services and continuously improve an individual's quality of life. All stakeholders must be engaged in the process of measuring how well services assist people in achieving an everyday life.

10. EXPAND OPTIONS FOR COMMUNITY LIVING

Expand the range of housing options in the community so all people can live where and with whom they want to live.

11. INCREASE COMMUNITY PARTICIPATION

Being involved in community life creates opportunities for new experiences and interests, the potential to develop friendships, and the ability to contribute to the community.

12. PROVIDE COMMUNITY SERVICES TO EVERYONE

Some people are waiting for community services. The goal is to build a system with capacity to provide services for all people who need supports.

13. EVALUATE FUTURE INNOVATIONS BASED ON EVERYDAY LIVES PRINCIPLES

Future consideration of service models and reimbursement strategies must be based on the principles of person-centered planning, individual choice, control over who provides services and where, and full engagement in community life. Innovative approaches should be evaluated based on the recommendations of Everyday Lives.

14. PROMOTE RACIAL EQUALITY

Communities are richer, more just, and stronger when we honor and respect the whole of racial diversity. Access to a quality, person-centered, culturally competent system of supports and funding must be equally available regardless of race. Services must include planning over a lifespan and address racial disparities, including outcomes. The duty to ensure that racial diversity is promoted and supported, at all levels within the services system, must be embraced.

What is the LifeCourse Framework and How Will it Help You?

The LifeCourse framework emphasizes two things:

1) human beings are interdependent, and family is the primary arena for experiencing and understanding the wider social world and

2) experiences in early life are linked to experiences later in adulthood.

Families are the core unit in our society, serving as a source of support for all its members. For people with disabilities, the role of family is central to their growth and development, facilitating learning and their inclusion in all facets of community life. The experiences that children have early in life are the foundation for their development into adults.

The LifeCourse Framework teaches when we talk about providing supports to families, we generally focus on providing actual goods and services. But families need more. The LifeCourse Framework classifies family support into three areas:

1. Discovery: Families are empowered when they have access to information. Sometimes, what we need first is good information to understand what we need to do, to make decisions or simply know what's going on.

2. Connecting: Making connections with peers, people who can help and people who have been in your shoes.

3. Goods and Services: The day-to-day tangible items you buy or use from public and private organizations in your community. These are the things that we connect with to make our daily lives possible and successful.

The Three Buckets: Strategies for Supporting Families

All families need supports that change as the family members transition throughout their life stages and as roles, needs, and abilities of family members change. Strategies to address different needs fall into three "buckets." **1) Discovery and Navigation** which means having the information that you need; **2) Connecting and Networking** with peers and resources; and **3) Goods and Services** available within our communities and service systems.

The PA Community of Practice – Discovery & Connections

The Community of Practice – The Office of Developmental Programs has adopted several strategies that provide individuals with disabilities and families opportunities to receive information, learn, and network with each other. The organizations listed below are led by individuals with disabilities and families in partnership with other stakeholders in the system.

The Office of Developmental Programs Regional Collaboratives bring stakeholders together in their naturally connected communities to create networks and discover local strategies to support families. The Regional Collaboratives are supported by ODP Regional leadership.

LifeCourse Tools – to Plan for a Good Life

We are all on a path and where we are today leads to where we will be in the future.

Life is about relationships and experiences. At each stage of our lives, there are people we want to be with and experiences we want to have. Children want to play, teens want to experience independence, adults want to work, and everyone wants to have a little fun in their lives. Along the path we meet people and build relationships that remain important to us throughout life.

The LifeCourse Framework was created to help you and your family to develop a vision for a good life. The LifeCourse tools offer a different way of thinking, encouraging high expectations, having life experiences to move life in the desired direction, and identifying and integrating multiple types of support.

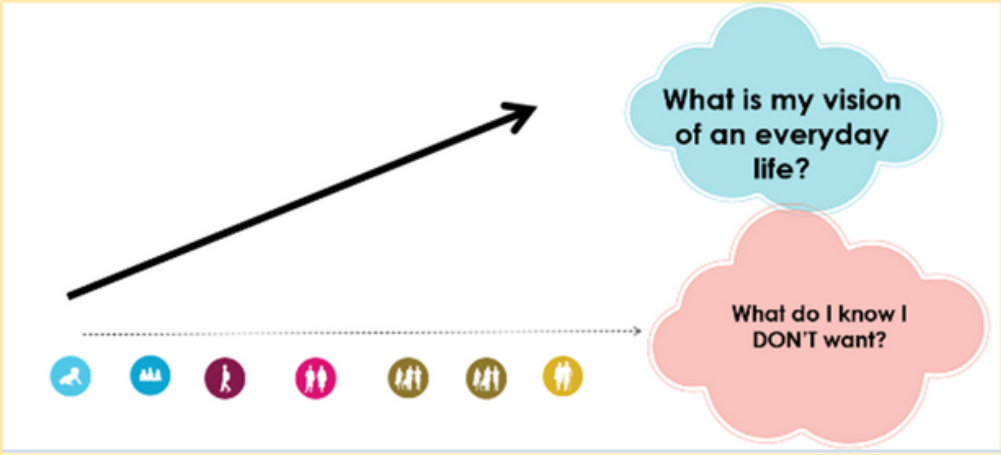
The LifeCourse Framework will help you plan the future by helping:

- Examine what you really want and expect out of life.
- Figure out what you need to know and do to get there.
- Identify what resources are available to you and how they can help you get to the future you want.

The following section is an introduction to some of the LifeCourse tools. These and many additional tools and guides are available at LifeCourseTools.org.

What happens to us early in our lives can have a significant impact on our quality of life and well-being in the future. The Trajectory Planning Tool will help you think about what a good life means to you and identify what you know you Do and DON'T want. Both are equally important for planning.

1) The Trajectory Planning Tool

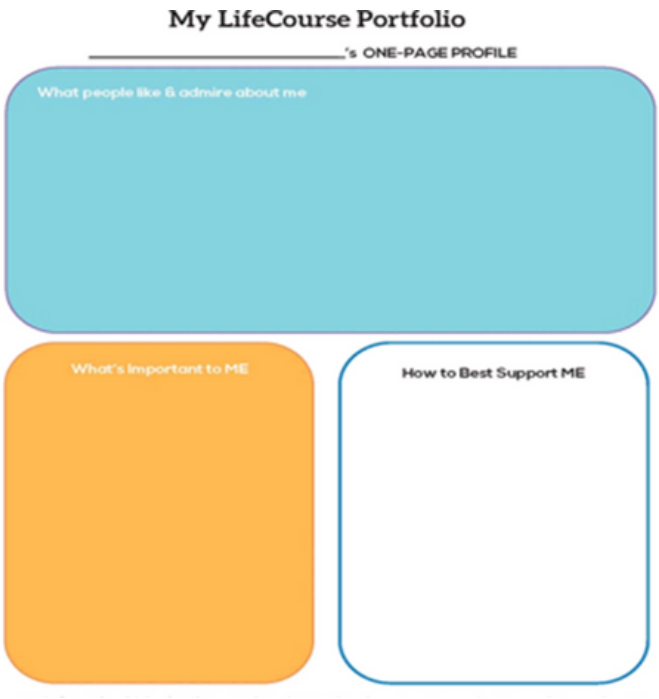


Trajectory across all ages: For additional guides for trajectory planning specific to school age, transition to adulthood, adulthood and aging go to [Quick Guides in the Life Experience Series.]

The One Page Profile

One Page Profiles

A One Page Profile captures all the important information about a person on a single sheet of paper under three simple headings: what people appreciate about me, what's important to me, and how best to support me. This information makes it easier for everyone to get to know the person by understanding what truly matters to them.



This information is basic to developing both a vision and a plan. For additional resources go to [One Page Profiles H. Sanderson Assoc.]

2) The Domains Vision Tool

Life Domains Vision Tool – How We All Experience Our Day to Day

People lead whole lives made up of connected domains that are important to a quality life.

- Daily life and employment
- Community living
- Health Lifestyles
- Social, spirituality and leisure interests
- Advocacy and being a citizen

These are interconnected. What happens in one area affects the other.

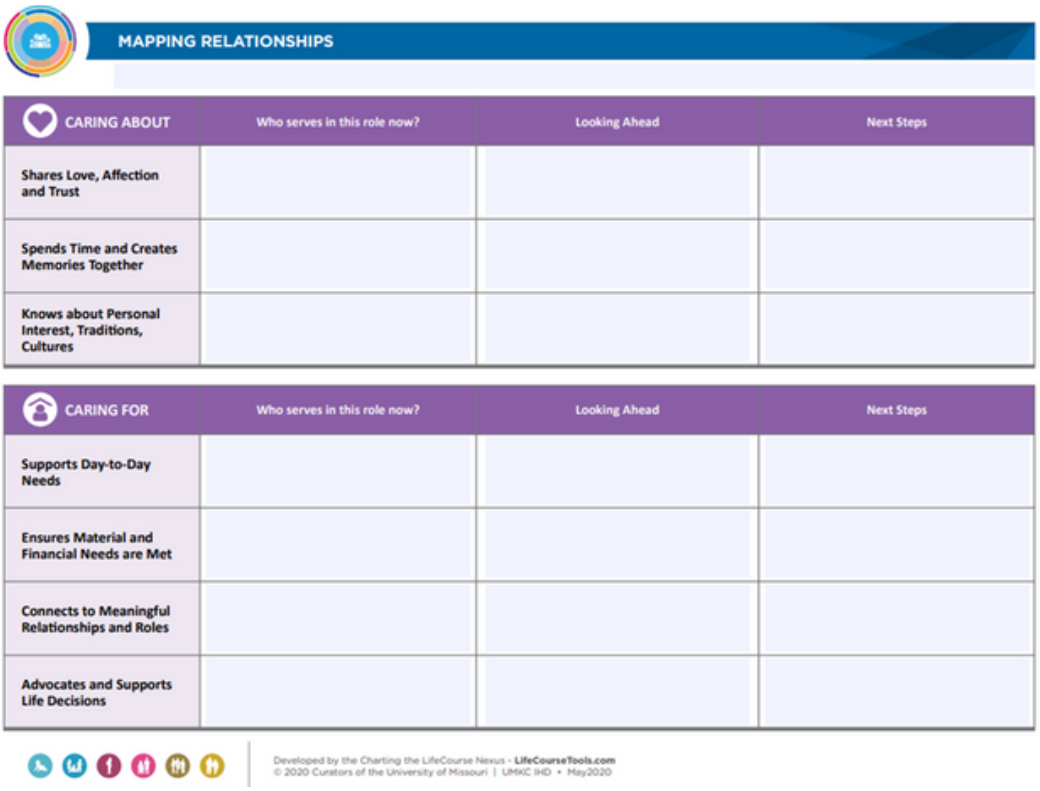
LIFE DOMAIN VISION TOOL | PERSON CENTERED

Name of Person Completing: _____ **Date:** _____

On Behalf of: _____

LIFE DOMAIN	DESCRIPTION	MY VISION FOR MY FUTURE	PRIORITY
	**Daily Life & Employment:** What do I think I will do or want to do during the day in my adult life? What kind of job or career would I like?		
	**Community Living:** Where would I like to live in my adult life? Will I live alone or with someone else?		
	**Social & Spirituality:** How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?		
	**Healthy Living:** How will I live a healthy lifestyle and manage health care supports in my adult life?		
	**Safety & Security:** How will I stay safe from financial, emotional, physical or sexual harm in my adult life?		
	**Advocacy & Engagement:** What kind of valued roles and responsibilities do I or will I have, and how can I have control of how my own live is lived?		
	**Supports for Family:** How do I want my family to still be involved and engaged in my adult life?		
	**Supports & Services:** What support will I need to live as independently as possible in my adult life, and where will my supports come from?		

3) Mapping Relationship Tool



MAPPING RELATIONSHIPS

CARING ABOUT	Who serves in this role now?	Looking Ahead	Next Steps
Shares Love, Affection and Trust			
Spends Time and Creates Memories Together			
Knows about Personal Interest, Traditions, Cultures			

CARING FOR	Who serves in this role now?	Looking Ahead	Next Steps
Supports Day-to-Day Needs			
Ensures Material and Financial Needs are Met			
Connects to Meaningful Relationships and Roles			
Advocates and Supports Life Decisions			

The Mapping Relationships tool will help you identify the different people and ways that they support you. Some of the people in your life might fulfill a lot of different roles while others might have only one significant role. It can help you have conversations about the future and who may fill those roles when others are no longer able.

4) Transition to Daily Life and Employment Tool

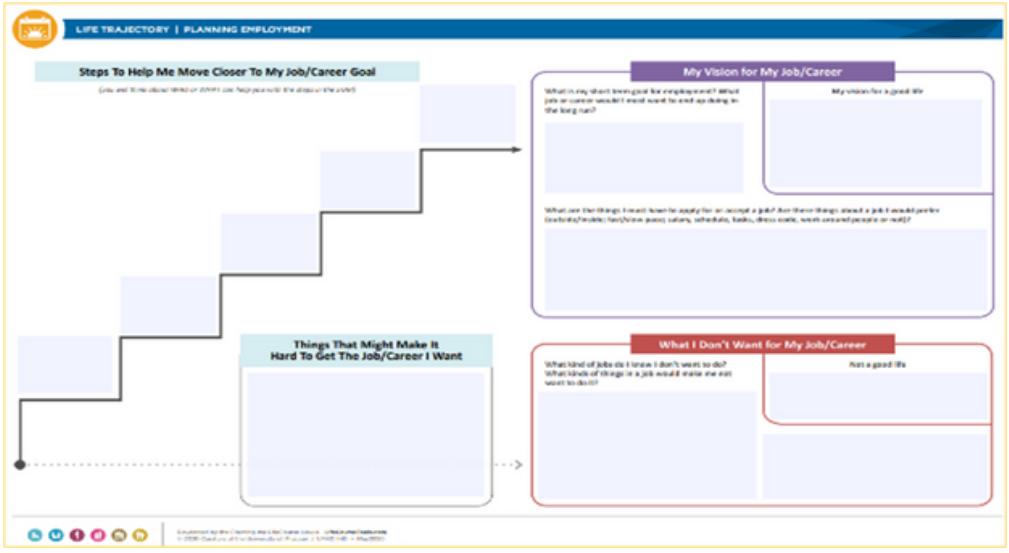
There are many transitions throughout our lives. The major transitions are from childhood to adolescence, from school to adult life, and retirement. But throughout our life we are transitioning to new homes, new jobs, new friends. We leave some things but are purposeful about keeping some things in our lives from the past.

Planning for transitions means starting early, deciding where you want to be next and then planning the next steps you need to take to get there. Your family, friends and your Supports Coordinator can help you plan that transition and help you get to your new destination. Planning to Adulthood guide is available at [Daily Life and Employment.]

Transition to Daily Life and Employment

Before you know it, school is ending, and adult life is beginning. This guide is designed to help you and your family think about questions to ask, things to do, and resources to lead you to a job, career, volunteering, college or continuing education, and ultimately, the life you want.

The LifeCourse tool below can help you think through all the steps of transition.



5) Integrated Supports Tool

It takes a variety of supports to achieve our good lives, not just the formal services system.

Integrated supports include:

- Our personal strengths, assets and interests
- Relationships that provide informal support
- Community resources we count on
- Technology
- Public and private services

6) Supported Decision Making Tool

The Supported Decision-Making Tool

To support individuals making their own decisions, this tool will help with identifying personal priorities and the supports needed for understanding options, communicating choices, and following through with decisions. It can be completed by the person in need of support, or with help from family, friends or professionals.

The tools for Supported Decision-Making can be found at The Supported Decision-Making portfolio

The Office of Developmental Programs has more information and resources about the LifeCourse Framework and tools on the www.myodp.org website.

We encourage you to register with the MYODP website so that you will receive information and regular notices related to services. You will also receive the Office of Developmental Programs monthly newsletter.

For more information on the PA Family Network, which provides training in LifeCourse, or to schedule family workshop sessions in your area, contact the PA Family Network at pafamilynetwork@visionforequality.org or call 717-839-5437 or 1-844-PA FAMILY (1-844-723-2645).

Who does what?

The Commonwealth's system to deliver services is both large and complex. This chapter describes how the service system is structured. It includes information about state and county offices and local agencies involved in delivering services to individuals and families. This information will help identify who is responsible for funding and delivering services and who monitors the quality of services.

Overview of the System Structure

To understand the process for obtaining services, it is helpful to understand the structure of the service system, beginning with the Office of Developmental Programs, so that you understand the roles and responsibilities of each office and agency. The diagram on the following page describes the layers of the service system including state and county government offices; private agencies, and the role of each in delivering services.

Chapter 2

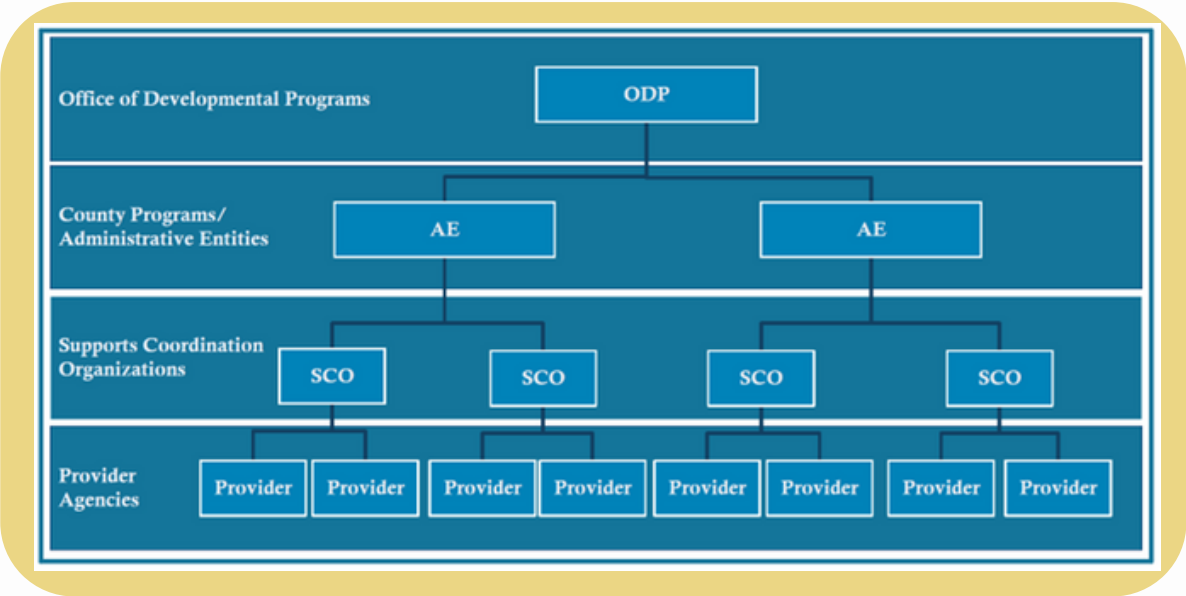
The Service System Structure

The following offices are part of DHS:

- Office of Child Development and Early Learning (OCDEL)
- Office of Children, Youth and Families (OCYF)
- Office of Developmental Programs (ODP)
- Office of Income Maintenance (OIM)
- Office of Long-Term Living (OLTL)
- Office of Medical Assistance Programs (OMAP)
- Office of Mental Health and Substance Abuse Services (OMHSAS)

For more information on each of these offices, please visit the DHS Website and Compass to apply for services.

NOTE: This chapter is not a "how to chapter." It describes the service system structure. Later chapters will explain components of the system and steps you must take to receive services.



What is the Role of ODP?

ODP has responsibility over the system of services for people with developmental disabilities. ODP develops policy, promulgates regulations, budgets, and provides funds for services, licenses provider agencies, and administers the federally approved waivers. ODP conducts many of its responsibilities through four Regional Offices including provider licensing inspections, investigations, outreach and training, and oversight and monitoring of the County/Administrative Entity (AE) agreement.

The Office of Developmental Programs

The Office of Developmental Programs (ODP) is responsible for setting policy and administrating services to individuals enrolled with ODP and to their families. The goal of the program is to support everyone to live where they want, pursue work, enjoy leisure and recreational activities, and develop friendships and relationships with others.

A wide range of services are designed to support individuals and their families in their home and community. Services include but are not limited to:

- Supports coordination – each person chooses a Supports Coordinator who helps plan and access services.
- Employment services – to assist in finding a job and developing the skills.
- Community participation services – to support participation in activities such as volunteering, shopping, visiting the library, joining community groups.
- Habilitation – assistance to the individual to carry out daily activities.
- Home and vehicle modifications to improve accessibility.
- Family and care giver training.
- Respite care.
- ODP includes the option for individuals and families to direct their own services (self-direction) with the authority to hire and manage people to support them. These services are listed and described in chapter 6.

County/Administrative Entities (AE)

The 48 County Administrative Entities (AEs), through an Operating Agreement with ODP, carry out administrative functions that enable individuals to enroll in services and ensure that services are available and meet quality standards. The County AE is your first stop in the services system.

The County/AE is responsible for:

- Determining eligibility and enrolling individuals in the ODP service system.
- Managing capacity in the Medicaid Waiver; and managing enrollment of individuals into services and ensuring that individuals have choice of providers.
- Reviewing individual service plans and authorizing services.
- Providing individuals with a notice of their Right to Fair Hearing and Appeal.
- Maintaining an adequate network of services providers; providing technical support; providing orientation and training for providers; conducting provider qualification reviews.
- Overseeing incident management including reviewing incident reports, conducting investigations, conducting trend analysis by provider, training providers, training individuals and families on their rights.
- Maintaining a Human Rights Committee.
- Conducting quality management activities including developing a plan, setting objectives in line with ODP priorities, collecting and analyzing data, and implementing improvement strategies.
- Maintaining the Independent Monitoring for Quality (IM4Q) function.
- Conducting provider risk screening.

- Central Region Office in Harrisburg
- Northeast Region Office in Scranton
- Western Region Office in Pittsburgh
- Southeast Region Office in Philadelphia

ODP is committed to involving individuals with disabilities and families in the development of policies, new programs and setting priorities. This collaboration resulted in the development of the Everyday Lives publication which guides the direction of ODP's programs.

The first step in accessing services is through the County/Administrative Entity (AE). To locate your County Office, call the ODP Customer Service Hotline at 1-888-565-9435 or click on Directory of Administrative Entities. For a step-by-step description of the process in accessing services see Appendix D of this book.

Support Coordination Organizations (SCO)

SCOs are responsible for developing an individual support plan (ISP), and then locating, coordinating, and monitoring needed services and supports. Sometimes these are also called "case management" services. By managing your plan and services, the SCO connects you and your family to both community resources and paid supports.

Supports Help Promote Your Independence.

After qualifying to enroll in the services system, you and your family choose a Supports Coordination Organization to work with you. The Supports Coordinator (SC) works with you, your family, and your advocates, using the LifeCourse Tools whenever possible, to identify the supports necessary to live the best life possible. Your SC will coordinate your assessments, help, and guide you during your individual support planning process, work with you to identify your outcomes and goals, assist in finding providers, and monitor your services. You should be able to discuss your life and vision for the future freely with your SC. Chapter 7 discusses the ISP in depth.

What qualifies a SCO?

All Supports Coordination Organizations must be qualified by ODP to provide supports coordination services. The qualification process ensures that the SCO can document the following:

- Functions as a conflict free entity – the agency does not have a fiduciary relationship with any organization providing direct services.
- Verification that all employees have obtained required educational, work experience, and proper clearances.
- Supervisors oversee no more than 7 support coordinators.
- Written procedures regarding crisis response with 24-hour access to personnel.

There are over 65 Supports Coordination Agencies around the state. Not all of them provide services statewide. Your County/AE will give you information about the agencies that serve your area. The list of agencies can be reviewed at Supports Coordination Services.

Self-Advocacy

Self-Advocates United as One (SAU1) is a group of people who envision a world where people with developmental disabilities and their families are united to share knowledge, empower others, and use their voices to transform their communities and people's lives. The Mission of SAU1 is to support the self-advocacy of people with disabilities for positive impact in our communities and in people's lives. The SAU1 Vision is a world where people with developmental disabilities and their families are united to share knowledge, empower others, and use their voices to transform their communities and people's lives.

Provider Agencies

Provider agencies are the front line of the service delivery system. Providers deliver the services authorized by the AE in the Individual Support Plan (ISP). How the services are delivered is outlined in the ISP. Much like the AEs and SCOs, provider agencies also sign an agreement with ODP which includes conditions providers must meet to provide waiver services.

Family Advocacy

Partnership with PA Family Network is a family directed program that provides information, connections and support through Family Advisors; individual and family mentoring; informational materials and workshops on the LifeCourse and how to make the LifeCourse tools work for your family.

What Kinds of Providers are There?

There are over 1000 providers that vary in size and specialty. Some are large and provide services in many counties, while others may support fewer people in limited areas. Some provider agencies provide a wide array of services, others specialize in only one or two services. Your SC can help you find providers in your area for the services you need. Later in this guide you will find a chapter to advise on how to choose a provider.

A full list of providers is available at Provider Directory. In addition, ODP also has an online list of Provider Profiles to assist you in making an informed decision about a Provider.

What Qualifies a Provider?

Providers must be registered with ODP and must complete a provider qualification application. For every service provided through the waiver, there are general qualifications as well as requirements specific to each of the services. New providers must go through a provider orientation and training prior to being qualified. Providers must meet all requirements established through regulation and policy.

How are Services Monitored for Quality?

There are multiple approaches to how services are monitored by ODP, AEs, and SCOs including the following:

- Supports Coordinators are required to monitor services at regular intervals by visiting individuals in a variety of settings while services are being delivered and speaking with you in person about your experiences.
- Licensing inspections are conducted annually of facilities such as group homes and day programs and are governed by regulation.
- County/AEs also conduct provider oversight through incident management and through the requalification process.
- Regional Quality Oversight Groups review region-specific findings.
- Local Independent Monitoring for Quality (IM4Q) teams that are not involved in service provision conduct interviews with a sample of individuals in each county. Findings of these teams are acted on by County/AEs and ODP.
- Individuals and families can report issues to their support coordinator, the County/AE or directly to ODP through the customer service hot line at 1-888-565-9435.

Can I Choose My Provider?

A requirement in the Medicaid Program for HCBS is that individuals be given the right to choose any willing and qualified provider. You may interview providers, review information available on the internet, and discuss your options with anyone you choose prior to making a choice of provider. You also have the right to change providers at any time. Chapter 8 in this guide will help you to choose a provider.

Chapter 3

Programs, Services, and Eligibility

I. State Funded Services Pennsylvania's MH/ID ACT of 1966

The Mental Health and Intellectual Disability Act of 1966 established intellectual disability as the eligibility standard for services and provided funds for services for the first time. Funds (referred to as base funds) are appropriated by the legislature and allocated by DHS to the County/AE programs to provide services. Counties are required to pay a portion of some of the cost of services. The funding appropriated by the legislature is flexible but limited. It may support people who are not eligible for Federal Medicaid programs and those who are on the waiting list to receive waiver services. These services called base funded services are limited.

The service system for people with disabilities has evolved over many decades and can seem complicated. It began as a state effort in the 1960s and in the 1970s the federal government began to fund services. Over the decades, programs have been added like additions on a house. The system is therefore a collection of programs including base services, state plan services, waiver services, institutional services, etc. The types of services provided and even eligibility to receive services in these programs can differ. This document provides a description of the different programs and types of services offered, and who is eligible to receive services.

II. Federally Funded Programs under Federal Medicaid Program

Most services provided by ODP are funded through federal programs which are described in this section. The federal Medicaid program provides funding for approximately 50% of the cost of services; the Pennsylvania legislature must appropriate funds for the other 50%. Targeted Supports Management (TSM) provides supports coordination for individuals of any age with intellectual disabilities and/or autism; children birth through 8 who have a diagnosis of developmental disability with a high probability of resulting in an intellectual disability or autism; and for children birth through 21 with medically complex conditions. TSM supports coordination is provided through private supports coordination agencies.

What Is a Home and Community Based Services (HCBS) Waiver? Waivers provide most of the funding for the supports and services for individuals with intellectual disabilities, developmental disabilities, medically complex conditions, and autism. The waiver programs help people to live in their homes and communities, rather than in institutional settings, while still receiving the services and supports they would otherwise receive if they did live in a facility.

Home and Community-Based Waivers, which must be approved by the federal government, allow states the authority to:

• Specify who is eligible for the waiver program.
• Define the number of people who may receive services.
• Determine the types of services that may be provided, the provider qualifications and any service limitations.

WHAT DOES WAIVER MEAN?

In 1981, Congress amended the Social Security Act 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. To do this, Congress gave states flexibility to "waive" certain Federal requirements so that they could create these HCBS programs. This is the origin of the term "waiver."

Waivers are approved by CMS for a period of 5 years after which the state must submit a renewal application that requires the state issue a draft application for public comment prior to submission.

Choosing between institutional care or HCBS: Because HCBS Waiver services are an alternative to institutional services (ICF/ID), individuals must be determined to meet an institutional "level of care" and must be offered the choice between an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IDs) or the HCBS program. Those wishing to receive HCBS services must affirmatively choose them in writing.

Completing the eligibility process and the form to choose the waiver does not create a risk for an individual being placed in an ICF/ID. This is simply a process that is required that must be completed to receive waiver services.

Federal Medicaid Programs in More Detail

Below is a description of each of the ODP Programs funded under Medicaid. Links to each of the approved programs including the most current and complete description of eligibility and the services can be found in Chapter 5 and at ODP Everyday Lives Waiver Descriptions.

1. Targeted Supports Management (TSM) – Supports Coordination Services
Supports coordination services include developing an individual support plan with the individual and a team of individuals chosen by the person, locating, coordinating, and monitoring to assure that the individual's needs are met and that their health and safety is assured. All individuals are eligible for supports coordination including individuals with ID, autism and children Birth to age 8 with a developmental disability with the likelihood of ID or autism at a later age and children Birth through age 21 who have medically complex care needs.

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2. Person/Family Directed Support Waiver (P/FDS) The Person/Family Directed Support Waiver supports individuals of any age to live more independently in their homes and communities by offering a variety of services that promote community living, employment, communication, self-direction, choice, and control.

Individuals are eligible at birth with no age limit to participate, there is an individual cost limit of $41,000 per person per fiscal year. If there is a need, the limit can be exceeded by $15,000 for Supported Employment or Advanced Supported Employment services. The cost of supports broker services and supports coordination is excluded from the limit. At the time of this publication, this waiver supported over 13,400 people. Over 57,000 people receive support coordination services either funded by county base funds, the Medicaid Targeted State Plan Service, and the Medicaid Waivers.

3. Community Living Waiver (CLW)

The Community Living Waiver supports individuals of any age to live more independently in their homes and communities by offering a variety of services that promote community living, employment, communication, self-direction, choice, and control. There are no age limits for the waiver. There is an individual cost limit of $85,000 per person per fiscal year. The cost of supports coordination is excluded from the annual limit. At the time of this publication, this waiver supported over 4,800 people.

4. Consolidated Waiver

The Consolidated Waiver supports individuals of any age and the greatest needs to live more independently in their homes and communities by offering a variety of services that promote community living, employment, communication, self-direction, choice, and control. There are no age limits for the waiver. There is no individual cost limit. Services are determined by assessed need. At the time of this publication, this waiver supported over 18,500 people.

5. Adult Autism Waiver

The Adult Autism Waiver (AAW) supports adults with an autism spectrum disorder (ASD) to live more independently in their homes and community by offering a variety of services that promote community living, employment, communication, choice, and control. Individuals must be age 21 or older. There is no individual cost limit. At the time of this publication, this waiver supported 714 people.

6. Adult Community Autism Program (ACAP)

ACAP, is not a waiver. It is a managed care program which supports adults with autism spectrum disorder (ASD) who are age 21 and older. It is a fully integrated, comprehensive system of care that includes physical health, behavioral health, social, recreational, transportation, employment, therapeutic, educational, crisis, in-home support, and independent living services. ACAP is offered in Dauphin, Lancaster, Cumberland, and Chester counties and is limited to 200 individuals.

7. Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID)

ICF/ID is a residential service available for individuals in need of, and receiving, active treatment services. Active treatment refers to aggressive, consistent implementation of a program of specialized training, treatment, and health services. All services are based on an evaluation and individualized program plan (IPP) developed by an interdisciplinary team. Facilities must meet federal building codes and program certification requirements.

ICF/ID facilities can be as small as four individuals living in standard housing in the community and as large as hundreds of individuals. PA state institutions are ICF/ID facilities. There are also private agencies that operate both small and large facilities.

Over 2,200 individuals receive services in ICF/ID programs.

Program Eligibility

Eligibility refers to the conditions an individual must meet to receive services. Eligibility is a complicated topic because as the service system developed over decades and as programs were added, eligibility was established for each new program. So, there are some differences across programs. Since Medicaid waivers and state plan services are amended frequently, the surest way to get accurate information about the eligibility standards is by linking directly to the program on the DHS website. [ODP Everyday Lives Waiver Descriptions.]

Eligibility Definitions for ODP Programs

The onset of disability for all programs must have been prior to 22nd birthday and be recommended based on a medical evaluation. Individuals over age 22 with no prior testing should contact the County/AE for more information.

- **Intellectual disability eligibility** is defined as having:
  - A full-scale IQ assessment that is at least two standard deviations below the mean – approximately 70 or below and

- Significant limitation in meeting the standards of **maturation, learning, personal independence, or social responsibility of his or her age and cultural group; and b.** Substantial adaptive skill deficits in *three or more* areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction and/or capacity for independent living based on a standardized adaptive functioning test. Note: for base services, only two areas of deficit are necessary.

- **Autism** eligibility is defined as having:

    - A diagnosis of autism spectrum disorder. Individuals may also both an ID diagnosis, but autism must be present for the autism waiver and ACAP.

    - Significant limitation in meeting the standards of **maturation, learning, personal independence, or social responsibility of his or her age and cultural group; and b. Substantial adaptive skill deficits in three or more areas of major life activity**: self-care, receptive and expressive language, learning, mobility, self-direction and/or capacity for independent living based on a standardized adaptive functioning test.

- **Developmental Disability** eligibility is defined as having:
    - A condition of substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in an intellectual disability or autism and manifested prior to the age of 9 and the disability is likely to continue indefinitely, and Individual is 8 years of age or younger.

    - Substantial adaptive skills deficits in three or more areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction and/or capacity for independent living based on a standardized adaptive functioning; and

- **Medical Complexity for Children Birth to 21** eligibility is defined as having:
    - One or more chronic health conditions that meet both of the following:
        (a) cumulatively affect three or more organ systems; and
        (b) requires medically necessary skilled nursing intervention to execute medical regimens for technology used for respiration, nutrition, medication administration or other bodily functions.

- **Financial eligibility:**
    - For Medicaid Programs, the person's income can be no greater than 300% of the SSI Federal Benefit.
    - For ACAP the person's income can be no greater than 100% of the SSI Federal Benefit.
    - For county MH/ID based funded services there is no asset or income limit.

ODP Program Chart – Eligibility, Age, and Annual Caps

Program	Eligibility	Locations	Annual Cap	Age
Base Services	Intellectual Disability Substantial adaptive skills deficits in two or more area	Offered by County/AEs	None	Birth +
Targeted Case Management	Intellectual Disability, Autism, or Developmental, Children Medically Complex Substantial adaptive skills deficits in three or more area	Statewide	None	Birth +
Consolidated Waiver	Intellectual Disability, or Autism, or Developmental Disability (B -8) Substantial adaptive skills deficits in three or more area	Statewide	None	Birth +
Community Living Waiver	Intellectual Disability, or Autism, or Developmental Disability (B-8) Substantial adaptive skills deficits in three or more area	Statewide	$85,000	Birth +
Person Family Directed Support Waiver	Intellectual Disability, or Autism, or Developmental Disability (B-8) Substantial adaptive skills deficits in three or more area	Statewide	$42,000	Birth +
Adult Autism Waiver	Autism Spectrum Disorder (ASD) Substantial adaptive skills deficits in three or more area	Statewide	None	21 +
Adult Community Autism Program (ACAP)	Autism Spectrum Disorder (ASD) Substantial adaptive skills deficits in three or more area	Dauphin, Cumberland, Chester Lancaster counties	None	21 +
ICF/ID	Intellectual Disability Substantial adaptive skills deficits in three or more area **requires active treatment**	Private Agencies	None	Birth +

Types of services

Services are designed to support people where they want to live, with whom they want to live, enabling them to live the everyday life they choose. A good everyday life includes being part of a family and community, feeling valued, having opportunities to learn and grow, and to contribute to the community. There is a purpose for services and that purpose is to enable each person to have a good everyday life.

The list of services below are available in most but not all programs. The chart following the services identifies the waiver programs that provide the services. For a full description of the services, the purpose of the service, how often and for the length of time it can be provided, as well as the qualifications providers must meet, see Appendix C. You may also review each program at ODP Everyday Lives Waiver Descriptions.

Waiver Services At – A – Glance

- **Assistive Technology** – equipment or product used to increase, maintain, or improve an individual's functioning.
- **Benefits Counseling** assists working individuals in managing their resources.
- **Behavioral Support** includes a comprehensive assessment and development of strategies to support the individual, the provision of interventions and training to the individual, staff, caregivers.
- **Communication Specialist** supports individuals with nontraditional communication needs by determining the need, educating the individual and his or her caregivers on the individual's communication needs and the best way to meet them.
- **Community Participation Support** provides support for community inclusion and building interest in and developing skills. The expected result is the individual developing a range of valued social roles & relationships; building natural supports; increasing potential for employment; and experiencing meaningful community participation & inclusion.
- **Companion Services** are provided to individuals aged 18 and older who live in private homes for the limited purposes of providing supervision or assistance to ensure the individual's health, safety and welfare and to perform activities of daily living.

- **Consultative Nutritional Services** are provided by a licensed dietician to assist unpaid caregivers and/or paid support staff in carrying out a treatment/service plan, and that are not covered by the Medicaid State Plan.
- **Education Support** may cover the cost of tuition for adult education classes offered by a college, community college, technical school, or university, on campus peer support, adult education or tutoring program for reading or math instruction. The individual must have an outcome related to employment or a skill attainment goal documented in the service plan.
- **Employment** – a range of services to assist in finding employment, learning job skills, and maintaining employment.
- **Family/Caregiver Training and Support** – training and counseling services for unpaid family members or caregivers who provide support to an individual. This service is intended to develop, strengthen, and maintain healthy, stable relationships among the individual and all members of the individual's informal network.
- **Family Medical Support Assistance** – This service assists with management of services in the participant's private home related to the medical needs of participants with a Needs Group 3 or 4 who use medically necessary technology and require nursing.
- **Home Accessibility Adaptations** – service that includes making modifications to the private home of the individual including homes owned or leased by relatives or friends.
- **Homemaker/Chore Services** – Homemaker services enable the individual or the family member with whom they reside to maintain the home. Chore services are those needed to maintain the home in a clean, sanitary, and safe condition. These may only be provided when neither the individual, nor anyone else in the household, can perform the function.
- **Housing Transition and Tenancy Sustaining Services** are pre-tenancy and housing sustaining supports to assist individuals in being successful tenants in private homes owned, rented, or leased by the individuals.
- **In-Home and Community Support** – provided in home and in community settings to assist individuals in acquiring, maintaining, and improving skills necessary to live in the community, to live more independently, and to participate meaningfully in community life. Included are activities of daily living, developing practices to promote good health, manage medical care, develop relationships with members of the broader community, exercise rights as a citizen, make decision.

- **Life Sharing** – supports for individuals living in a private home of a host family. The host family can be the individual's relative(s), legal guardian, or persons who are unrelated to the individual. The responsibilities of care givers are based on an individual support plan. A qualified provider agency provides training, support, and supervision of the arrangement.

- **Music, Art, and Equine Assisted Therapy** – services provided to individuals who could benefit from the provision of therapy to maintain, improve or prevent regression of the individual's condition and assist in the acquisition, retention or improvement of skills necessary to live and work in the community.

- **Participant-Directed Goods and Services** – services, equipment or supplies not otherwise provided through other services offered in the ACAP and PFDS, CLW, and AAW waivers, the Medicaid State Plan, or a responsible third-party. Participant-Directed Goods and Services must address an identified need in the participant's service plan and must achieve specified objectives in the ISP.

- **Residential Habilitation** – community homes (group homes) that provide supervision and support to enable individuals to live in and engage in community life. Homes can be for no more than four individuals and located in the community to maximize community participation. Homes are licensed. Homes can be unlicensed if they serve three or few individuals over the age of 18 who needs 30 hours or less of support per week.

- **Respite** – services that are provided to supervise and support individuals living in private homes on a short-term basis for planned or emergency situations, giving the person(s) normally providing care a period of relief that may be scheduled or due to an emergency.

- **Shift Nursing** – health counseling, care supportive to or restorative of life and well-being, and executing medical regimens as prescribed by a licensed physician or dentist. Shift Nursing services can only be provided to adult individuals.

- **Specialized Supplies** – Incontinence supplies that are medically necessary and are not a covered service through the MA State Plan, Medicare, or private insurance; diapers, incontinence pads, cleansing wipes, under pads, vinyl or latex gloves, and personal protective equipment. Specialized Supplies can only be provided to adult waiver individuals aged 21 and older.

- **Supported Living** – These are direct and indirect services provided to individuals who live in a private home that is owned, leased, or rented by the individual. Individuals will be supported to live in their own home in the community and to acquire, maintain or improve skills necessary to live more independently and be more productive and participatory in community life.

- **Supports Broker** – a service available to individuals who elect to self-direct their own services. Designed to assist individuals with employer-related functions to be successful in self-directing some or all the services.
- **Supports Coordination** – a service that involves the primary functions of locating, coordinating, and monitoring needed services and supports for individuals. Everyone enrolled in the waiver receives support coordination services.
- **Therapy – Physical; Speech/Language; Occupational; Orientation, Mobility and Vision** – direct services provided to assist individuals in the acquisition, retention, or improvement of skills necessary to live and work in the community. The services include training to caregivers.
- **Transportation** – a service that enables individuals to access services and activities specified in their approved service plan. Transportation may be delivered by providers, family members or other licensed drivers. Payment ranges from reimbursement per mile, per trip, or to a public transportation vendor.
- **Vehicle Accessibility Adaptations** – adaptations consist of certain modifications to the vehicle that the individual uses as his or her primary means of transportation to meet his or her needs.

ODP Service Chart by Waiver

Service	Consolidated Waiver	Community Living Waiver	PFDS Waiver	Autism Waiver and ACAP
Benefits Counseling	x	x	x	x
Assistive Technology	x	x	x	x
Behavioral Support	x	x	x	x
Communication Specialist	x	x	x	x
Community Participation Support	x	x	x	x
Companion Services	x	x	x	x
Consultative Nutritional Services	x	x	x	x

Education Support	x	x	x	x
Supported Employment	x	x	X	x
Advanced Supported Employment	x	x	x	x
Family/Caregiver Training and Support	x	x	x	x
Home Accessibility Adaptations	x	x	x	x
Homemaker/Chore Services	x	x		x
Housing Transition and Tenancy Sustaining Services	x	x	x	
In-Home and Community Support	x	x	x	
Life Sharing	x	x		x
Music, Art, and Equine Assisted Therapy	x	x	x	x
Participant Goods and Services	x	x	x	x
Residential Habilitation	X licensed and unlicensed	X unlicensed		X unlicensed
Respite	x	x	x	x
Shift Nursing	x	x	x	x
Specialized Supplies	x	x	x	x
Supported Living	x	x		x
Supports Broker	x	x	x	
Supports Coordination	x	x	x	x
Therapy - Physical; Speech/Language; Occupational; Orientation, Mobility and Vision	x	X	x	x
Transportation	x	x	x	x
Vehicle Accessibility Adaptations	x	x	x	x

For more information, please reference Individual Support Plan (ISP) Manual for Individuals Receiving Targeted Support Management, Base Funded Services, P/FDS Waiver Services, Community Living Waiver, or Consolidated

Where Do I Begin?

The path to accessing all services begins in the county where you live. This section provides information on where and how to make application to receive services. For a detailed step by step description of the process in accessing services see Appendix D of this book.

Chapter 4

Applying for Services

Registering with the County/AE for Services

An important step to applying for services and supports is registering with the local County/Administrative Entity (AE). To locate your County/AE Office, call the ODP Customer Service Hotline at 1-888-565-9435 or click on Directory of Administrative Entities.

Once contact is made with the County/AE Office, a representative for the office will set up an intake appointment. Individuals will be asked to provide information and documents to the appointment that include:

- Social Security Card (if you have one)
- Birth Certificate
- 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 or Psychological evaluations (if available)
- Legal guardian or custodial papers (if applicable)

The County/AE representative will ask individuals/families to sign a Release of Information form. This form authorizes the County/AE to obtain medical records and other supporting documents. County/AE programs can assist individuals and families to complete needed assessment and psychological evaluations. School records may also include the required information. Once the County/AE receives all required documentation, they will determine whether an individual is eligible for services. The County/AE must provide written notice of eligibility to all applicants within in 14 days. If notification is not received in that time, call your County/AE.

Choosing a Supports Coordinator

If you are determined eligible, (guidance if you are ineligible is below) the County/AE will provide you with information about supports coordination agencies so that you can choose the organization that will help you develop a plan and access services. Your Supports Coordinator will be your guide to the services system.

Applying for Medicaid at the County Assistance Office

To be eligible for waiver funded services, an individual must first be enrolled in the Medicaid program. Individuals can make application at the local County Assistance Office, which is different than the County/AE. The County Assistance Office is operated by the Department of Human Services and processes applications to enroll in Medicaid as well as several other public programs such as

Temporary Assistance for Needy Families (TANF) (income support), **Supplemental Nutrition Assistance Program (SNAP)**, and **Low-Income Home Energy Assistance Program (LIHEAP)** (heating assistance). You may be eligible for other benefit programs as well.

To find your local office, follow this link – county assistance office (CAO)

Applying for Services

The Supports Coordinator assists in accessing services and supports funded with the ODP program as well as those available through other community resources. Receiving services through ODP programs will depend on whether you meet the eligibility requirements for the services.

Applying for County Administered Base Fund Services: For services funded directly by the county, the Supports Coordinator will make a request directly to the county. As explained earlier, the county administered base funded programs are small, but they may meet an immediate or a onetime need.

Applying for Medicaid Waiver Services: The Supports Coordinator will also provide an application for the Medicaid Waivers to determine service eligibility. Once the paperwork is completed, a letter will be sent explaining the likelihood of meeting the eligibility for a waiver.

If funding is available, enrollment, and services may begin. However, being determined eligible does not mean that services can begin. Each waiver has a limited number of people that can be served. There are waiting lists to enroll in waiver services. If services are not available immediately, the Supports Coordinator will ask you to complete a Priority of Urgency of Need for Services (commonly referred to as PUNS) form with your Supports Coordinator to identify what services you need and when you need them. You will then be placed on the waiting list. When funding is available, you will go through the formal eligibility determination for the Waiver.

Choice of HCBS: Anyone who is eligible for Intellectual Disability and/or Autism services and is enrolled in Medical Assistance must be provided with the opportunity to choose their preference in service delivery. You can choose between ICF/ID and HCBS. Every accommodation available to the individual (for example, communication devices, interpreters, or physical assistance as needed) must be used to provide the opportunity to the individual to communicate a preference in services. Your choice in services (ICF/ID or HCBS) is determined by signing a Home and Community-Based or ICF Application and Service Delivery Preference form (DP 457) which indicates your choice of HCBS or ICF Services. This is presented to the individual/family by the AE or SCO.

What should I do if I am told I am not eligible for any services?

All applicants must be notified in writing if they are determined ineligible for any services. This includes eligibility for Medical Assistance, for state and county funded programs, for ICF/ID services and waiver services. Eligibility can only be determined after a thorough review of the application and all required documentation. Written notice of a denial that also informs the individual of their right to appeal the decision must be provided.

Refer to Chapter 9 of this publication to learn more about rights and application

A step-by-step guide to this process is contained in the Appendix D: Step-by-step Waiver Application

Waiting Lists

The waiting list is comprised of individuals who are eligible to receive services and supports through the Office of Developmental Programs (ODP) waivers, who due to insufficient resources, are waiting for services until funding becomes available. ODP allocates ID/A waiver capacity to County/AEs annually. The waiver capacity commitment is the maximum number of people that can be at any point in time 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 one of three categories of need – emergency, critical or planning – depending on their specific situation. The person with the most urgent need will have priority for enrollment.

Prioritizing individuals for services

The Prioritization of Urgency of Need for Services (PUNS) process is designed to identify who is waiting for services, what they need and the urgency of their need. The categories to determine urgency are:

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

This information is used by the State in planning for future service's needs and informs the budgeting process. Your Supports Coordinator will assist you in completing the PUNS form.

The PUNS form includes the services that are currently being received as well as the services needed now or will need in the future. Individuals receiving services through the capped waivers who have additional needs related to their health and safety should complete a PUNS form. Waivers that do not have a cap must meet all health and safety needs and therefore a PUNS is not necessary.

If you have questions about the PUNS form or process, you can call your Regional Office or the ODP Customer Service Line at 1-888-565-9435.

PUNS COMPLETION

The PUNS should be completed during a face-to-face meeting with the 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. Honesty in describing needs can make a difference in which category the individual is assigned and how soon an individual might be able to receive services or supports.

After the individual or family signs the form at the meeting, a copy the PUNS form will be given to the individual and family in approximately three weeks, along with a letter describing the individuals rights and what to do if there is a disagreement with the information on the PUNS form. This is the information that is entered into the system by the Supports Coordinator.

PUNS forms should be updated yearly or whenever there is a life-changing situation such as a graduation or serious illness of a caregiver. All updates require a signature.
It is important for the individual to know which PUNS category they are in. Remember, people in the emergency category are the top priority when funding becomes available.

ODP retains waiver capacity to address unanticipated emergencies such imminent risk institutionalization within 24 hours, substantial self-harm or substantial harm to others and this imminent risk is precipitated by at least one of the following situations: illness or death of a caretaker; sudden loss of the individual's home (for example, due to fire or natural disaster); of the care of a relative or caregiver, without advance warning or planning.

What Can I Do if I Am on The Waiting List?

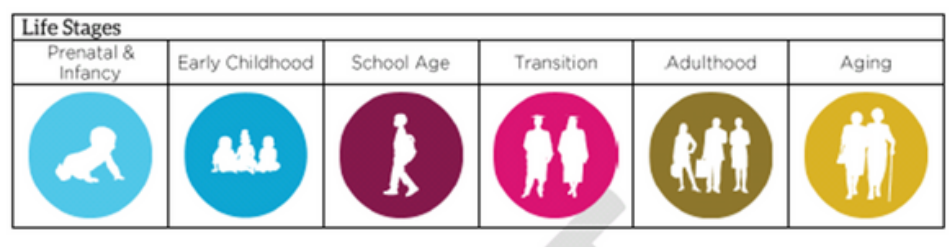
Waiting for services can be difficult but it is important to remember that ODP is not the only resource available. Everyone who applies to be enrolled in the ODP program will be assigned a Supports Coordinator. A Supports Coordinator can offer information about other resources or programs that may be able to access for services, assist in developing an Individual Support Plan (ISP) to identify goals and outcomes, and help think about what other supports may be available in the community.
The Charting the LifeCourse Tools may also be helpful in planning for an everyday life and figuring out how to find support from other sources in the community, The Integrated Supports Star may be especially helpful. (Chapter 1)

Other Community Resources

People with disabilities who need supports to live in their community can access a variety of public and private programs. Some are related to age, some to income level, others by the type of need that a person has. A description and associated links of some of those public programs are listed below. Private programs such as United Way, the Rotary, faith-based organizations, YMCA/YWCA programs, municipal recreation programs, or adult education programs can assist to meet individual needs and can also provide opportunities for staying connected to the broader community. Building these networks expands that range of supports that can be relied upon.

- **Graduation**
- **Developing/maintaining natural supports – family, friends, neighbors, community members**
- **Connecting with PA Family Network (PAFN)**

Supports for Children



Early Intervention (EI) Services provides support and services to families with children birth to age five, who have developmental delays and disabilities. Early Intervention support and services are designed to meet the developmental needs of children with a disability as well as the needs of the family related to enhancing the child's development in one or more of the following areas:

- **Physical development, including vision and hearing**
- **Cognitive development**
- **Communication development**
- **Social or emotional development**
- **Adaptive development**

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, developmental, and specialty services.

- **Early: Assessing and identifying problems early**
- **Periodic: Checking children's health at periodic, age-appropriate intervals**
- **Screening: Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems**
- **Diagnosis: Performing diagnostic tests to follow up when a risk is identified, and**
- **Treatment: Control, correct or reduce health problems found**

Children's Health Insurance Program (CHIP) – is Pennsylvania's program to provide health insurance to uninsured children and teens who are not eligible for or enrolled in Medical Assistance.

Health Care Services

Income Assistance for Individuals and Households

Supplemental Security Income (SSI) – When an individual reaches the age of 18 they can apply as an adult and not have their parents' income included in the application; the individual cannot have countable assets of more than $2,000 to be eligible. Contact the local Social Security office.

Temporary Assistance for Needy Families (TANF) – Case Assistance is available to individuals and families with low income and limited resources through TANF or General Assistance.

Physical Health Care is provided through the Medical Assistance program that covers physical health services, both inpatient and outpatient.

Behavioral Health Services are provided through the Medical Assistance program and include behavioral health and drug and alcohol treatment services.

Community Health Choices provides physical health services for dually eligible individuals (individuals receiving both medicare and medicaid), and individauals with physial disabilities.

Heating Assistance/LIHEAP helps families living on low incomes pay their heating bills in the form of a cash grant.

SNAP (Supplemental Nutrition Assistance Program) provides financial assistance to increase purchasing power at grocery stores and supermarkets with an Electronic Benefits Transfer (EBT) ACCESS Card.

PA Able offers individuals with qualified disabilities and their families and friends, a tax-free way to save for disability-related expenses, while maintaining government benefits. An Able account allows individuals to build assets to cover future expenses without jeopardizing Medicaid and SSI benefits.

Office of Vocational Rehabilitation (OVR) provides vocational rehabilitation services to help persons with disabilities prepare for, obtain, or maintain employment. Services are available for students with disabilities transitioning to adulthood.

Employment Support

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. Contact your local county assistance office (CAO) to find out more about how MAWD works.

Information, Training and Guidance

ASERT is a resource for children and adults with autism spectrum disorder (ASD) that provides documents, forms, recordings of public webinars, and recordings of live training sessions, and access to support groups.

Legal Services
A group of organizations is available to assist Pennsylvanians who cannot afford an attorney with legal matters. Legal Help (pa.gov).

MyODP is a resource for children and adults receiving services through the Office of Developmental Programs that provide information on services, official notices, training, and provider agencies.

The Health Care Quality Units (HCQUs) provide information and training to providers, County/AE programs, individuals and families on how to best meet the physical and behavioral health care need of people in the service systems.

AiD in PA – AID in PA is a resource collection for Pennsylvanians in the autism and intellectual disability communities. A joint effort between Autism Services, Education, Resources, and Training (ASERT) and the statewide Health Care Quality Units (HCQUs), this site is designed to connect individuals with disabilities, families, professionals, and community members with resources that can best serve them in different situations.

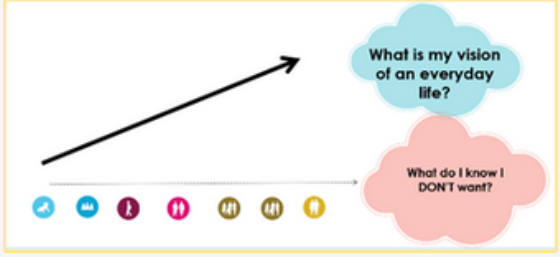
Self-Advocates United as 1 (SAU1) – Self Advocates United as 1 is a group of people who envision a world where people with developmental disabilities and their families are united to share knowledge, empower others, and use their voices to transform their communities and people's lives.

PA Family Network (PAFN) – Vision For Equality – The PA Family Network was created under the leadership of Vision for Equality and is supported by the Office of Developmental Programs (ODP) as part of Pennsylvania's Community of Practice: Supporting Families Throughout the Lifespan. The mission of the Pennsylvania Office of Developmental Programs (ODP) is to support Pennsylvanians with developmental disabilities to achieve greater independence, choice and opportunity in their lives.

Services and Supports – Supporting a Vision of an Everyday Life

Services available through the Office of Developmental Programs have several purposes:

- Support personal growth and development.
- Support people's ability to engage fully in community life.
- Support the life you want.



Services and supports can assist family, friends and employers with achieving a vision of an everyday life.

Paid services can be woven in to enhance the support you receive from family, friends, and community resource.

Reminder: the LifeCourse Framework helps plan a future and determine what services will be most valuable. (Reference Chapter 1)
The chapter organizes the services within the domains of the LifeCourse Framework.

Daily Life and Employment

The services in this section support individuals in their everyday life – school, employment, volunteering, engaging in the community, daily routines, and developing life skills. Work is an important part of life. It provides opportunities to work with others, increases our income, and contributes to our communities. In addition, work also contributes to good physical and mental health.

Pennsylvania is an employment first state, which means all people will be offered the opportunity to work and the services to help them succeed. Services are designed to remove barriers and build in incentives to work.

Concerns about income and maintaining eligibility for services can be addressed through establishing an ABLE Account to build up a savings account without jeopardizing benefits.

Questions?

In-Home and Community Support, Respite or Companion Services – How Do I Know Which One?

The decision to choose respite or companion services is determined by the individual's assessed need. Individuals may have one, or all, of these services in their plan. There are limits on the number of hours per day, week, or year that many services can be accessed. Please check the definitions listed previously and/or with the SC.

In-Home and Community Support should be used when learning skills and working toward achieving the goals and outcomes in the plan.

NOTE: After each definition there will be a guide to show which of the waivers it applies to. KEY:(PFDS) Person/Family Directed Support Waiver, (CLW) Community Living Waiver, (C) Consolidated Waiver, (AAW) Adult Autism Waiver, (ACAP) Adult Community Autism Program.

Companion Services can be used in situations where supervision is needed as well as minimal assistance to stay healthy and safe. These services are helpful when an individual is not learning, enhancing, or maintaining a skill. The outcome related to companion services only relates to assistance to and supervision to ensure health and welfare.

Respite Services is the correct service when the family or caregiver, who are normally and primarily responsible to support an individual, is absent or needs relief from providing care on a short-term basis.

What do I do if I need more hours of services than the service definition allows?

If more hours for services are needed than what the service definition offers for a particular service, (Like In-Home and Community Supports) a request can be made to the SC to complete the variance form (DP1086). The need for this variance (difference) must be discussed with the SC, and the ISP must reflect the need for the change. The SC will submit the request to the authorizing County/AE for review of assessed need. If approved, the request for Variance will be sent by the County/AE to the appropriate ODP Regional Office for a decision.

How do I find the right provider for the services I need?

One way to get help is to contact the County/AE, or for AAW, The Bureau of Supports, Autism and Special Populations (Formerly the Bureau of Autism Services). These numbers can be found 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 the County/AE. Visit them and ask questions. See if they can provide the needed services. The Supports Coordinator is also another person that can be contacted to discuss the individual's needs.

Things to Remember:

- **The individual has a right to choose any willing, qualified provider in Pennsylvania.**
- **The individual may cross County/AE lines to find services and supports.**
- **The individual may be able to access some services through providers in neighboring states if they are willing to serve you.**
- **The individual may change providers at any time if they are not satisfied with the services they are receiving.**
- **If the individual moves to another County/AE, their waiver moves with them. Individuals and families should work with the new County/AE and the providers in the County/AE they are moving into to assure a smooth transition to new providers if necessary. (ACAP is not transferable except within the counties where it is a program.)**

ALL providers must meet provider qualification standards to deliver services. ODP has set requirements for education and training for the services in the waivers. Each provider must demonstrate that they meet or exceed those standards before they are permitted to provide services in PA.

There are a few other ways to figure out who provides services in the area where you live:

- Use the Office of Developmental Programs' on-line resource directory.
- Ask a Supports Coordinator.
- Ask other families and friends.
- If an individual is enrolled in a waiver, they need to decide how they would like their supports and services managed.
- An individual can select the providers who provide their services.
- Or an individual can self-direct their services by becoming an employer or managing employer to direct their services.

When selecting one or more traditional providers to manage the services, here are some things to think about when interviewing a provider:

- What method ensures that the individual is treated with dignity and respect by the staff and treated as an individual?
- Are 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 the individual's needs?
- 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?

Once a provider is selected and they agree to provide services, they are expected to hire the necessary staff. Some providers will allow individuals to participate in the staff selection process. Providers are not required to do that so, if it is important to the individual, they should ask about participation in staff choice when selecting a provider/agency.

Can services be provided when traveling or on vacation?

- In-Home and Community Support
- Residential Habilitation (licensed and unlicensed)
- Life Sharing (licensed and unlicensed)
- Supported Living
- Shift Nursing
- Supports Coordination
- Specialized Supplies
- Supports Broker
- Behavioral Support
- Companion
- Respite

These services may be provided anywhere during temporary travel. The only exception is Respite Camp which can only be provided in Pennsylvania, Washington DC, Virginia, or a state contiguous to Pennsylvania.

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 Pennsylvania. Temporary travel can occur anywhere if the participant's health and welfare can be met during the temporary travel.

County/AEs shall ensure that this travel policy is explained to all participants at the time of waiver enrollment and reviewed annually at the time of the ISP meeting. The SC shall document this annual review in a service note in HCSIS.

The following conditions apply to the travel situation:

- The provision of waiver 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 participant's health and welfare during travel.
- The roles and responsibilities of the participant and the direct service professionals providing waiver services are the same during travel as at home.
- The participant is responsible to fund their own travel costs through private or non-system funds.
- Travel costs for agency staff, contracted personnel, or individual providers may be funded through private funds of family members of the participant or non-intellectual disability system funds generated through fundraising efforts or other means.
- If the participant decides to pay for the travel costs, there must be documented team consensus that this was the voluntary and willful decision of the participant.

The waivers will not fund the travel costs of the participant, the provider, or the direct service professionals:

Chapter 5

Self-Direction through Participant-Directed Services

Participant-Directed Services provide individuals and families with the ability to directly control services and supports. Directing services enables individuals and families to hire the people they want to support them, including friends and family members, and to schedule the support when it would be most helpful. There are two models of participant-directed services that provide the individual with control over their services and supports:

Self-direction refers to the ability of individuals and families to direct the supports and services that are received. Directing services and supports can be important for some individuals and families to have an everyday life for small things like what to eat or wear, to major life decisions such as where to live or whom to live with. The freedom to make decisions about our lives and to determine our future are essential for our personal growth, positive mental health, and happiness. When people need services and supports to live an everyday life, it is important that those services and supports accomplish what is necessary to have the life that they want. The Life Course tools build self-direction into decision making and life planning by helping individuals and families think through all options, anticipating future needs, and thinking through what people need to have a good everyday life.

In both models the individual will get assistance to carry out the responsibilities of an employer through **Financial Management Services (FMS)**.

1) The individual/family can be the employer with the authority of an employer (Vendor Fiscal/Employer Agent (VF/EA); or

2) The individual can choose to be a co-employer or managing employer along with an agency (Agency With Choice).

Financial Management Services (FMS)

The primary functions that FMS perform are:

- To reduce individuals'/representatives' employer-related burdens by providing appropriate fiscal and supportive services; and
- To assure the State and Administrative Entities /County/AE 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.

There are two models of FMS to chose from in the ODP system:

1) Vendor Fiscal/Employer Agent (VF/EA). Under the Vendor Fiscal/Employer Agent (VF/EA) model, the individual is the common law employer. The VF/EA FMS receives approval from the IRS to be an "employer agent" on behalf of the individual for the limited purposes of handling employment and income taxes. The individual is the "Employer of Record."

Using this model, the individual will be able to:

- Recruit and hire 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 workers when appropriate.

2) Agency with Choice (AWC) FMS. In this model the AWC FMS is the legal employer/ "Employer of Record." The individual is the managing employer and directs their workers daily activities. This means that the individual and the AWC will be co-employers.

As managing employer, the individual works with the FMS to:

- Recruit and refer potential support workers to the FMS for hire;
- Provide and/or participate in training 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.

Supports Broker Services

Both models allow the individual to access supports broker services to assist with employer functions, like recruiting, interviewing, hiring, scheduling, and managing workers.

The individual may also designate a surrogate to assist in hiring and managing services and to act on behalf of the individual as the employer. A surrogate is someone known well and is trusted to help.

Who can direct their own services?

All individuals may direct their own services if enrolled in the Consolidated Waiver, Community Living Waiver, and the Person/Family Directed Supports Waiver. This is not available in the Adult Autism Waiver or ACAP. If served within one of those programs and want to direct the services received, talk with a Supports Coordinator about the possibility of moving into one of the other waivers.

Individuals may also choose to direct their own services if living in a private home, in their own home or apartment, or the home of a family member.

What services can you direct?

The services that can be self-directed include and are limited to: Companion, Family/Caregiver Training and Support, In-Home and Community Support, Supports Broker Services, Homemaker/Chore, Transportation, Supported Employment, Respite. (PFDS)(CLW)(C)

Individuals receiving residential habilitation services may use support broker services only when transitioning to participant directed services.

What Can I Do if I Am on The Waiting List?

Individuals who Self-Direct also have access to the following services:

Home Accessibility Adaptations, Vehicle Accessibility Adaptations, Assistive Technology, Education Support Services, Specialized Supplies

What rules need to be followed for participant-directed services?

**Vendor goods and services are available through Self-Directed Services such as home adaptations, vehicle accessibility adaptations, assistive technology, education support services, and specialized services

There are a number of rules for directing your own services. Below are some of the main rules:

- **All support workers that are hired must meet the criteria and qualifications for the services they are hired to provide. A Supports Coordinator or Supports Broker can help with understanding the criteria for each service.**

- **Having a Backup Plan – All individuals are required to have a back-up plan to address situations when a paid support person (paid relative or non-relative) or legal guardian does not report to work. ODP recognizes, however, that there may be extenuating circumstances that cannot be addressed through the plan. In general, these situations include, but are not necessarily limited to:**

1. Unexpected circumstances such as inclement weather, sudden illness, or the unplanned extension of medical leave, that prevent a regularly scheduled worker from arriving at the job site and where another worker/caregiver is not immediately available to work;

2. Situations where a regularly scheduled worker is terminated or refuses to provide care without providing adequate notice (e.g. the worker notifies the employer that he or she refuses to work on the day he or she is scheduled to provide the service or is dismissed due to gross non-compliance or misconduct); or

3. The sudden loss of a caregiver who provided uncompensated support that kept the provision of services by relatives at or below 40/60 hours per week.

4. If any of the above situations occur, ODP requires the back-up plan to be reviewed and revised as necessary to prevent recurrence of the above.

5. When the maximum number of hours per week are worked, either the 40 hours per week or the 60 hours per week, and the relative or legal guardian continues to work, the entire work week in which the limit was exceeded will be counted towards the allowable 90-day exception maximum.

Hiring Relatives

Individuals may be interested in having their parents, sisters, brothers, grandparents, legal guardians, and other relatives provide supports. Individuals may also want to consider hiring friends, neighbors, and other people they know and trust as support.

There are specific requirements for hiring relatives and family members.

The basic requirements for support workers 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).

Policies

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.

A relative is any of the following related by blood, marriage or adoption who have not been assigned as legal guardian for the participant: a spouse, a parent of an adult, a stepparent of an adult child, grandparent, brother, sister, aunt, uncle, niece, nephew, adult child, or stepchild of an individual or adult grandchild of an individual. For the purposes of this policy, a legal guardian is a person who has legal standing to make decisions on behalf of a minor or adult (e.g. a guardian who has been appointed by the court).

If an individual lives in their own home, or in their family's home, family members can be hired to provide some services through the waivers.

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

- The individual has expressed a preference to have the relative/legal guardian provide the service(s).
- The service provided is not a function that the relative or legal guardian would normally provide for the individual without charge in the usual relationship among members of a nuclear family.
- The service would otherwise need to be provided by a qualified provider of services funded under the waiver.
- The service is provided by a relative or legal guardian who meets the qualification criteria that are established by ODP in Appendix C-3 of the approved waivers.

Services that relatives or legal guardians can provide are limited to the following:

- In-Home and Community Support,
- Companion,
- Life Sharing,
- Supported Employment,
- Shift Nursing and
- Transportation (Mile).
- Supports Broker services and Respite services may be provided by relatives and legal guardians who are not the participant's primary caregiver when the conditions in the bulleted list above are met. The primary caregiver is the person who normally provides care to the individual.

Relatives or legal guardians may also 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 in the bulleted list above are met.

Guidance regarding limits on the number of hours of In-Home and Community Support and Companion by relatives, legal guardians

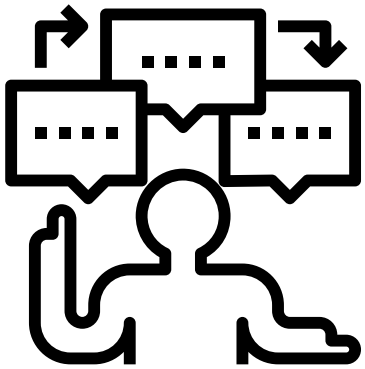
- Any one relative or legal guardian may provide a maximum of 40 hours per week of authorized In-Home and Community Support, Companion, or a combination of the two services (when both services are authorized in the ISP).
- Further, when multiple relatives and/or legal guardians provide the service(s) each individual may receive no more than 60 hours per week of authorized In-Home and Community Support, Companion or a combination of In-Home and Community Support and Companion (when both services are authorized in the ISP) from all relatives and legal guardians.

Legally responsible individuals may also provide the following services that do not have a personal care component:

- Supported Employment; and
- Transportation Mile solely to drive a minor child to and from a waiver service or a job that meets the definition of competitive integrated employment.
- In-Home and Community Support and Companion services that are authorized on an ISP may be provided by relatives and legal guardians of the individual.

An exception may be made to the limitation on the number of hours of In-Home and Community Support and Companion provided by relatives and legal guardians at the discretion of the employer when there is an emergency or an unplanned departure of a regularly scheduled worker for up to 90 calendar days in any fiscal year.

"The future is not something we enter. The future is something that we create. And creating that future requires us to make choices and decisions that begin with a dream."—Leonard Sweet.



SUMMARY: Forming a vision and beginning to plan for the future should be the driving force in developing a plan to create a full, inclusive, quality life in the community. This section will take individuals and families through the process, so everyone knows what to expect.

Chapter 6

Individual Support Planning

Evaluations and Assessment of Need

Once eligibility for services is determined, and prior to the initial planning meeting, individuals and families will participate in evaluations and assessments to identify needed supports. The Supports Intensity Scale (SIS™) and PA Plus and Oregon Supplement is the required statewide needs assessment for the Person/ Family Directed Support (P/FDS), Community Living (CLW) and Consolidated waivers.

The Adult Autism Waiver (AAW) and the Adult Community Autism Program (ACAP) use the Scale of Independent Behavior – Revised (SIB-R), the Quality-of-Life assessment, and the Parental Stress Scale. In addition to the required assessments, the individual and team may also gather information from other evaluation and assessment tools. This may include functional behavior assessments, person centered planning tools, vocational assessments, and other formal and informal assessments which may be helpful to identify your specific needs.

What are the Supports Intensity Scale® (SIS™) and PA Supplement?

The SIS™ and PA Supplement (specific to the Person/ Family Directed Support (P/FDS), Community Living (CLW) and Consolidated waivers) is a means of measuring the supports needed to live an everyday life. It is a standardized needs assessment, which means everyone is asked the same questions and receives the same measurements regardless of where they live or who does the assessment. The information from the assessment is made available to the Supports Coordinator (SC), who will then share the results with the individual and anyone whom they choose, including members of the ISP team. The results help develop the ISP. All needs identified in the evaluation process must be addressed within the Individual Support Plan. Not all needs require direct paid services, however, the ISP must describe how the need will be addressed through informal, unpaid support or through other resources.

EVALUATIONS AND ASSESSMENTS

SUPPORTS INTENSITY SCALE

The Supports Intensity Scale (SIS™) is a nationally recognized assessment instrument developed by the American Association of Intellectual Disabilities and is used by many different states to determine need. Topics included in the SIS-A include home living, community living, lifelong learning, employment, health and safety, social activities, protection and advocacy, exceptional medical and behavioral support needs, communication, and assistive technology.

PA SUPPLEMENT

The PA Supplement is a separate set of questions administered at the same time as the SIS-A to provide more information related to vision, hearing, ambulation, communication, safety needs, and information regarding the use of and/or need for assistive technology. In addition, the PA Supplement also considers information regarding the need for extensive supports.

By answering a series of questions with a PA trained assessor (interviewer), areas of life are examined to see how much support is needed, how often support is needed, and what kinds. The SIS™ focuses on what supports are needed to have an everyday life, not on what an individual cannot do.

The SIS™ and PA Supplement are used with other sources of information to help you and your team before and during the Individual Support Plan (ISP) planning process.

Who receives a SIS™ assessment and when?

As part of the process, everyone found eligible and applying for services through the Person/ Family Directed Support (P/FDS), Community Living (CLW) and Consolidated waivers will receive a SIS™ assessment. Assessments are typically done before the initial ISP, and then every five years, unless the circumstances change, and a new assessment is needed.

Who is involved in the SIS™ interview?

The individual and at least 2 respondents, people chosen by the individual and who can give good information about support needs, should be at the meeting. Respondents must be people who know the individual well, for at least three months, and can describe their needs in a variety of settings. The person receiving services, their family members, direct support professionals, providers, friends, coworkers, and others may participate. It is up to the individual to decide who they want to invite to the assessment meeting. An assessor (interviewer), who lives in Pennsylvania and has extensive training, will conduct the interview. The Supports Coordinator may participate as a respondent if they meet the criteria, or they may attend to listen and observe to inform ISP development.

What is the assessment process?

Whether the SIS™ assessment or the Scale of Independent Behavior – Revised (SIB-R), the Quality-of-Life assessment, or the Parental Stress Scale are administered, a scheduler will contact the individual by telephone and discuss who will be attending and participating in the assessment process, as well as meeting times, dates, and other requested attendees. Every attempt will be made to schedule assessments prior to the individuals ISP review date to allow the team access to the results before the ISP meeting.

INDIVIDUAL SUPPORT PLAN (ISP)

The ISP is a plan designed by using a Person-Centered Planning approach. Person-Centered Planning discovers and organizes information that focuses on your strengths, choices, and preferences. The LifeCourse tools can help do this. It involves bringing together people that will support the individual in the planning process, listen to the individual, describe the individual as fully as possible with a true focus on understanding who they are, and dreaming and imagining possibility.

The ISP Development Process – it is not only about services

This chapter describes how an ISP is developed in the service system. But having a plan is important whether or not the individual is in the service system or getting services. Knowing where you are going in life and figuring out how to get there is important for each of us. Services can help, but they alone are not enough. Our relationships, community resources and activities, and our own creativity are as important.

The ISP process, led by the individual and the Supports Coordinator (SC), is the most critical activity in helping to envision a good life and develop outcomes to achieve the desired life. It is a way to help explore the experiences, opportunities, and resources available to the individual through family, friends, and the community.

It is also a way to identify what services can enhance those resources and opportunities. The ISP meeting is held at least annually, but also may be called whenever it is felt a change in the plan is necessary.

The Supports Coordinator assists the individual with understanding the ISP process. This includes thinking about relationships that are important to them; activities that are enjoyable and important; what kinds of growth experiences the individual would like to explore; what kind of job the individual might like; whether there are any health or safety risks that must be planned for; what the immediate needs are as well as the needs they anticipate for the future, and what types of services would be best for achieving the quality of life that individual hopes to have.

WHO IS ON MY ISP TEAM?

In preparation for the support plan development, the SC encourages meaningful participation from the individual. The SC also assists in ensuring the necessary supports and accommodations are provided so that everyone can participate.

The SC supports the individual in determining who should be present and involved in the development of the ISP. It is important to include people who know the individual the best and who will offer detailed information about preferences, strengths, and needs.

The ISP team consists of:

- **The individual**
- **The Program Specialist or Family Living Specialist**
- **The SC**
- **Direct care staff**
- **People who are important in the individual's life and they choose to include**

The Supports Coordinator is responsible for reaching out to determine preferences about the date and location of the ISP meeting. The SC should make at least three attempts to contact the individual to discuss this information. After the discussion takes place, the SC is responsible for accommodating those preferences to the extent possible.

Some things the SC should discuss with the individual regarding the meeting location include:

- It should be a place where they feel comfortable.
- It should be accessible to all ISP team members.
- It should have enough space to accommodate all ISP team members.
- It should be as free from distractions as possible, so the ISP team members can focus on what everyone has to say during this very important meeting.

If by the third attempt, the individual refuses or has not provided input on their preference in scheduling the meeting, the SC will proceed in scheduling the meeting in accordance with current state guidelines.

ISP Invitation Letter

Once the ISP meeting details are confirmed, the SC develops the ISP meeting invitation letter and sends it to the individual, their family, team members and other people of the individual's choice who may contribute valuable information during the planning process. The invitation must be sent to all ISP team members at least 30 calendar days prior to the annual ISP meeting.

Please note the SC can develop an ISP invitation letter that identifies all team members who are invited to participate in the ISP meeting or send a separate invitation letter for each invited team member.

The ISP Team Meeting

The ISP is developed by the individual and their ISP team. The meeting is facilitated by the SC; however, the individual can lead the ISP meeting, if they choose.

All ISP team members play vital roles in the ISP meeting. It is to the individuals' benefit to fully participate. Be prepared to share knowledge, perspective, and insight, so that the SC develops the ISP based on that information. Each ISP team member ensures that information provided is current and is presented professionally and with sensitivity. The information collected presents a complete picture of the individual. Specific examination of information will be part of the ISP process, including possible changes in the current living situation or health status, incident reports, monitoring findings or other changes that will impact the health and welfare, services and supports or ability to have an everyday life. Service options must be promoted and fully explored with every individual.

To achieve an ISP that is relevant and leads to the life the individual wants to live, the process needs to happen in plain language and in a way that everyone, including the individual, can understand and participate freely. It is important for everyone to be sensitive to the experiences the individual and their family have had including cultural differences. If the individual communicates differently (like sign language, Picture Exchange Communication, etc.) or if the primary language of the family is not English, the ISP process should use their way of communicating. Someone who knows the individual and the family well can interpret, or a paid interpreter can be used.

ANNOTATED ISP – Review the form before your ISP Meeting

Before the first ISP meeting, it may be helpful for the individual and family to review the ISP Form (also called the annotated ISP). This will ensure they are prepared with information and have considered personal goals and expected outcomes.

A copy of the ISP form is available from the SC, or at [Individual Support Plan.]

WHAT INFORMATION SHOULD GO INTO THE 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 the individual's needs. The team will also receive a copy of this form to refer to whenever needed. Each plan should be written so that anyone who reads it will know who the individual is, what is important to them, what they need, and how to support them in their life.

INDIVIDUAL SUPPORT PLAN (ISP) – QUESTIONS

The following questions will help the entire ISP team begin thinking of important information about the individuals' preferences used in developing the ISP. It may be helpful for the individual and those who support them to make a list of these questions before the annual ISP meeting. Make some time to go over each question and write down answers to bring to the ISP meeting. Everyone should include their first name on their list of questions, and answers so the SC can easily identify who provided what information on the individuals behalf. The individual can also bring their own questions and ideas.

Questions Related to Individual Preferences

What do people like and admire about you?

With your family, friends, and people who know you the best, discuss what people like about you. What do they think you have done that you should be proud of? What are you good at? What do people think about when they think about you?

What makes sense for you?

When answering 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, or be improved in your life right now.

What are the activities you would like to participate in or explore?

Using the LifeCourse Trajectory, you can look at what experiences or opportunities you would like to have in your life that will lead you toward the vision of your good life or an everyday life.

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 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 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.

What does <u>not</u> make sense?

When answering 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.

Areas 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:

Outdoor Appliances

Your ability to use outdoor appliances. (examples: gas grill, lawn mower, weed whacker). This information should include the level of supervision required.

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.

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.

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.)

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.)

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?

Stranger Awareness

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

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.

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.

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.

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, ABLE account, and information about property you may own.

Service and Supports: Developing Outcomes in Your ISP

Each ISP Team uses outcome statements to determine the needed services and/or supports. The health and safety of the individual must always be addressed throughout this process. All outcomes should be written down in the ISP, even if they are not supported by formal services. Outcomes or goals should look like the vision the individual shared in their Life Trajectory.

An outcome is a desired result. Outcomes show what will happen as a RESULT of the actions taken or the support received. Outcomes represent what is important to the individual, what they want to happen, what they would like to maintain based upon the assessed needs and things they would like to change. Information gathered during the ISP meeting about things that could make a difference in the individual's life and meet the assessed needs is used in developing outcomes. Any barriers and obstacles that might affect success in meeting outcomes, especially if these barriers impact health and welfare, should be addressed. Outcomes are written in plain language. Outcomes should build on the information and assessments that the ISP Team gathers during the planning process and reflect a shared commitment to action.

NOTE: The AAW and ACAP waivers use the term "goal" or "objective" instead of "outcome". A goal/objective is what is what the individual desires. It is what the individual is trying to achieve as opposed to expecting to achieve.

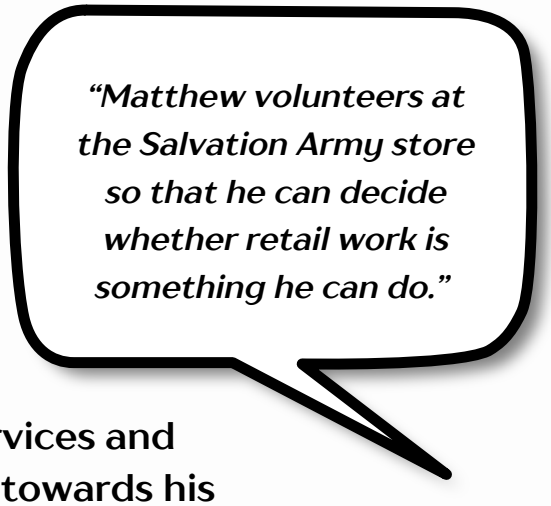
WRITING AN OUTCOME STATEMENT

Outcome statements will link what the individual and team will be doing to the outcome the individual wants through phrases such "in order to" and "so that" because they are helpful in connecting how the outcome will make a difference in the individuals life.

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

"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 – 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:



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 an individual may 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 how long you need the service(s), the cost of each service, who is paying for it and who is providing the service. In some situations, you might think that you need more service(s) or supports than is generally allowed.

Each Individual's Approval of the Plan: **The ISP Signature Form**
The ISP Signature Form is a Department approved form that the individual is asked to complete and sign at the end of the ISP meeting. Signing the ISP Signature Form says that the individual attended the ISP meeting, and agree with all information that was discussed, the content of the ISP and information that was changed as a result of the meeting. The individual will answer a series of questions that states they understand what took place and what is available to them.

If there is a disagreement with the content of the ISP, there is a place on the Signature Form where the individual can sign and indicate that they have an objection. The County/AE or the Bureau of Supports for Autism and Special Populations (for AAW or ACAP) 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.

If the individual and their team have concerns that certain services do not meet the individual's needs because it has a limited number of hours, the team can request that the SC fill out a VARIANCE form (DP1086). A Variance is a requested change in the rules of a service definition or the way a service is usually provided. Things such as needing Enhanced Services (more intense support) or more funding for assistive technology also qualify for a Variance form to be completed.

What if I have an ID/A Waiver and Disagree with something in the ISP?

If the individual is in the Person Family Directed Support (P/FDS), Community Living or the Consolidated waiver and the individual wants to ask for a change to the ISP or the services in the ISP that the team does not agree with, then the individual can complete a Waiver Service Request form and submit it to the County/AE. It must be submitted within 10 days of the team meeting. The Supports Coordinator will provide the form and assist with completion. The County/AE must provide a written approval or denial of the request within 20 calendar days of when they receive the form.

If the County/AE 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 County/AE partially approves the request, then partial or time-limited services will be approved through a critical revision of the ISP.

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

My vision of a good life

The process for the Adult Autism Waiver and ACAP is somewhat different. Counties are not involved. Ask the Supports Coordinator how a request to change the ISP is made and ask them to assist with the request.

The right to appeal applies to the Adult Autism Waiver (AAW) and Adult Community Autism Program (ACAP).

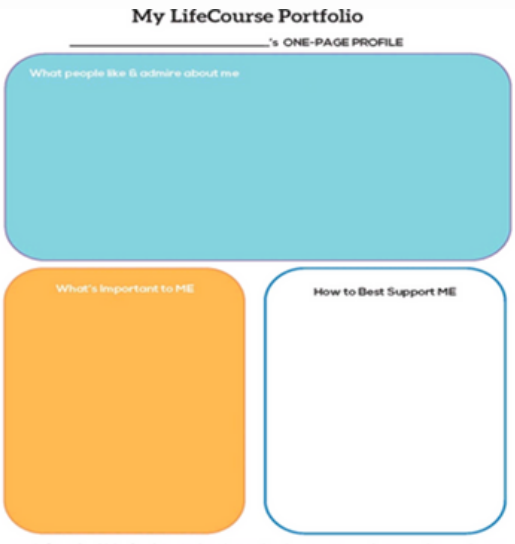
For further information on appeals and what your rights are in the waiver programs, you can turn to Chapter 5 of this publication.

Using the LifeCourse Tools to Help Develop the ISP

The LifeCourse Tools are comprised of values and principles that were created to help those of all abilities and all ages develop a vision for a good life based on an understanding of your dreams and preferences. In creating an everyday life, you need be encouraged to think about what you need to know and do, how to identify or develop supports, and how to discover what it takes to live the life you want to live.

The LifeCourse Portfolio

One Page Profile: A one-page description is a person-centered thinking tool developed by the Learning Community and adopted into the LifeCourse portfolio.



The One Page Profile includes 3 parts:

1. **Like and Admire**
2. **Important to Me**
3. **How to Best Support Me**

One Page Description tools are a tool that can assist with positive support and change regardless of age and circumstances. They should be flexible and are useful for specific situations. They also provide an at-a-glance way of knowing what really matters to you as you move throughout the lifespan. You can use the information in your One Page Profile in the

Individual Preferences section of your ISP – right at the beginning of the planning process. This will assure that the ISP contains the right information about what is important to you and that the services identified in your plan reflect how you wish to be supported.

The Trajectory: In developing your ISP, you can make sure your Outcomes reflect your vision of a good life. The day-to-day experiences on your Trajectory should be included in your plan so that you are supported to engage and participate in those community activities with your family and friends. You may focus on your current situation and stage of life, but you may also find it helpful to look ahead to think about life experiences that will help move you toward the life you want and one which includes all facets of community life.

The experiences and opportunities along your Trajectory can be supported by paid services and other supports. In the past, conversations about supporting people with disabilities and their families mainly revolved around the supports offered by the disability service system. We are trying to help families, as well as organizations and policymakers, understand that we ALL access a variety of supports to make it through our daily lives.

The Integrated Supports Star can help you find supports. It is a problem-solving tool. In the center of the star, place your goal or concern you want to address. Around the center are 5 points each representing an integrated support that we all use to be successful in our everyday life including: Personal Strengths and Assets, Technology, Relationships, Community Based, and Eligibility Services.

In each part of the star, identify your current supports in that area. Think about your goal, specific experiences you want in your life, or a current concern. Now you can brainstorm or identify potential supports that may be helpful in creating a positive solution to assist you in achieving your desired outcome.

Everyone needs supports to lead good lives. Using a combination of lots of different kinds of supports which include paid and unpaid supports helps to create an inclusive, quality and community life. The eligibility specific supports, like waiver services, can help bolster other points of the star. For example, In-home and Community Supports can help you to develop relationships with people and provide services in community settings, like the YMCA, your church, or at the grocery store. The paid services can be used to improve your independence and build your capacity and skills to engage in community activities.

Every funded service must be linked to an outcome. However, not every outcome requires a funded service. There may be Outcome Statements that are important to the individual but do not relate to, or are not supported by, a funded service. Resources and opportunities available to the person through their family and community connections can result in achieving the outcome.

Updating Your Individual Support Plan

ISP teams must review your services once every 365 days at the Annual Review meeting. Your team should review what needs may have changed at the ISP meeting, as needs change throughout the year. If, at any time, the ISP team or County/AE or BSASP determines the services that were included in the ISP because of previously made decisions have changed, the ISP should be revised to reflect the current needs of the individual. If you disagree you do have the right to an appeal.

CRITICAL REVISION – A revision to the ISP is used when you have a change in need which requires a change in current services, addition of services or a change in the amount of funding required to meet your needs. The ISP team members should discuss and agree on changes made to the ISP before all critical revisions are approved and authorized. If the individual, family member or any other team member disagrees with the content of the ISP, this should be documented on the ISP Signature Form.

Chapter 7

How to Choose a Provider

- Home and Community Service Information System (HCSIS)

Provider Profiles are designed to serve as a reference primarily for individuals and families so that they may choose intellectual disability/autism service providers based on information that is important to them.

The Services and Supports Directory is a tool for individuals with an intellectual disability/autism, their families, and circle of support to locate services and service providers in Pennsylvania. The directory can help you locate particular service providers or search for services and supports provided in an individual's community. Provider information in HCSIS includes:

- **Search the Provider Online Directory**
- **Provider Demographics**
  1. Corporate Name, Address and Phone number
  2. Contact person
  3. Website address
  4. The services available in your community (County) or nearby communities
  5. Other Non-Licensed Facilities

While it does not include all providers of service because not all providers are required to hold a license, the Provider Licensing Directory is an easy access directory of licensed human services facilities operating in Pennsylvania. You can access information on providers from across the commonwealth. Begin by selecting the type of service you are seeking from a dropdown menu. Providers commonly working with Office of Developmental Programs are listed under the following fields:

- **Community Homes — (Group Homes with eight people or fewer)**
- **Large Community Homes Services — (Group Homes with nine people or more)**
- **Family Living — (Family Living/Lifesharing/Companion Living)**
- **Intermediate Care Facility/Intellectual Disabilities (ICF/ID)**
- **Vocational Facility (Workshops)**
- **Day Training Services for Adults (Facility Based Adult Day Training)**

Once you have selected the service type, the search can be narrowed by county, zip code, a specific place (facility name), and/or legal entity name (an agency name). When the criteria for the search are entered and you click "Go," a list of all facilities matching the criteria will appear. The information will include:

- **The name and address of the provider.**
- **The capacity (number of individuals who may live/ work at the facility).**
- **The type of operation (profit, non-profit).**
- **The status of the facility (licensed or unlicensed).**
- **The status of the license (full or provisional). A provisional license means the facility was cited for a regulation violation(s) and is in the process of correcting the violation(s). If the violation is considered minor, the facility may have a full license with an approved plan of correction in place.**

You may then use the list provided to contact service providers to find more information about the specific nature of available services. If you are having difficulty locating provider information, you can contact your local County Mental Health/Intellectual Disabilities office for further information, or call the ODP HelpLine at 1-888-565-9435 (1-866-388-1114 for hearing impaired individuals) for assistance.

Supports coordination is a critical service that involves the primary functions of locating, coordinating, and monitoring needed services and supports for individuals and their families. Supports Coordinators can also assist individuals and families with selecting a provider. For more information about the agencies providing supports coordination services, please visit the SCO Directory on MyODP. (If you do not already have a MyODP account, you may login as a guest to access this content)

Recommended Questions for Families and Individuals Selecting Providers

- How can I arrange a visit?
- How would you describe the philosophy and values of your agency?
- May I talk to individuals and families who use your services?
- May I talk with some of your staff?
- May I have a copy of your annual report?
- May I visit the places where you provide services?
- For how long have you provided services and supports in this county and in other counties?
- What are the qualifications of the staff that would be supporting me/my relative?
- What training do you provide to staff who work directly with individuals? To supervisors?
- How long do staff remain with your agency (by position, by site)?
- What is the agency's management structure in my county, at particular sites? (e.g. Is there an office nearby? Is the site managed from afar?)
- How long has the CEO been with this agency? Can you tell me about him/her and his/her background?
- How long have other management staff been with this agency?
- Can I see your QA&I report?
- Can I see your licensing inspection report?

SUMMARY:

This section will help you to understand the rights that are guaranteed to you and how to seek assistance, if you feel your rights are not being followed.

ODP advocates the following regarding rights: People with an intellectual disability and/or autism (ID/A) enjoy the same right to self-determination as everyone else. Therefore, you must have opportunities, respectful support, and the authority to have control over your own life. You have the right to advocate on your own behalf. Everyone has the right to participate in the community, to feel like a valued member of their community, and live a life of their own choosing. All people have human and civil rights.

Chapter 8
Understanding Your Rights

Human Rights and Civil Rights

Human Rights are the basic rights and freedoms to which all humans are entitled, often held to include the rights to life, liberty, equality, and a fair trial, freedom from slavery and torture, and freedom of thought and expression. Civil Rights are the rights belonging to an individual by virtue of citizenship, especially the fundamental freedoms and privileges guaranteed by the 13th and 14th Amendments to the US Constitution and by subsequent acts of Congress, including civil liberties, due process, equal protection of the laws, and freedom from discrimination. [1]

Your Rights in the System

To help ensure your rights, the Department of Human Services (DHS) has regulations to govern most of the services offered through the Office of Developmental Programs (ODP). The Chapter 6100 regulations include several sections that outline your specific rights, as they relate to the services you receive.

This section concerning individual rights applies to all people and all services.

The rights described in the 6100 regulations apply to everyone receiving HCBS funded services through ODP.

RIGHTS IN CHAPTER 6100 REGULATIONS

The following is an overview of many of the Individual Rights listed in the 6100 Regulations.

Exercise of rights.

- You may not be deprived of your rights
- Your provider must help you to learn and understand your rights, using whatever accommodations you need.
- You may not be punished for exercising your rights.
- If there is a court order restricting your rights, it must be followed.
- A court-appointed legal guardian may exercise rights and make decisions on your behalf in accordance with the conditions specified in the court order.
- You may choose a person to help you make decisions or exercise rights on your behalf.

Rights of the individual.

- You may not be discriminated against because of race, color, creed, disability, religious affiliation, ancestry, gender, gender identity, sexual orientation, national origin, or age.
- The civil and legal rights you have according to law remain the same. These include the right to vote, speak freely, practice the religion of your choice, or choose not to practice a religion.
- You are not abused, neglected, mistreated, exploited, abandoned or subjected to corporal punishment.
- You must be treated with dignity and respect.

- **You have the right to:**

1. Make choices and accept risks.
2. Participate in activities and services in the community.
3. Control your own schedule and activities.
4. Privacy both in terms of your body and your possessions, including the right to access and secure your possessions.
5. Live and work in the community.

- **You also have the right to:**

1. Choose a willing and qualified provider.
2. Choose where, when, and how to receive needed services.
3. Voice concerns about the services you receive.
4. Assistive devices and services that enable you to communicate.
5. Help develop and implement your ISP.
6. Access your case record.

Additional rights in residential service locations

You have a right to:

- Receive visitors (scheduled and unscheduled), as well as to meet privately and communicate with whomever you choose, at any time.
- Be able to privately communicate and share contact information with whomever you choose (this includes being able to send and receive mail without others reading it).
- Be able to use the phone without restriction and to carry on private conversations (this includes any telecommunication).
- Manage and access your own finances.
- Choose who you wish to share your bedroom.
- Furnish and decorate your bedroom and the common areas of your home (if it does not interfere with other's choices – see section 6100.184 relating to negotiation of choice).

You also have right to lock your bedroom door and the 6100 regulations provide several rights in that regard as follows:

- Locking may be provided by a key, access card, keypad code or other entry mechanism accessible to you to enable you to unlock and lock your door.
- Access to your bedroom to others is only permitted in a life-safety emergency or with your permission on each occasion you grant access.
- If you need assistive technology to lock and unlock your door you have a right for it to be provided.
- Locks must allow easy and immediate access in the event of an emergency.
- Your DSP will have a key or device to allow them to lock/unlock the door.

And you have the following rights as well:

- You have the right to access food at any time.
- You have the right to make health care decisions.

In addition to your bedroom door, you have the same rights regarding the door to your home.

Negotiation of choices

- You may exercise your rights if you do not violate anyone else's.
- Your provider will help you to make choices according to their procedures regarding choices and resolving problems.
- Your rights may only be changed in regard to the individual plan and then only in terms of keeping you or others healthy and safe.

Facilitating personal relationships

- As you direct, your provider will help you to visit whomever you choose, including when an accommodation is needed.
- As you direct, your provider will help you to involve whomever you choose to help make decisions, plan, or take part in activities.
- Unless you indicate otherwise, your provider will involve your family and friends.

Informing of rights

- The provider must inform you of your rights, explain your rights to you, and explain how to make a report if you feel your rights have been violated, when you first begin receiving services and annually thereafter.
- The provider must keep a statement signed by the individual, or the individual's court-appointed legal guardian, acknowledging receipt of the information on individual rights.

In addition to your Individual Rights, as listed in the 6100 Regulations, ODP has protections in place to help you navigate its system. The following section helps you know what to do it you have difficulty or problems. These ODP processes are based County/AE and State policies and are intended to help you.

What do you do if you have a problem?

- Identify the problem and how it affects you.
- Write it down; include names and dates of events and conversations.
- Keep careful records of all conversations and correspondence.
- "Get it in writing" from the County/AE.
- Always keep information about your rights with other documents you receive.
- Establish timeline for resolution.

You have a right to complain about any services or supports you receive if they are not meeting your needs. This includes the services you receive through your SC or any provider. Some disagreements need a formal complaint or appeals process—some do not.

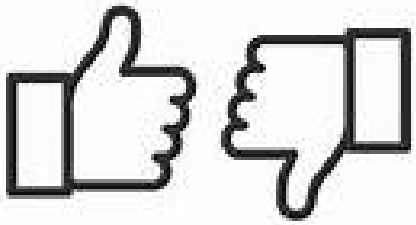
When you have a problem, contact your SC and describe the problem. Let your SC know how you would like it resolved. If your SC cannot help or resolve the problem, you may discuss the issue with your SC Supervisor. If your SC Supervisor cannot resolve the problem, you may take it to your County/AE, or contact ODP directly at the Customer Service Line Number at 1-888-565-9435.

It is your responsibility to be a good advocate – to speak up for yourself! Write down every time you talk to somebody (include date/time/name). Keep copies of all paperwork that you are given or that you send to people. Take someone (friend/family or advocate) to any meeting or have them sit with you to take notes. And ask for any decisions in writing. This does not mean that you will always win, but it can help keep things from getting more confusing.

Disagreements Regarding County or Base funded services

When you receive services funded through County/AE or base funding, you have the right to disagree with, and possibly appeal, certain situations or decisions made by the County. The process to handle disputes at this level are different than those funded through the waivers.

If the County office says you are not eligible for ID/A services, you have the right to receive a written notice explaining why you were denied. You have the right to disagree with what was decided. Notify the County/AE, in writing, that you disagree with the decision. Local Agency Law will apply. (Further information regarding the application and eligibility for services is described in Chapter 2 of this publication).



Local Agency Law

Each County program will appoint an impartial reviewer to hear issues and arguments.

A hearing will be scheduled. It can be recorded at no cost to you. You can also request a transcript of the hearing, but at your own expense.

You can provide testimony, documentation, and new information during the hearing. The reviewer may ask you questions.

The County can also present information and facts about the decision.

You can ask questions of the County Program.

If you have services in place, but the County reduces or terminates those base funded services, they are required to give written notice. Unlike waiver recipients, the County Program and/or provider can discontinue services due to lack of money. You are not entitled to have the services remain in place while you appeal the decision through the County process. However, you should argue and request that services remain until a resolution is found. The Local Agency Law appeals process (described above) applies here.

Disagreements Regarding Waiver funded services

Once you are enrolled in the P/FDS, CLW or Consolidated Waiver, you have the right to appeal decisions that impact your access to services.

- **Be notified in writing of any AE/County or ODP decision concerning waiver services.**
- **Submit a "Waiver Service Request" form (DP1022) if your team disagrees about needed services. (details below)**

If you are enrolled in the AAW or ACAP, and would like to appeal decisions that impact your access to services you should:

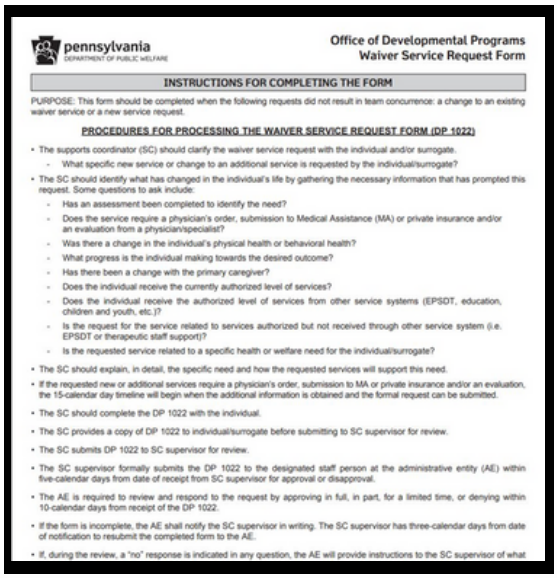
- Appeal if you are denied eligible waiver-funded services of your choice.
- Appeal if you are denied using the willing qualified Medicaid waiver provider of your choice.
- Appeal if services are denied, reduced, suspended, or terminated after the County/AE has authorized them.
- Appeal if services are denied, reduced, suspended, or terminated even if you have not received written notice regarding the decision.
- Appeal even while you are receiving services.
- Disagree with your PUNS form; however, you have no right to appeal through the Bureau of Hearings and Appeals. ODP policy bulletins do not affirm the right to appeal a PUNS.

You should be provided with a copy of your appeal rights by the County/AE or ODP any time a decision is made which effects your services and when you apply for services.

If the County/AE initiates an action on waiver services and does not provide the written notice as required, you will have six calendar months from the effective date of the action to file an appeal. When this appeal is filed, services will be reinstated retroactively to the date of discontinuance and will continue until an adverse decision is rendered after the appeal hearing.

Services that are denied without first being authorized in the ISP cannot be provided pending appeal. In these circumstances, you are afforded 30 calendar days to appeal the denial of the service.

When waiver services are being provided and the County/AE determines that the services are going to be reduced, suspended, or terminated, you should receive written notification from the County/AE of this action. You will have 10 days to file an appeal for services to be maintained during the appeal process.



pennsylvania
DEPARTMENT OF PUBLIC WELFARE

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

What is the Waiver Service Request Form?

For waiver participants, if the ISP team does not agree about a request for service, or the service you are requesting is not eligible for waiver funding, there is a process to make that request in another way. This is the purpose of the Waiver Service Request Form. The form is available online or your Supports Coordinator can provide one to you and can also help you to complete it.

Completion of the Waiver Service Request Form (DP1022) begins the 30-day requirement within which the AE must provide a written response to your request. This process is helpful to resolve disagreements quickly without going through the formal appeals process.

What decisions can I appeal?

The waivers outline the types of decisions you can appeal. The formal Hearing and Appeals process is in place for the following actions:

- **Not being offered a Service Delivery Preference (ICF or Home and Community Based Services).**
- **Denied Service Delivery Preference choice.**
- **Ineligibility for ICF Level of Care.**
- **Denied services of choice including amount, duration, frequency, and scope.**
- **Denied choice of willing and qualified provider.**
- **Action taken to deny, suspend, reduce, or terminate an authorized waiver service.**

How do I File an Appeal?

A Fair Hearing is filed by the individual, at the time of a denial, suspension, reduction, or termination of services. ODP has a "Fair Hearing Request Form" – Form DP458 (available on MyODP.org) – that you should use to submit your Waiver related appeal. The County should send you this form with their decision letter. Complete the form and submit it to the Department/County/AE detailed within the notice. The form must be signed to be considered complete.

What is the Appeals Process?

After you file an appeal to the office that made the denial, you will have the option to participate in the following:

> **Optional Pre-hearing Conference with the Department, County/AE who made the denial –** During this meeting you may be able to reach an agreement. If so, then there is no need for a hearing and the process stops with the agreement. If no agreement is made, then a Fair Hearing is scheduled.
>
> **Hearing with a Hearing Officer–** Filing for a Fair Hearing with the Bureau of Hearings and Appeal (BHA) means you will present your case in front of a Hearing Officer (also called an administrative law judge). The Hearing Officer will ask questions and then make a ruling. You will also be notified later in writing as to the Hearing Officer's decision.

When you file an appeal about a decision made by the County/AE, this will also initiate a Service Review. The Service Review assists the family, AE and ALJ in the interpretation of the Waiver and the issue.

A Service Review happens simultaneously with the fair hearing process and is triggered when you file for a Fair Hearing based on a decision made by the County/AE. This is applicable to waiver participants only in P/FDS, CLW and CW. The Regional Office will review your situation to determine whether the County/AE is following all the rules and regulations about the service. Service reviews were added to the process because it ensures that people who really know the ID/A system are reviewing the cases prior to the case going to a Hearing Officer.

What Happens at the Fair Hearing?

Hearings are held locally (in person) or over the telephone. You may represent yourself or have someone act as a representative for you. Your case will be heard by an Administrative Law Judge. This is a formal process to have your case reviewed by the judge. The Administrative Law Judge will determine whether the County/AE or ODP followed all rules and regulations that apply to your situation. During the hearing, you may provide testimony, documentation, or information. The judge may ask you questions. The County/AE may also present information and facts about the decision. You may ask questions of the County/AE. The final decision from the Fair Hearing will be made within 90 days of filing.

If you disagree with the hearing results, you may ask the Secretary of Human Services for a reconsideration. The reconsideration request must be in writing, addressed to the Secretary of Human Services, but mailed to the Director of Bureau of Hearings and Appeals (BHA). The request must detail the reason for reconsideration and must be sent within 15 days from the date of the Hearing Officer's decision. You may also appeal to the Commonwealth Court.

Keep in mind that once the case goes to a Fair Hearing, the Hearing Officer is not an expert in the ID/A waiver programs and may not know the ID/A system. The Bureau of Hearings and Appeals hears cases from all types of state-run programs —any waiver program, SNAP, MA, etc. The Regional Office will make a recommendation based on any findings within 15 days of the appeal. The recommendation from the Regional Office Service Review will be mailed to you and the County/AE. If you are not satisfied with the outcome or the issue is not resolved, it can go to a hearing. The recommendations from the Service Review may be presented during the Fair Hearing Process, however it is not sent to the Bureau of Hearings and Appeals (BHA).

For more basic information about appeals or to obtain assistance from a legal organization contact Disability Rights Pennsylvania (disabilityrightsPA.org) 1-800-692-7443 or the Pennsylvania Health Law Project (phlp.org) -1-800-274-3258.

What are the Timelines for Waiver Appeals?

If the County/AE or ODP proposes to reduce, suspend, or terminate any current services, they MUST send written notice at least 10 days in advance of the cut-off. If you file an appeal within 10 days of the date of the notice, most waiver services MUST be maintained until there is a resolution of the appeal.

OTHERWISE, YOU HAVE 30 DAYS TO FILE AN APPEAL IN MOST CIRCUMSTANCES.

10 DAY RULE

As soon as the County/AE or ODP mails out the 10-day advance notice of termination, suspension, or reduction of waiver services, you have 10 days to file an appeal with the Bureau of Hearings and Appeals. Unless appealed, the changes in the 10-day advance notice will take effect. The individual/family has 30 days to file an appeal with the Bureau of Hearings and Appeals. If you do give notice within 10 days, your services may not be altered in any way.

This does not apply to services that have not yet started.

The 10-calendar day advance notice is determined from the mailing date of the written notice. The mailing date must be noted at the top of the written notice. The mailing date will be the actual date that the written notice is postmarked by the United States Postal Service. KEEP THE ENVELOPE WITH THE LETTER YOU RECEIVE!

You may file by telephone, however, if you do, then you must follow up with a written appeal within three days. You may ask for assistance to file a written appeal when you call.

Your Supports Coordinator is responsible for explaining your rights to you, assisting you in filing an appeal to any decision that impacts your services, and helping you understand the process and timelines for hearings and appeals. You may also wish to contact a local advocacy organization for assistance. The appendix of this publication has listings for many of the statewide organizations that can help.

An everyday life is the opportunity to fully participate in your community, to achieve greater independence, and to have the full range of opportunities enjoyed by all.

A quality life, as described by the Everyday Lives: Values in Action is:

"I want life my way. I, my family, supporters, and the community make sure the services I choose are proved to be of high quality."

Chapter 9

Ensuring a Quality Life for All

Within the intellectual disabilities/autism system you have the right to choose providers, the staff that supports you, and the right to change your mind, your plan, and the people/providers you selected. When combining the Everyday Lives: Values in Action with the LifeCourse philosophy and tools, you can create and maintain a high quality of life within your community.

What does quality mean to you?

When we talk about quality, we can think about it from more than one perspective. Quality of life is a very personal measure. You can think about your vision and what matters most to you.

Some questions to consider:

- Are you living the life you want?
- Do you have the support you need to build and keep relationships with your friends and family?
- Are you able to access the services you need to be successful -- at work, in the community, and in your personal life?
- Are you happy with the quality of the staff who support you?
- Do you feel safe, secure and respected?
- Are you able to have choice and control in your day-to-day life?
- Is your provider offering services that are person-centered and promote self-determination?

The people who support you and the services you receive should always align with your vision for an everyday life. The LifeCourse Framework and Tools are helpful in helping you to describe and share your vision. Chapter 1 of this publication walks you through the process of outlining your vision and identifying services and supports. Use the LifeCourse Portfolio to guide conversations and planning with your team. Your ISP is a person-centered document that makes sure that you have what is important to you and that services are provided in a way that reflects your preferences, needs, and desired outcomes.

How does the Office of Developmental Programs measure and assure quality?

1. Provider Qualifications

Another way that ODP assures quality is through the provider qualifications process. Providers offering services to individuals within the system must meet qualifications set by ODP. This process specifies requisite skills and competencies for enrollment for waiver providers, as well as the structure that affords all qualified providers the opportunity to enroll as Medicaid Providers.
Standards or qualifications for provider participation are at the discretion of the process is a first step in assuring that providers deliver ongoing and consistent quality services. In addition, this process affords all providers the opportunity to become a qualified provider in Pennsylvania and share this status with individuals and family members, as they make informed choices regarding the services they receive.

2. Provider Profiles

Additionally, ODP created online Provider Profiles. With input from stakeholders, including individuals and families, ODP designed an online resource to share information about the quality of individual provider agencies. The Provider Profile will show data from Independent Monitoring for Quality (IM4Q) in the areas of individual and family satisfaction, choice, inclusion, dignity, and quality of physical settings. The Provider Profiles help you make decisions and select providers for the services you need. View Provider Profiles at this link: MyODP.org

3. Incident Reporting

An "INCIDENT" is when something happens that is not good, can cause you harm, or did cause you to be hurt. This can be things like someone taking your money, hurting or abusing you, or a whole list of things the regulations describe below. 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 provided the protections of the incident management policy. Providers who receive funds or are licensed by ODP must report incidents.

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 1-888-565-9435.

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, emergency closure, fire, hospitalization, individual-to-individual abuse, injury requiring treatment beyond first aid, law enforcement activity, missing person, exploitation (misuse of funds/money), neglect, behavioral health crisis event, rights violation, suicide attempt, medication errors, serious illness, serious injury, 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 SC 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

All incidents are subject to investigation by trained and certified investigators. If you are the victim of an incident, you will be provided the results of the investigation.

4. ODP Quality Assessment and Improvement (QA&I) Process

In 2017, ODP launched Quality Assessment & Improvement (QA&I) to monitor Administrative Entities, Supports Coordination Organizations and Providers. By collecting information about the experience of specific individuals served by each part of the service system, ODP is able to evaluate how well the system works for individuals. Findings from the QA&I process are used to set targets for improvement in each part of the system. The findings of the reviews are made available to the public.

5. Independent Monitoring for Quality

The Independent Monitoring for Quality Program (IM4Q) is another tool that the state and each County/AE use to ensure quality of paid services and unpaid supports being provided. Individuals are randomly selected each year to participate in the IM4Q process. The in-person interviews are conducted locally by independent monitoring teams. Using a standardized questionnaire, you and your family members have the opportunity to give feedback on the supports and services being received. Considerations (suggestions for quality improvement) may be written by the IM4Q team, you or a family member. These considerations are addressed by the Support Coordination Organization (SCO) and the Administrative Entity (AE). Participating in the IM4Q survey offers you the opportunity to express how your life can be improved and provides a process through which the system can respond to your needs. The IM4Q data is collected statewide and may be used to inform systemic changes to the service system, to help insure an everyday life for all. For additional information about the IM4Q program, you can go to Temple University – Institute on Disabilities

Quality at the Local Level

Quality Councils engage stakeholders to review and discuss quality measures. The council is made up of professionals and interested parties. The council's purpose is to assess the quality of services provided in the local community and provide recommendations for improvement based on the analysis of data. The councils will then establish quality management (QM) priorities, identify and adopt improvement strategies, and choose performance measures to evaluate the results of implanted change.

Each County/AE also has a Mental Health/Developmental Programs (MH/DP) Advisory Board. This board is mandated by Article III Section 302 of the MH/MR Act of 1966. The board is to consist of at least 13 members of the community, with representation drawn from at least six different categories. The board meetings (4-6 times a year) are open to the general public.

The board shall have the power and its duty is (as per Article III, Section 303 of the MH/MR Act of 1966):

1. To review and evaluate the county's mental health & developmental program needs, services, facilities and special problems in relation to the local health and welfare needs, services and programs.
2. To recommend to local authorities not less than two persons for the position of administrator.
3. To develop, together with the administrator, annual plans for the mental health & developmental programs required by Sections 301 and 509.
4. To make recommendations to the local authorities regarding the program and any other matters relating to mental health & developmental program services in the County/AE, including purchase of service contracts and the extent of funds required to implement the program.
5. To review performance under the mental health & developmental programs and to recommend a system of program evaluation.

Overall Quality Strategy

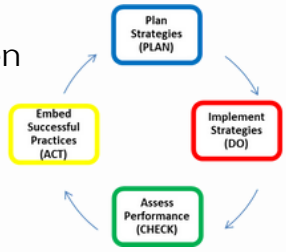
All stakeholders play an important role in quality. ODP's Information Sharing and Advisory Committee (ISAC) publishes an annual report regarding the status of the Everyday Lives recommendations for the public. You can learn more about the ISAC Committee, including the meeting schedule, handouts and agendas at www.myodp.org

The following information was pulled from the introduction to the 2018 Annual Report. It provides a broad overview of the quality improvement process for ODP.

"It is how we are living the vision that matters."
Savannah Logsdon-Breakstone, ISAC member

Following the publication of Everyday Lives: Values in Action, the Information Sharing and Advisory Committee (ISAC) has become ODP's Stakeholder Quality Council. The ISAC has created a detailed series of recommendations, strategies, and performance measures to guide the Office of Developmental Programs (ODP) and gauge its progress in achieving the important goals put forth in Everyday Lives. These strategies and recommendations developed by the ISAC are intended to serve as a guide for everyone engaged in developing, providing, and advocating for services in the ODP system: administrative entities, providers, support coordination agencies, advocacy organizations, local quality councils, and all entities involved on the ISAC.

Many of the recommendations and strategies have already been incorporated in draft waiver applications, regulations, policies, the Supporting Families Collaborative, employment initiatives, and trainings.



As these recommendations and strategies are carried out, the quality improvement framework will be used to gauge progress and continue to plan improvements in the system. Together we will plan, implement, and assess whether we have achieved the outcomes we intended, make changes as needed, and finally embed successful practices in the system. This publication offers a glimpse of where we are today to help us move forward for a better tomorrow.

In line with its commitment to continuous quality improvement, the ISAC reviewed 2018 accomplishments and performance data for each recommendation. While strategies outlined in the Appendix of this document will continue to be implemented for all recommendations, ISAC members agreed to focus additional efforts in 2019 to improve two areas of concern that surfaced during their review:

- Providing training and support for individuals in the areas of healthy sexuality and healthy relationships.
- Ensuring staff interact with individuals with dignity and respect.

The ISAC will continue to serve as the entity that provides sustained, shared leadership and a platform for collaborative strategic thinking for the ODP system. Strategies will continue to evolve as counties, support coordinators, service providers, advocates, and others work in partnership to improve services.
You can find the full report at the following link on the MyODP website.

Chapter 10

Succession Planning

As family members supporting someone with a disability, we must plan for the time when we can no longer provide the necessary support. This is called "succession planning" and the first step to doing it is to identify and develop other individuals/caregivers (or agencies) who may succeed us in providing vital support within our various roles in an individual's life. To make certain that we are properly supporting someone with a disability when making this plan, let's begin with a reminder of our values.

The foundation of Everyday Lives: Values in Action is two statements:

- We value what is important to people with disabilities and their families, who are striving for an everyday life.
- People with disabilities have a right to an everyday life; a life that is no different than that of all other citizens.

The Core Belief, as we know from Charting the LifeCourse: "All people have the right to live, love, work, play, and pursue their life aspirations in their communities." This should be foundation for all discussion and planning regarding what happens in the future. Having a vision and finding the right supports are essential to this plan. Maintaining those supports over time can be challenging; however, most individuals with intellectual and developmental disabilities live with and are cared for by their families. Succession planning asks families to think about what will happen when a family or caregiver is no longer able to provide the daily supports, and to create plans that will provide continued support of a person's everyday life. Making this plan begins with open and honest conversations within families and with their supporters and allies. It is very difficult and sometimes painful to imagine how illness, aging, or death of a family member will impact the lives of those we love. This is true for all families, but in situations where family members rely on one another for daily support, the impact is more dramatic and life changing. It requires courage to discuss these difficult topics. Many parents of individuals with intellectual and developmental disabilities fear that the lives they helped to create for their child, the supports they have developed and fostered over time, the success their son or daughter has achieved will all be at risk, if they are not there to make sure these goals continue.

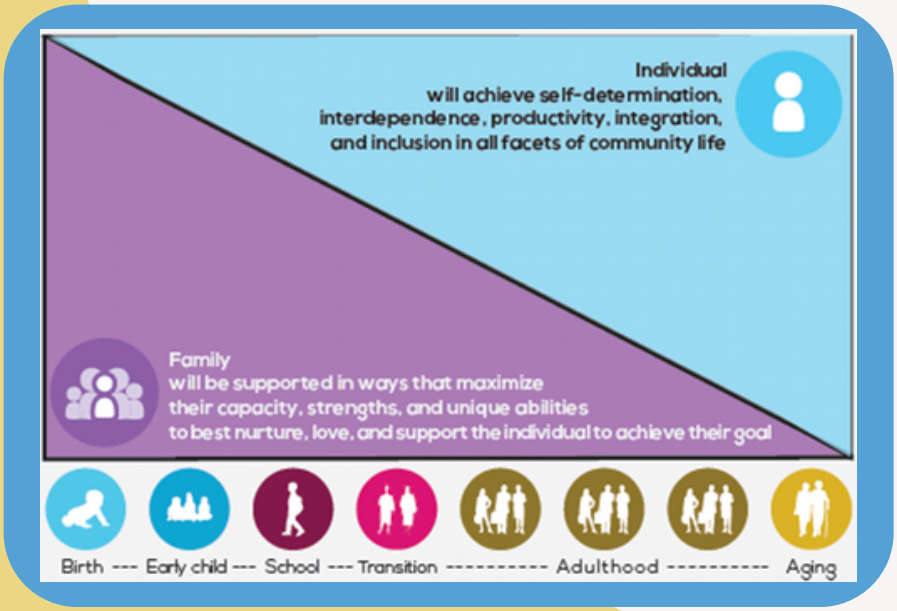
Confronting those uncertainties helps us to deal with them. Questions that keep many parents up at night include:

Who will be there for my son or daughter when I am no longer here?
How will my loved one have freedom, choice and control over their lives long into the future?
On whom can I rely and trust to do what I do?
Who knows and loves my son or daughter as well I do?
Will my son's or daughter's future be safe, healthy, happy and secure without me?

This chapter discusses the steps that you, your family and your supporters can take to ensure that you can have the lives you have envisioned, even when there are changes.

The Family Unit

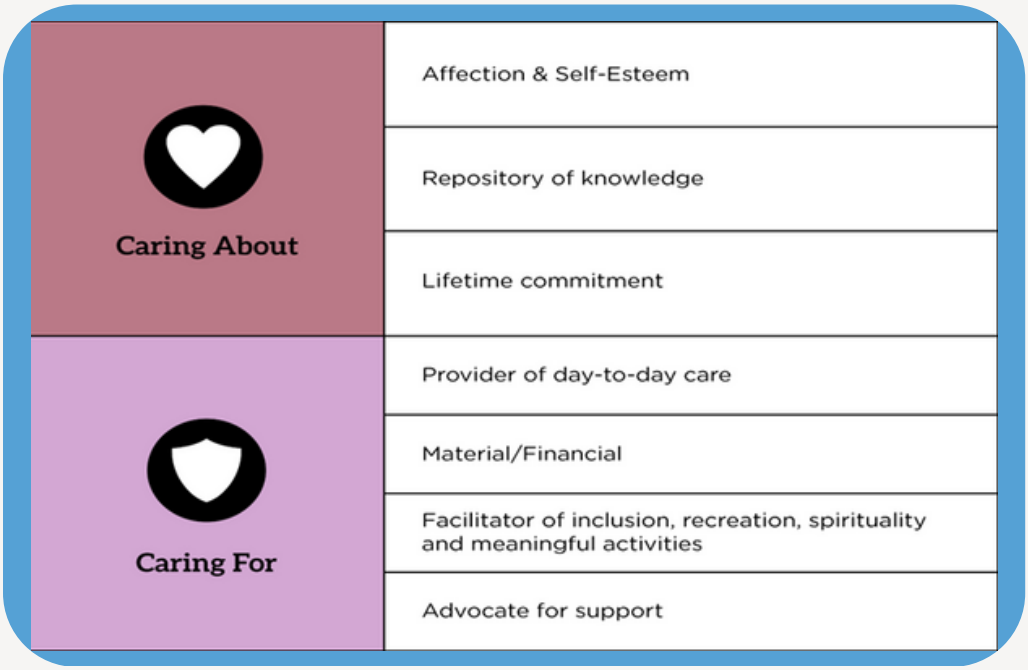
It is important to recognize that all people, no matter their age, exist within a family system. The role of the family changes and evolves as the child grows and changes, from infancy through childhood, school age, transition to adulthood and adult years into aging. During infancy and the early years, the child is more dependent on their parents or family unit. During the transition years and through young adulthood, the person begins taking on decision-making, exercising choice and control, and setting their own vision for the future. Self-determination is a characteristic developed within a person, and as with other learned qualities, parents can start teaching skills and providing opportunities for children to learn self-determination as they grow. As the young person becomes more self-determined, the role of the parent and family changes. The Charting the LifeCourse Framework and tools can help focus planning and discussions at each life stage and help everyone plan for the future, which means building an everyday life for all.



This figure shows how the family role may change over time, as the individual grows and increases their capacity for self-determination. Ultimately, supporting families means that each member of the family should be supported to fulfill their role and feel success.

Reciprocal Family Roles

Here is a graphic illustration of the various roles family members play in each other's lives. Caring About someone is one role played within a family. Caring For is another role. Qualities involved in each role are described below the graphic.



Caring About refers to the emotional support families offer one another. Many members of families fulfill these roles and Care About one another. Here are some examples of the roles:

Affection and self-esteem: Parents love their children. Brothers, sisters, other members of your family and important friends or allies may also fulfill this role. These are people who genuinely care for you. These are people who make you feel good about yourself!

Repository of knowledge: Parents know their children well and have volumes of information from birth to the present day. There are things parents "just know." Parents need to share this information, verbally or in writing, with others who care about you to assure that this knowledge isn't lost. Sharing our stories and history with others can help ensure continuity when other people step into this role in the future.

Lifetime commitment: A parent will continue to love their child and make sure they are cared for long after they are no longer able to physically provide the day-to-day care needed. Siblings, cousins, and other family members are often also committed to caring about you throughout their lifetimes. It is vital to support these relationships over time.

Caring For refers to the tangible support families provide for each other. Here are some roles involved when we Care For someone:

Provider of day-to-day care: Parents make sure their child is safe and well cared for on a daily basis throughout childhood. This responsibility may continue into adulthood when a son or daughter has a disability. The daily care may include a variety of activities including getting dressed, cooking, taking care of the home, and going out into the community.

Material and financial: Parents provide for the material and financial needs of their children during the school years – food, shelter, clothing, etc. However, when a child has a disability, this type of support may continue much longer. Long-term financial and material needs must be addressed in future planning.

Facilitator of inclusion and membership: Parents make sure their children have opportunities to meet people, have fun, participate in their faith or religious rituals, and connect with their community. They often serve as the gatekeeper and facilitator of inclusion in a variety of community groups and organizations.

Advocate for support: Parents and family help find and access supports and services from various sources, like school, government agencies, and the community. They often advocate and navigate systems on their family member's behalf.

Creating Reciprocity

The Caring About and Caring For chart is also helpful in thinking about how ALL members of a family support one another. Creating opportunities for a loved one with a disability to fill these roles for others will help foster ongoing connections and maintain relationships over time. Support isn't a one-way street. We all can play the important roles of Caring About and Caring For each other. You can facilitate connections to facilitate opportunities for your loved one to demonstrate their capacity for both Caring About and Caring For others. For example, sending cards for birthdays or holidays, hosting family get-togethers, and inviting friends and family to enjoy community activities are all ways that members of a family show they Care About and Care For each other.

"Caring About and Caring For" as a Planning Tool

As a family is thinking about succession planning, the chart below can be expanded to create a worksheet for the future. Often it is overwhelming for a parent to figure out who will do everything that they do to help their loved one. If a parent thinks about the Caring About and Caring For roles as opportunities for other family members to contribute, based on their skills and talents, then the need to identify one person to handle everything is not always necessary.

You can add a column with guided questions. Identify who plays that role now, and then figure out who may be able to fill that role in the future. It is possible to have several people in each role. Knowing one another and building upon these relationships will be important, as you begin to share responsibilities. Once you identify the Caring About and Caring For people, it becomes easier to manage conversations.

Further, adding another column to capture action steps or vital information for those fulfilling that role will help in assuring continuity and quality moving forward.

Here is an example of how this concept can be expanded and developed into a mapping tool:

CHARTING the LifeCourse

Mapping Family Roles

This tool is to help families think through the roles they play in their loved one's life, and to help them plan for who else could help fulfill those roles now and in the future.

Reciprocal Roles		People's Roles in _Sarah_____'s life	Looking Ahead	What's important to know, make sure continues, or make happen?
Caring *ABOUT*	Affection and Self-Esteem	Who loves and cares about him/her? Mom, Dad, Sisters, Boyfriend, Boyfriend's family	Who else makes him/her feel loved? Aunts/Uncles/Cousins, Friends Alisha and Marissa, some of her sister's friends (Andrea and Leia)	One on one /quality time is very important to Sarah. Building more relationships with friends will be important for the future, as well as making sure she has time with future nieces/nephews, etc.
	Repository of Knowledge	Who else knows things that others don't know well? (celebrations, traditions, habits, history) Sarah, Mom, Dad, Big Sis Jenny	With whom does he/she have special memories or experiences? Aunts/Uncles/Cousins;	We need to write down all of Sarah's medical history and needs. This would be the piece that others would not know if something were to happen. Sarah knows and can communicate traditions/habits.
	Lifetime Commitment	Who has a lifetime bond with him/her? Mom, Dad, sisters, Friend Marissa, longtime boyfriend/future husband Manny	Who else would step up when/if needed? Aunt Carol, Uncle Jim, Uncle Gary, Uncle Charlie, Cousin Ginny, Cousin Leigh, Manny's family	Emily & Sarah don't get along well now, but Emily would be there for her if she was needed. Working on their relationship is important, as Emily is significantly younger than Jenny
Caring *FOR*	Provider of day-to-day care	Who makes sure activities of daily living and healthcare needs are met? Sarah, Mom, Dad, Arc staff	Who else could provide oversight for these needs? Manny/Manny's family, Jenny's friends Andrea and Leia	Sarah is very independent with ADLs, but needs help with medical appointments/prescriptions, etc. Setting up automatic reorders and delivery may help.
	Material and Financial Needs	Who makes sure his/her day-to-day basic and quality of life needs are met? Sarah, Mom, Dad, Jenny, Arc staff	Who else could help make sure this happens? Manny, Uncle Harvey, Uncle Jim, Uncle Gary, Jenny's friends Andrea and Leia	Managing money is an area where Sarah may be able to develop skills to become more independent, but financial support will always be important.
	Facilitator of Inclusion and Membership	Who helps connect him/her to inclusive opportunities and maintain relationships? Sarah, Mom, Dad	Who would be good at helping him/her connect with and maintain inclusive activities? ??	Sarah wants to be involved in other organizations with more opportunities to meet people. Her current work schedule makes that really difficult – need to explore more opportunities for her to make connections.
	Advocate for Support	Who helps him/her advocate in planning meetings? Sarah, Mom, Jenny	Who else could help advocate for/with him/her? Manny	Need to do an Integrated Support Star (divided) to explore this further. Not sure of options at this point.

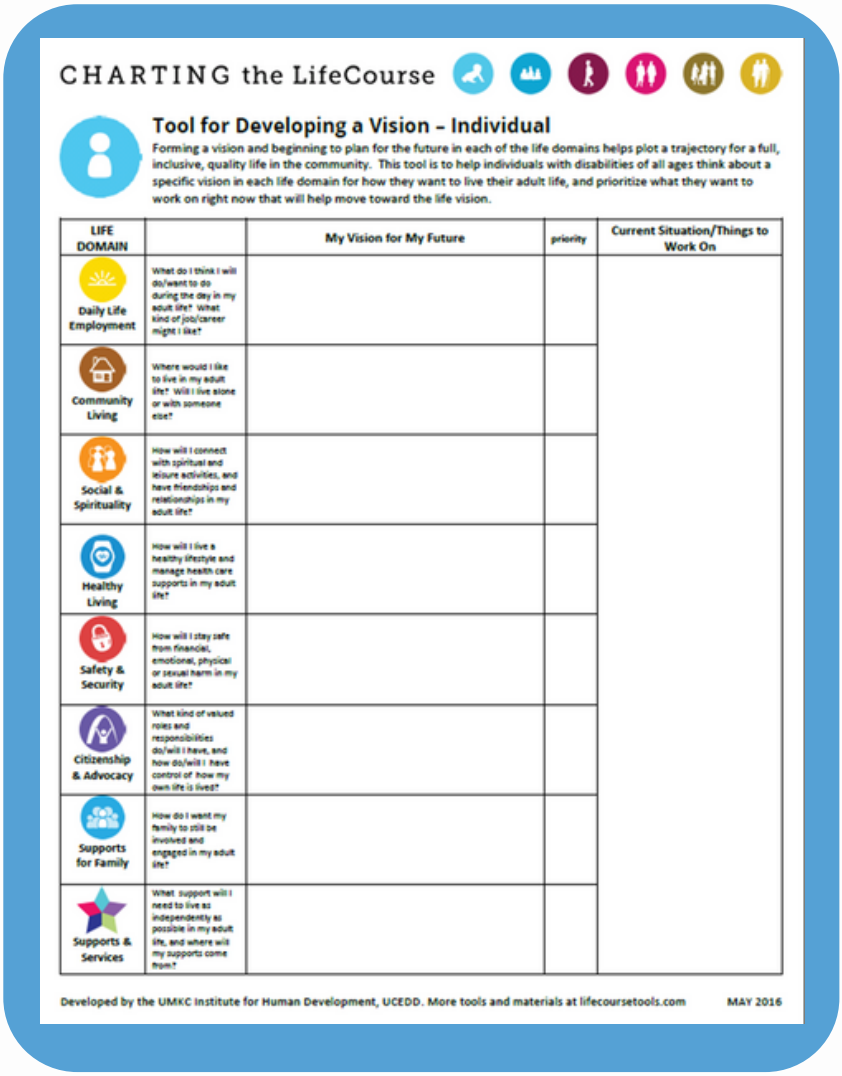
Developed by the UMKC Institute for Human Development, UCEDD. More tools at lifecoursetools.com MAY 2017

Thinking and talking about the different roles of Caring For and Caring About is one way for a family to begin the hard conversation about who will begin to fill roles that are typically and primarily handled by the parents. In this way, family members can think about how they can share caregiving responsibilities in the future.

Using LifeCourse Planning Tools for Planning for the Future

Creating a Vision by Life Domain

The Charting the LifeCourse Tools can be used by families for planning for the future. The Creating a Vision by Life Domain may be especially helpful, because it breaks down the big picture into categories or life domains, which help to organize and prioritize what needs to happen. Another important feature of this tool, like many others in the toolkit, is that there are two sides. One side is from the perspective of the family and the other is from the perspective of the individual. This helps teams make sure they are focusing on the individual's vision of their life, and allows the team to honor and respect that the person has the right to chart their own course and control their future. Family members play an important role in supporting that vision, but ultimately the person should have choice, control, autonomy, freedom, and self-determination in all life domains.



CHARTING the LifeCourse

Tool for Developing a Vision – Individual

Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help individuals with disabilities of all ages think about a specific vision in each life domain for how they want to live their adult life, and prioritize what they want to work on right now that will help move toward the life vision.

LIFE DOMAIN		My Vision for My Future	priority	Current Situation/Things to Work On
Daily Life Employment	What do I think I will do/want to do during the day in my adult life? What kind of job/career might I like?			
Community Living	Where would I like to live in my adult life? Will I live alone or with someone else?			
Social & Spirituality	How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?			
Healthy Living	How will I live a healthy lifestyle and manage health care supports in my adult life?			
Safety & Security	How will I stay safe from financial, emotional, physical or sexual harm in my adult life?			
Citizenship & Advocacy	What kind of valued roles and responsibilities do/will I have, and how do/will I have control of how my own life is lived?			
Supports for Family	How do I want my family to still be involved and engaged in my adult life?			
Supports & Services	What support will I need to live as independently as possible in my adult life, and where will my supports come from?			

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Aging Life Stage

Another important tool that can be used to plan for the future is the Charting the LifeCourse Aging document. This resource captures the important questions that need to be considered as a person ages. It is important to remember that as parents age, their children age too. For all of us, growing older can bring significant changes to our lives. Often, we look forward to retirement, but what will we do to stay active and healthy? As we age, our families and friends may not be around anymore, or won't be able to be a part of our lives in the same way they once were. How will the "golden years" be happy, healthy, and productive?

This 4- page resource is designed to help your loved one, your family and team think about what a good life means later in life, and how best to support you at this life stage.

Who can help?

The Supports Coordinator can play an important role in assisting families planning for the future. Sometimes families hesitate to begin talking about succession planning because they don't know how to start. The SC can help the family think about whom to invite into the conversation. By encouraging families to invite others to team meetings and planning discussions, they are building the extended family's relationships with them, helping those team members begin to understand how the system should work, explaining the Individual Support Planning process, and creating the opportunity for dialogue and relationships between family members beyond the parent and the providers of services. This is especially important when a service provider will be handling much of the day-to-day services and supports. It is vital for the people who Care About the person to build trust and relationships with those who are Caring For the person. The Supports Coordinator is the essential link between all members of the team.

Financial and Legal Issues

Legal and financial considerations are important aspects of succession planning. Special needs trusts, wills, insurance, trustees, power of attorney, supported decision making, medical decision making, guardianship, and ABLE accounts can all play an important role in the future. Everyone is unique, therefore, there is no "one right way" to plan for the future.

During succession planning, it is very important that the family discuss how to guarantee that individuals who are identified to support your loved one will have the authority and resources to fulfill their obligations.

It can be complicated, but it is best to have papers and plans in place, before things happen that aren't expected. It is also very important to make sure that your loved ones know where important documents are kept. If you have a fire safe lock box, who has the key? Do you have a safety deposit box and will others be able to access that in an emergency?

Several financial planning options are available to assist individuals with special needs to maintain a high quality of life well into the future. Special Needs Trusts and ABLE accounts are designed to permit financial resources to remain available to assist an individual with disabilities who receives, or may receive in the future, Medical Assistance (also known as Medicaid or MA) and/or Supplemental Security Income (SSI) benefits, and/or Medicaid Waiver or other services managed by the county Mental Health/Intellectual Disabilities (MH/ID) office or Bureau of Supports, Autism, and Special Populations.

Special Needs Trusts (SNT) – There are 3 different trusts available in the state of Pennsylvania, each of which is defined by how it is funded:

- A "Third Party Funded SNT" involves funding by a third party other than the beneficiary.
- A "Self-Funded SNT" involves funding with the beneficiary's own monies.
- A "Pooled SNT" involves individual accounts funding a common fund with a non-profit fiduciary, similar to a mutual fund program.

ABLE Accounts – A Pennsylvania ABLE Account gives individuals with qualified disabilities and their families and friends, a tax-free way to save for disability-related expenses, while maintaining government benefits mentioned above. The account can be set up by the individual or a parent or guardian. You do not need a lawyer or an accountant to open or maintain an ABLE Account. Go to PaAble.gov for more information.

Tips to get started

Getting started is often the hardest part of planning for the future. Here are some tips that will help you begin thinking and talking about what happens next.

Create a vision for a good life, or everyday life, and share it with everyone.

Give a copy of your LifeCourse Portfolio and/or talk about what you want with your family and friends, your Supports Coordinator and service provider.

Get together with those who are important to you! Invite your family and friends to a relaxed get-together -- with snacks, music, and games. This will help you stay connected with people who care about you. If you can do this regularly, it will help everyone feel comfortable with each other when it comes to talking about difficult topics.

Parents should talk with all their children about the future. Each of us has decisions to make as we age, and including all of our children, siblings and other important family members in those discussions early will avoid conflict, misunderstanding, and confusion if an unanticipated change happens.

Start with a few simple steps. Don't try and make all the decisions at once. Learn about financial planning, one step at a time.

Talk with the Supports Coordinator about the future and what services may be available. It is important to understand what services can be accessed to meet the needs that are currently being met by the family.

Primary caregivers should begin sharing information with other family members (or those thought of as family) and asking for their help on a regular basis. It isn't easy to ask someone to do things for you, but if you start with a couple of simple tasks, people will feel confident and less anxious about stepping in later.

Keep important documents organized and make sure people know where to find them in an emergency. Make sure providers, especially your Supports Coordinator, have contact information for the important people in your life. If something happens to the primary caregivers, service providers will need to know whom to call and how to reach them.

Contact local advocacy resources and keep your ears open for information and trainings that will help you through this planning process.

Call the PA Family Network. We can set up individual mentoring to help you use the Charting the LifeCourse tools in envisioning the future, identifying the Caring About and Caring For people in your life, and designing a strategy for accessing supports and services.

Resources to help you

There are several organizations that publish workbooks and checklists for future planning. Vision for Equality published a workbook that is free to families and available for download. You can find it at www.visionforequality.org/. This workbook was developed by families and for families. Other valuable planning tools from the AARP, The Arc of US, Philadelphia Coordinated Health Care, and other groups are free and may be useful for you. Regardless of which tool you choose, getting started and having courageous conversations is essential for your peace of mind and the best possible future for the whole family.

Appendix A

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.

Eligibility
To be determined to be qualified to receive services under the Medicaid Waiver Program

Employment Networks (EN)
An Employment Network (EN) is approved by Social Security Administration (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.

Enroll
To officially register in a waiver, service, or with your County MH/ID program.

Facility
A building where programs or services take place.

Fair Hearing and Appeal
The right to have a hearing before the Department of Human Services, 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.

Home and Community Based Services Waiver (HCBS Waiver)
provides for supports and services beyond those covered by the Medical Assistance (also referred to as Medicaid) program that enables a person to remain in a community setting.

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 (Medicaid)
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 Human Services 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 Human Services 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 QDDP 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 them. A person living in their own home or family's home can choose to arrange and manage their own services and use Financial Management Services for payroll. They 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 Agency
A public agency that ODP has deemed qualified to provide HCBS Waiver services.

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 Developmental Disability Professional (QDDP)
The QDDP determines whether a person meets ICF/ID level of care criteria. A QDDP 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 (CW), Community Living (CLW), Adult Autism (AAW) and Person/Family Directed Support (P/FDS) Waivers and through other intellectual disability funding. Service definitions provide a standardized definition, unit and billing code for each service.

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.

Supplemental Security Income (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 them, or in the case of some persons with a cognitive disability, an individual acting on their behalf.

Technology Dependent
A person's dependence on technology to replace a vital bodily function or to sustain life.

Targeted Support Management (TSM)
Medical Assistance funded case or service management for persons with intellectual disability.

Under-served 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, Community Living 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, Community Living Waiver and in the Person/Family Directed Support Waiver.

Appendix B

Acronym Guide

AAA
Area Agency on Aging

AAC
Augmentative and Alternative Communication

AAW
Adult Autism Waiver

AAIDD
American Association on Intellectual and Developmental Disabilities

ABA
Applied Behavioral Analysis

ACAP
Adult Community Autism Program

ACRE
Association of Community Rehabilitation Educators

ADA
Americans with Disabilities Act

ADL
Activities of Daily Living

AE
Administrative Entity

AEOA
Administrative Entity Operating Agreement

ANE
Abuse, Neglect, Exploitation

APC
Approved Program Capacity

APS
Adult Protective Services

APSE
Association of People Supporting Employment First

ARB
Architecture Review Board

ARC
Administrative Review Board

ASD
Autism Spectrum Disorder

ASERT
Autism Services, Education, Resources and Training (Collaborative)

ASL
American Sign Language

AT
Assistive Technology

AWC
Agency with Choice

BCS
Bureau of Community Services

BFO
Bureau of Financial Operations

BFS
Base-funded Services

BHA
Bureau of Hearings & Appeals

BH MCO
Behavioral Health Managed Care Organization

BIS
Bureau of Information Systems

BPE
Business Planning Estimate

BPQM
Bureau of Policy and Quality Management

BS
Behavioral Specialist

BSASP
Bureau of Supports for Autism and Special Populations

BSP
Behavior Support Plan

CAO
County Assistance Office

CAP
Corrective Action Plan

CAR
Communication Assessment Report

CART
Communication Access Realtime Translation

CBI
Capacity Building Institute

CBT
Cognitive Behavioral Therapy

CDI
Certified Deaf Interpreter

CDS
College of Direct Support

CES
College of Employment Services

CESP
Certified Employment Support Professional

CHC
Community HealthChoices

CI
Certified Investigator or Certified Investigation

CIR
Certified Investigator Report

CIS
Client Information System

CIT
Certified Investigator Training

CLA
Community Living Arrangement

CLS
Certification and Licensing System

CLW
Community Living Waiver

CMS
Centers for Medicare and Medicaid Services

CSL
Customer Service Line

CO
Change Order (PROMISeTM)

CO
Central Office

COMPASS
Commonwealth of Pennsylvania Application for Social Services

CoP
Community of Practice

CPS
Community Participation Support

CPS
Child Protective Services

CRR
Community Reassessment Report

CtLC
Charting the LifeCourse

CW
Consolidated Waiver

DCAP
Directed Corrective Action Plan

DD
Developmental Disability or Dual Diagnosis

DDTT
Dual Diagnosis Treatment Team

DHHDB
Deaf, Hard of Hearing, DeafBlind

DHS
Department of Human Services

DNA
Data Not Available

DOH
Department of Health

DRP
Disability Rights Pennsylvania

DSP
Direct Support Professional

eCIS
Electronic Client Information System

ECM
Enterprise Case Management

ECS
Enhanced Communication Services

EDE
Essential Data Elements (Survey)

EDL
Everyday Lives

EDLC
Everyday Lives Conference

EDL: VIA
Everyday Lives: Values in Action

EDW
Enterprise Data Warehouse

EI
Early Intervention

EIM
Enterprise Incident Management

EPSDT
Early Periodic Screening, Diagnosis or Treatment

ESC
Error Status Code (in PROMISeTM)

EVV
Electronic Visit Verification

FAI
Functional Assessment Interview

FAST
Functional Assessment Screening Tool

FBA
Functional Behavioral Assessment

FEA
Functional Eligibility Assessment

FFP
Federal Financial Participation

FMAP
Federal Medicaid Assistance Percentage

FMS
Financial Management Services

FPIG
Federal Poverty Income Guidelines

FY
Fiscal Year

GAINWELL
MMIS IT vendor for PROMISeTM (formerly DXC). GAINWELL is not an acronym

GAS
Goal Attainment Scale

HCBS
Home and Community Based Services

HCL
Health Care Level

HCQU
Health Care Quality Unit

HCSIS
Home and Community Services Information System

HHS DC
Health and Human Services Delivery Center

HIPAA
Health Insurance Portability and Accountability Act

HLE
High Level Estimate

HLR
High Level Review

HRST
Health Risk Screening Tool

HSRI
Human Services Research Institute

IADL
Instrumental activities of daily living

ICF/ID
Intermediate Care Facility/Intellectual Disability

ICF/IDD
Intermediate Care Facility/Individuals with Intellectual and Developmental Disabilities

ICF/ORC
Intermediate Care Facility/Other Related Conditions

ICN
Internal Control Number

ID
Intellectual Disability

ID/A
Intellectual Disability and Autism

IDEA
Individuals with Disabilities Education Act

IEP
Individualized Education Program

IM
Incident Management

IM4Q
Independent Monitoring for Quality

IM4Q AST
Independent Monitoring for Quality Annual Statewide Training

IM4Q LP
Independent Monitoring for Quality Local Program

IOD
Institute on Disabilities (Temple University)

IRRC
Independent Regulatory Review Commission

ISAC
Information Sharing and Advisory Committee

ISP
Individual Support Plan

IU
Intermediate Unit

LEAP
Life Experience Appraisal Protocol

LIS
Licensing Inspection Summary

LOC
Level of Care

MA
Medical Assistance

MAR
Medication Administration Record

MAS
Motivational Assessment Scale

MAWD
Medical Assistance for Workers with Disabilities

MCI
Master Client Index

MCO
Managed Care Organization

MedAdmin
Medication Administration

MFP
Money Follows the Person

MH/DD
Mental Health/Developmental Disabilities

MHFA
Mental Health First Aid

MH/ID
Mental Health/Intellectual Disabilities

MMIS
Medicaid Management Information System (PROMISeTM)

MPI
Master Provider Index

MRX
ID assigned in CIS and HCSIS to an ODP Base enrolled individual to allow claims submission in PROMISe. (not an acronym)

MyODP
Office of Developmental Programs' Resource and Training Website

NADD
National Association for the Dually Diagnosed

NASDDDS
National Association of State Directors of Developmental Disabilities Services

NCI
National Core Indicators

NCI AFS
National Core Indicators Adult Family Survey

NCI FGS
National Core Indicators Family Guardian Survey

NCI IPS
National Core Indicators In-Person Survey

NCI SoTW
National Core Indicators State of the Workforce Survey

NEAT
Needs Exception Allowance Tool

NL/NG
Needs Level/Needs Group

NPI
National Provider Identifier

OA
Operating Agreement

OBRA
The Omnibus Budget Reconciliation Act

OCDEL
Office of Child Development and Early Learning

OCYF
Office of Children, Youth & Families

ODEP
Office of Disability Employment Policy

ODP
Office of Developmental Programs

OHCDS
Organized Healthcare Delivery Service

OLTL
Office of Long-term Living

OMAP
Office of Medical Assistance Programs

OMHSAS
Office of Mental Health and Substance Abuse Services

OVR
Office of Vocational Rehabilitation

PADDC
Pennsylvania Developmental Disabiliities' Council

P/FDS
Person/Family-Directed Support Waiver

PADES
Pennsylvania Disability Employment and Empowerment Summit

PAO
Provider Applicant Orientation

PA Plus
Supplemental questions for Pennsylvania that accompany the SIS

PASSR
Pre-Admission Screening and Resident Review

PATC
Pennsylvania Autism Training Conference

PaTTAN
Pennsylvania Training and Technical Assistance Network

PBS
Positive Behavioral Support

PCP
Person-centered Planning

PCT
Person-centered Thinking

PDE
Pennsylvania Department of Education

PDS
Participant-directed Services

PECS
Picture Exchange Communication System

POC
Plan of Correction

PPECC
Prescribed Pediatric Extended Care Center

PPR
Plan to Prevent Recurrence

PPS
Prospective Payment System

PRE
Periodic Risk Evaluation

PROMISeTM
Provider Reimbursement and Operation Management Information System (in electronic format)

PUNS
Prioritization of Urgency of Need for Services

QA
Quality Assurance

QA&I
Quality Assessment and Improvement

QDDP
Qualified Developmental Disability Professional

QI
Quality Improvement

QIP
Quality Improvement Plan

QM
Quality Management

QMP
Quality Management Plan

QPN
Quarterly Progress Notes

QPRO
QuestionPro

RCA
Root Cause Analysis

RH
Residential Habilitation

RM
Risk Management

RON
Report of Need

RPM
Regional Program Manager

RPO
Regional Program Office

SC
Supports Coordinator

SCO
Supports Coordination Organization

SH
Supplemental Habilitation

SIS
Supports Intensity Scale

SLC
Service Location Code

SME
Subject Matter Expert

SNF
Skilled Nursing Facility

SPU
Special Populations Unit

SSA
Social Security Administration

SSD
Services and Supports Directory

SSDI
Social Security Disability Income

SSI
Supplemental Security Income

TBI
Traumatic Brain Injury

TDTS
Training Data Tracking System

TSM
Targeted Support Management (6100s)

UAT
User Acceptance Testing

VF/EA
Vendor Fiscal/Employer Agent

VOH
Virtual Office Hours

VTT
Virtual Targeted Training

WCM
Waiver Capacity Management

WO
Work Order

WIOA
Workforce Innovation and Opportunity Act

Appendix C

At-A-Glance Home and Community Based Services

HCBS At-A-Glance

The Social Security Act, as amended in 1981, allowed states to create Medicaid Home and Community-Based Services (HCBS) programs that would pay for home-based services for elderly or disabled individuals. States HCBS programs must be approved by the Centers for Medicare and Medicaid Services (CMS) in a process known as a 1915(c) waiver.

HCBS programs are sometimes called waiver programs because the state has gotten CMS to waive certain requirements of the Medicaid program. For example, a state must offer Medicaid services equally to all eligible people in the state regardless of their disabling condition. Under these rules a state couldn't run a Medicaid program that paid for prescriptions for physical conditions but not prescriptions for mental conditions. However, with a waiver a state can create an HCBS program that offers benefits to a certain population that it wants to assist, so it could offer HCBS benefits to individuals with physical conditions but not to individuals with mental conditions.

You can access a guide through the Autism NOW Center and the Autistic Self Advocacy Network

Waivers in Pennsylvania

In Pennsylvania, there are four waivers offered by the Office of Developmental Programs (ODP) for people with autism and/or an intellectual disability or developmental disability:

Adult Autism Waiver
Consolidated Waiver
Person/Family Directed Support (P/FDS) Waiver
Community Living Waiver

These waivers are designed to help individuals live more independently in their homes and their communities. We are able to provide a variety of person-centered services promoting independence.

Services offered through Consolidated, Person/Family Directed Support (P/FDS), and Community Living Waivers are:

- Behavior Specialist –- adults only
- Community Participation and Supports (CPS) –- adults only; connects an individual's talents and interests with community opportunities through skill building supports! Currently community-based, but looking into a small center option
- Supported Employment – adults only
- Job Finding
- Job Support
- Career Assessment
- Transportation – adults only; trip to/from a participant's home, a waiver service, activity in the community or resource including to/from a competitive employment opportunity
- Small Group Employment – adults only; support transition to competitive integrated employment (for example, mobile workforce)
- Speech and Language Therapy –- adults only
- In Home and Community Support (IHCS): all ages; help to increase skills in homes and communities
- Family/Caregiver Training and Support –- all ages; provide counseling or training with unpaid family members or caregivers to strengthen relationships, to support with developing expertise to help the individual increase skills, and to successfully return home and/or live in his/her own home

Supports and Services of the Adult Autism Waiver are:

- Speech and Language Therapy –- adults only
- Specialized Skill Development
- Behavioral Specialist Services (BSS) –- age 21 and older; prior would be through IBHS
- Systematic Skill Building (SSB) –- age 21 and older; provides support to acquire independence skills and to become a more integral part of their community
- Community Support –- age 21 and older; assist individuals in acquiring, retaining, and improving communication, socialization, self-direction, self-help, and other adaptive skills
- Career Planning – adults only; develop a plan for competitive integrated employment at or above minimum wage
- Supported Employment – adults only; can be direct or indirect for the benefit of the individual such as working with an employer to help resolve an issue
- Small Group Employment –- adults, support transition to competitive integrated employment (for example, mobile workforce)
- Transportation –- adults, by trip to/from a participant's home, a waiver service, activity in the community or resource including to/from a competitive employment opportunity

How do I know if my loved one is eligible for waiver services?

For someone to be eligible for any of these waiver services, they must have:

- IQ of 70 or below, or a diagnosis of autism spectrum disorder.
- Medical evaluation (ex. MA51) recommending ICF/ID or ICF/ORC (Other Related Conditions).
- Standardized assessment of adaptive functioning showing deficits in three or more areas.
- Testing / clinical judgement records or Standard Diagnostic Tool showing diagnosis of Intellectual Disability or Autism prior to age 22.
- There is no age limit for individuals with an intellectual disability or autism. Individuals with a developmental disability with a high probability of resulting in an intellectual disability or autism are eligible from age 0 through 8.

Referrals for waiver services should come from a Supports Coordinator.

Office of Developmental Programs' Supports Coordination Organization (SCO) Directory

DHS Waiver information

Appendix D

Step-By-Step
Waiver Application

Step by Step Summary of Applying for Services

1.Register for Services with your local County Office (MH/ID)

- ODP Customer Service Hotline at 1-888-565-9435. Necessary documents:
- Proof of current address (this is required)
- Social Security card if you have one
- Medicaid card, if you have one
- Birth certificate or copy
- Copy of psychological evaluation with IQ score; ask if school evaluation with the adaptive scale is acceptable

You must be notified within 30 days if you are eligible for ID/A services and supports. (Determination must be made by the County within 14 days of the receipt of all required documents and information).

2. Apply for Medical Assistance (MA) with the County Assistance Office

- Medical Assistance Customer Service Center 1-877-895-8930

The County Assistance Office must determine eligibility within 30 days of submission of your application.

3. Complete Application for the Medicaid Waiver and Service Delivery Preference with assistance of your Supports Coordinator

- Waiver Application and Service Delivery Preference Form
- A form that expresses your choice of HCBS in place of ICF/ID services

You must be notified within 20 calendar days of submitting completed forms if you are eligible for HCBS services. Always request a copy of documents that you complete and/or sign.

4. If a Waiver opportunity is not available immediately, you will complete a Prioritization of Urgency of Need for Services (PUNS) A standard instrument to determine the urgency of each person's need for services. Based on your questions, you will be placed in one of three categories that defines the urgency of your support needs:

- Emergency – in need of services immediately or within six months
- Critical – in need of services within two years
- Planning -in need of services within two to five years.

Appendix E

How Do I Get Started

ODP SERVICES

A quick guide to the Office of Developmental Programs and services for Individuals with an Intellectual Disability, Autism, and Children with a Developmental Disability in Pennsylvania

What is ODP?

The Office of Developmental Programs (ODP) within the Department of Human Services is responsible for the oversight of intellectual and developmental disability services in Pennsylvania.
Local County MH/ID Programs' verify program eligibility for services through ODP.

Program Eligibility

Must have a diagnosis of one of the following:

- Intellectual disability with a full scale IQ of 70 or below that occurred prior to the age of 22
- Autism diagnosis based on diagnostic tools that occured prior to the age of 22
- Developmental disability between age 0 through 8 with a high probability of an intellectual disability or autism
- Medically complex condition between age 0 through 21 with a current medical evaluation from a licensed medical provider

And also have:

- Substantial adaptive skill deficits in 3 or more of these major life activities: self-care, understanding and use of receptive and expressive language, learning, mobility, self- direction, capacity for independent living
- Intermediate care facility (ICF) level of care
- Medicaid eligibility (required for most services)

Where do I begin?

1. Make an appointment with your local County Office of Mental Health and Intellectual Disabilities (MH/ID). If you need help locating your local county office, call ODP Customer Service Hotline at 1-888-565-9435.
2. Take documents to the appointment that will help establish that you are eligible for services.
   Some examples are medical, psychological, and school records.

What Happens Next?

Once program eligibility is determined, the County Office of Mental Health and Intellectual Disabilities (MH/ID) will offer a choice of Supports Coordination Organizations (SCOs). SCOs will assign a Supports Coordinator to help determine what services are needed and what resources are available to help plan for a good life, an everyday life.

More information available at dhs.pa.gov, Compass.state.pa.us, and MyODP.org

Appendix F

Service Delivery Charts

Service	Consolidated Waiver	Community Living Waiver	PFDS Waiver	Autism Waiver and ACAP
Benefits Counseling	✓	✓	✓	✓
Assistive Technology	✓	✓	✓	✓
Behavioral Support	✓	✓	✓	✓
Communication Specialist	✓	✓	✓	✓
Community Participation Support	✓	✓	✓	✓
Companion Services Companion	✓	✓	✓	✓
Consultative Nutritional Services	✓	✓	✓	✓
Education Support	✓	✓	✓	✓
Supported Employment	✓	✓	✓	✓
Advanced Supported Employment	✓	✓	✓	✓
Family/Caregiver Training and Support	✓	✓	✓	✓
Home Accessibility Adaptations	✓	✓	✓	✓
Homemaker/Chore Services	✓	✓	✗	✓
Housing Transition and Tenancy Sustaining Services	✓	✓	✓	✓

In-Home and Community Support	✓	✓	✓	✗
Life Sharing	✓	✓	✗	✓
Music, Art and Equine Assisted Therapy	✓	✓	✓	✓
Participant Goods and Services	✓	✓	✓	✓
Residential Habilitation	licensed and unlicensed ✓	unlicensed ✓	✗	unlicensed ✓
Respite	✓	✓	✓	✓
Shift Nursing	✓	✓	✓	✓
Specialized Supplies	✓	✓	✓	✓
Supported Living	✓	✓	✗	✓
Supports Broker	✓	✓	✓	✓
Supports Coordination	✓	✓	✓	✓
Therapy – Physical; Speech/Language; Occupational; Orientation, Mobility and Vision	✓	✓	✓	✓
Transportation	✓	✓	✓	✓
Vehicle Accessibility Adaptations	✓	✓	✓	✓

Appendix G

ODP and DHS Overview

Office of Developmental Programs (ODP)

The Office of Developmental Programs is one of eight offices that are part of the Department of Human Services (DHS). ODP's mission is to support Pennsylvanians with developmental disabilities to achieve greater independence, choice, and opportunity in their lives. The office seeks to continuously improve an effective system of accessible services and supports that are flexible, innovative, and person-centered.
Everyday Lives: Values in Action is the guide for ODP as it develops policy and designs programs. Providers of services use these recommendations to support individuals and their families to achieve everyday lives.

The foundation of Everyday Lives: Values in Action is two statements:

- We value what is important to people with disabilities and their families, who are striving for an everyday life.
- People with disabilities have a right to an everyday life; a life that is no different than that of all other citizens.

ODP administers the commonwealth's intellectual disability and autism programs consisting of state operated Intermediate Care Facilities (ICF/IDs), known as "state centers", private ICF/IDs, and home and community-based services (HCBS) for individuals with an intellectual disability and/or autism. ODP administers federal Medicaid HCBS programs in partnership with county/Administrative Entities.

ODP primarily supports children and adults with intellectual disabilities and autism through services and supports available in the following HCBS programs:

- Adult Autism Waiver
- Community Living Waiver
- Consolidated Waiver
- Person/Family Directed Support Waiver
- Adult Community Autism Program – Available for adults with autism living in Dauphin, Lancaster, Cumberland, and Chester Counties in Pennsylvania
- ODP programs are funded through federal and state funds

The intellectual and developmental disability service system is based on a flexible and dynamic system of supports and services close to home and community. The system is tailored to the needs of persons living in their home community which include community residential and day support services. Community residential options include community homes, single apartments with a roommate, or a family living setting. Individuals can also be provided supports in their family homes or their own home.

ODP, in collaboration with the several other DHS program offices, supports a larger DHS initiative to support children with complex medical conditions to have the services necessary to live at home with family. ODP recently amended program eligibility and created new services to provide families with children with medically complex conditions the support they need to care for their child in their home.

Bureau of Supports for Autism and Special Populations – provides administration and program support for ODP's two programs for adults with autism, the Adult Autism Waiver, and the Adult Community Autism Program. This Bureau also provides training, resources and technical assistance related to supporting special populations (i.e., deaf/hard of hearing, children with medical complexities).

Bureau of Financial Management and Program Support – prepares budgets and budget revisions, county allocations, and federal expenditure reports. The bureau provides fiscal management for the private Intermediate Care Facilities (ICFs) for persons with intellectual disabilities program and Targeted Services Management program.

Bureau of Policy and Quality Management – develops and publishes policies and regulations, develops applications for federal funding and evaluates the effectiveness of programs in meeting goals and providing quality services. The Bureau also provides and coordinates training and manages communications related to ODP policy and programs.

Bureau of Community Services – responsible to direct the program planning, management and oversight of the community based intellectual disability and autism programs. These programs consist of the Consolidated Waiver, the Community Living Waiver, and the Person/Family Directed Services waiver. Additionally, this bureau participates in the planning and placement of individuals moving from facilities, public, and private ICFs.

Bureau of State Operated Facilities – responsible for the fiscal and program planning, management, and oversight of all state operated ICFs for individuals with intellectual/developmental disabilities, including the health and safety of all persons living there. This Bureau is also responsible for the planning and placement of individuals transitioning from the state operated ICFs to the community in collaboration with the Bureau of Community Services.

Pennsylvania Department of Human Services (DHS)

DHS' mission is to assist Pennsylvanians in leading safe, healthy, and productive lives through equitable, trauma-informed, and outcome-focused services while being an accountable steward of commonwealth resources. Our vision is that all Pennsylvanians live safe, healthy, and independent lives, free of discrimination and inequity.

DHS exists to help Pennsylvanians lead safe, healthy, and productive lives through equitable, trauma-informed, and outcome-focused services while being an accountable steward of commonwealth resources. DHS serves more than three million Pennsylvanians through services and programs the agency oversees. Our work extends even more broadly by providing the opportunity to empower our communities and support individuals and families across the commonwealth.

DHS' Priorities:

Advocating on Behalf of Vulnerable Populations
DHS oversees daily care and supportive services for Pennsylvanians through residential licensing work, oversight of day and residential treatment programs, supervision of Pennsylvania's county-administered child welfare system, and oversight of long-term care facilities. This work can reach children from birth and their earliest years in child care; services provided to children and youth through foster, child welfare, and behavioral health care systems; adults with disabilities; and our parents and grandparents in long-term care. These vulnerable populations may not always be able to advocate for themselves, and we take our responsibility to protect their health and well-being and strive for continuous growth and quality of services by licensed facilities and provider very seriously.

A Prescription for Housing

A person's home and living circumstances can have a direct impact on their daily well-being and their long-term health. Chronic homelessness and housing insecurity can lead to or exacerbate chronic physical and behavioral health conditions, leading to quality-of-life concerns and high medical costs that could be avoided or offset with stabilizing housing supports. As we seek to strengthen our health care system by embedding a whole-person focus, the importance of housing is a priority.

Expanding Medicaid Coverage Post-Partum to Support Perinatal and Parenting Families
The United States ranks last among industrialized nations in maternal mortality rate, and the Pennsylvania Perinatal Quality Collaborative's report on maternal mortality

rates from 2013-2018 found an extremely troubling, growing trend of pregnancy-related deaths — most of which occur after birth and are more common among Black women. We must reverse this trend.
DHS' eight program offices administer services that provide care and support to Pennsylvania's most vulnerable individuals and families.

Office of Administration (OA)

OA's mission is to create partnerships to deliver quality service to customers through collaboration, consultation and supports. Services provided by OA include administrative appeals/hearings, administrative services, equal opportunity in DHS programs, financial operations, fraud and abuse recoveries in medical assistance and third-party recoveries, procurement, and contract management.

Executive Support Services – ensures that DHS provides prompt public access to its public records while abiding by exemptions and protections in the Right-To-Know Law (RTKL) to safeguard certain information, including confidential personal information of department clients and other third persons. The Director of Transformation also reports to this office creating a culture of continuous quality improvement incorporating Lean principles. Finally, according to the Out of State Travel Policy, DHS employees planning to travel outside Pennsylvania must obtain approval from the DHS Deputy Secretary for Administration and the Governor's office prior to booking travel.

Bureau of Administrative Services – plans, directs and coordinates DHS' administrative support activities, including forms and publications, printing services, mailroom operations, signature authorization, agency records coordination, automotive fleet operations, guardianship programs, management of facilities and property, leasing and space, the surplus equipment warehouse, emergency planning, environmental safety, and continuity of operations.

Bureau of Equal Opportunity – provides technical assistance to DHS program offices and investigates civil rights complaints by clients, residents, patients, or students receiving services through programs administered by or through DHS. BEO also manages the DHS Limited English Proficiency Program, working with program offices to meet federal and state requirements.

Bureau of Financial Operations – provides financial and audit oversight, coordination, and support to executive management in the operation of its programs. These activities include the resolution of federal and other external audits; DHS-operated facility support providing technical assistance on finances to county and provider human services programs; and conducting performance audits and reviews of DHS-operated and funded programs.

Bureau of Hearings and Appeals – functions as the DHS entity charged with conducting administrative hearings and timely adjudicating appeals filed in accordance with state and federal regulations. It covers nearly 280 different areas, including the denial, suspension, termination, or reduction of any DHS-issued benefit.

Bureau of Procurement and Contract Management – responsible for actively supporting the goals of DHS and its program offices by purchasing and acquiring essential goods and services. This bureau also manages solicitations and the review and award process for grant agreements.

Bureau of Program Integrity – ensures MA recipients receive quality medical services and that MA recipients do not abuse their use of medical services; applies administrative sanctions; refers cases of potential fraud to the appropriate enforcement agency; and evaluates medical services rendered by medical providers and managed care organization provider networks.

Office of Child Development and Early Learning (OCDEL)

OCDEL's mission is to provide families with access to high quality services to prepare children for school and life success. OCDEL focuses on creating opportunities for the commonwealth's youngest children to develop and learn to their fullest potential. This goal is accomplished through a framework of supports and systems that help ensure children and their families have access to high-quality services. OCDEL is jointly overseen by the Department of Human Services and the Department of Education.

Bureau of Certification Services – responsible for the regulation of all child care centers, group child care homes, and family child care homes in Pennsylvania. The Bureau of Certification Services conducts inspections of child care facilities and supports providers to better meet and understand regulations.

Bureau of Early Intervention Services and Family Supports (BEISFS) – oversees the Early Intervention (EI) Program for infants, toddlers, and children from birth to school age, through their work with local administrators. BEISFS assures that all eligible children from birth to five with developmental delays receive services and supports that maximize their development, so they are successful in any early childhood education setting. Family Support Programs include, but are not limited to, Evidence-Based Home Visiting (EBHV) programs and Family Centers.

Bureau of Early Learning Policy and Professional Development – develops and implements standards for early childhood education programs and professionals to improve the quality of early learning for young children and provides financial support and technical assistance for programs and professionals. The Bureau is also responsible for establishing and maintaining the rules, regulations, and procedures for the subsidized child care program, Child Care Works.

Bureau of Early Learning Resource Center Operations and Monitoring – provides oversight and technical assistance to Early Learning Resource Centers (ELRCs). The Bureau is responsible for monitoring ELRC grantee program integrity and accountability, proper use of funds, and accurate application of program rules and procedures. ELRCs provide a single point-of-contact for families, early learning providers, and communities to gain information and access services that support high-quality child care and early learning programs.

Bureau of Finance, Administration and Planning – provides fiscal oversight for OCDEL's budget, systems development for quality data, and human resources planning for alignment and integration.

Business Partners:

- Early Intervention Technical Assistance (EITA) – EITA is part of the Pennsylvania Training and Technical Assistance Network and is administered through the Tuscarora Intermediate Unit. EITA works on behalf of BEISFS to provide training and technical assistance to local Infant/Toddler and Preschool EI agencies.
- Pennsylvania Key (PA Key) – The PA Key is administered by the Berks County Intermediate Unit. Created in 2007 by OCDEL, the PA Key implements the work and supports the policies developed and managed by OCDEL. Some of the services provided in support of OCDEL's mission include the Professional Development Registry, Infant and Early Childhood Mental Health Consultation, Program Quality Assessments for early childhood settings, contract management, and administrative support.

Office of Children, Youth, and Families (OCYF)

OCYF's vision is that all children and youth grow up in a safe, loving, nurturing, permanent family, and community. OCYF's mission is to support the provision of quality services and best practices designed to ensure the safety, permanency and well-being of Pennsylvania's children, youth, and families. The child welfare system in Pennsylvania is administered through 67 county children and youth agencies under the supervision of the state through OCYF.

In 2012, through collaboration with partners across the child welfare system, OCYF established the Pennsylvania Child Welfare Practice Model which focuses on children, youth, families, child welfare representatives, and family service partners working as a team with shared community responsibility to achieve the following:

- Safety from abuse and neglect.
- Enduring and certain permanence and timely achievement of stability, supports and lifelong connections.
- Enhancement of the family's ability to meet their child/youth's wellbeing, including physical, emotional, behavioral, and educational needs.
- Support families within their own homes and communities through comprehensive and accessible services that build on strengths and address individual trauma, needs and concerns.

- Strengthened families that successfully sustain positive changes that lead to safe, nurturing, and healthy environments.
- Skilled and responsive child welfare professionals, who perform with a shared sense of accountability for assuring child-centered, family focused policy, best practice, and positive outcomes.

OCYF provides regulatory guidance, oversight, and support for the operation of the county children and youth agencies and private providers who offer direct services to children and families. These services include child abuse prevention and treatment, in-home family support and preservation services, foster care, services to support older youth in transitioning to adulthood and adoption. OCYF provides direct services to delinquent children and youth through the operation of three secure youth development centers and two youth forestry camps. OCYF conducts its operations through the following four bureaus:

Bureau of Budget and Fiscal Support – provides support functions for OCYF and county child welfare agencies, including invoicing for state and federal revenue; budgeting; personnel; management of federal grants and revenue; fulfillment of needs-based budget mandates; and administrative, financial, and operational support.

Bureau of Children and Family Services – responsible for regulatory oversight and monitoring of the delivery of services by county and private children and youth social service agencies, including foster care agencies, adoption agencies, residential treatment facilities and supervised independent living facilities throughout the commonwealth.

Bureau of Juvenile Justice Services – responsible for the management, operations, program planning and oversight of all the youth development center/youth forestry camp facilities. These facilities are designed to provide state-of-the-art treatment, care, and custody services to Pennsylvania's most at-risk youth.

Bureau of Policy, Programs, and Operations – responsible for the development and publishing of policies, procedures and directives governing child welfare activities in the commonwealth and the administration of several grant programs that support the child welfare service delivery system. The Bureau also operates the 24/7 child abuse reporting hotline, ChildLine, and processes child abuse history clearance and FBI fingerprint results.

Office of Income Maintenance (OIM)

OIM's mission is to improve the quality of life for Pennsylvania's individuals and families. OIM promotes opportunities for independence through trauma-informed services and supports while demonstrating accountability for taxpayer resources. Assistance programs administered by OIM serve over 3 million Pennsylvanians, many of whom are elderly, disabled, and/or children.

OIM is responsible for the oversight of the Temporary Assistance for Needy Families (TANF) cash assistance program, Medical Assistance (MA), Supplemental Nutrition Assistance Program (SNAP), which is the new name for the food stamp program, home heating assistance (LIHEAP), employment and training services, and child support. All these programs are administered locally at the county assistance offices found across Pennsylvania, with the exception of child support, which is operated by the County Courts of Common Pleas.

OIM's programs work to fight food insecurity, improve the health and well-being of our residents, provide opportunities for children and families to thrive, and promote quality of life in Pennsylvania.

- SNAP – helps Pennsylvanians offset their food budget. People in eligible low-income households can obtain more nutritious diets with SNAP as their food purchasing power at grocery stores and supermarkets is increased.
- TANF (also referred to as cash assistance) – provides financial stipend to support pregnant women, dependent children and their parents, and children who live with other qualified relatives.
- Medical Assistance (often referred to as Medicaid) – provides healthcare services for eligible individuals.
- LIHEAP – helps families living on low incomes pay their heating bills in the form of cash and crisis grants.
- Child Support - helps custodial parents establish child support orders and ensure reliable financial support for children. It also helps non-custodial parents through employment services and payment arrangements.
- Child Care Works – this subsidized childcare program helps low-income families pay their childcare fees.
- Employment & Training Services – designed to help individuals start and succeed on their career pathway through education and training services to help remediate barriers to family sustaining employment.

Deputy Secretary's Office – oversees each bureau and the entirety of programs administered by OIM. The DSO also includes a branch for OIM communications. The OIM Communications Team identifies needed communications, develops plans for communications initiatives, and creates content for communications received by individuals, the public, stakeholders, and DHS staff.

Bureau of Child Support Enforcement – administers the Child Support Enforcement Program for Pennsylvania in accordance with Title IV-D of the Social Security Act, as amended. The Child Support Enforcement Program determines paternity when necessary and establishes and enforces child support obligations on behalf of custodial parents and their children, including those who receive cash assistance benefits from DHS. Federal and state law require that court-ordered child support be assigned to the Department up to the amount of assistance paid for custodial parents and their children if they are receiving cash assistance. The Commonwealth's Child Support Enforcement Program is nationally recognized as a leader in program performance and ranks first among the largest states in overall performance outcomes. The Commonwealth's Title IV-D Program exceeds all federal performance standards, which include establishment of paternity and court orders for child support and collection of child support obligations.

Bureau of Operations – responsible for the management of the CAOs whose staff members work to determine eligibility for programs designed to assist Pennsylvania's most vulnerable citizens. The programs that are managed by the CAOs include TANF, MA, SNAP, LIHEAP, and Employment & Training services. The bureau also has the primary responsibility for training new employees through a network of staff development sites as well as CAOs and providing training to all staff in the CAOs and district offices. The bureau operates offices in all 67 counties so that Pennsylvania's vulnerable citizens have a place where they can apply for benefits, renew existing benefits, and request supportive services. The bureau also operates a network of customer service centers that are designed to assist clients across the commonwealth over the phone via a toll-free number. The bureau resolves client problems and answers questions received on the telephone hotline, in person, or in letters and electronic mail from clients, legislators, and the public.

Bureau of Policy – develops, introduces, and clarifies policies and procedures, and manages the public assistance programs administered by OIM. The bureau is responsible for developing and maintaining the policies that are needed for OIM to function consistently across the program office and consistent with federal and state laws and guidelines. The bureau publishes these policies in handbooks and publishes supporting regulations, state plans, operations memoranda, policy clarifications, forms, and other documents. They also assist in system development to ensure policy is applied correctly in the system.

Bureau of Program Evaluation – monitors and evaluates the accuracy of eligibility decisions in CAOs, analyzes problem areas, and prepares plans to correct deficiencies in CAOs performance. The bureau is also responsible for satisfying major state and federal reporting requirements and ensuring accurate quality control and monitoring procedures. In addition, the bureau is responsible for the submission of TANF work participation data through the federal TANF Data Report, which includes efforts to ensure maximum hours of participation are recorded, to meet the federal work participation requirement.

Bureau of Program Support – provides administrative support to the other bureaus within OIM and serves as the liaison between those bureaus and other DHS offices. The bureau is responsible for budget and fiscal analysis, personnel administration, acquisition planning, space and equipment management, contract and grant monitoring, resolution of audits, management of the Electronic Benefits Transfer (EBT) System, and EBT risk management. The bureau conducts detailed financial monitoring and analyses and produces statistical monthly reports needed to support program administration decisions. The bureau is also responsible for the development, monitoring, and maintenance of OIM's automated information systems.

Bureau of Employment Programs – manages DHS efforts to assist public assistance recipients to prepare for, secure, and retain employment. The bureau manages a portfolio of programs designed to transition SNAP and TANF recipients to family sustaining wages through intensive barrier remediation services and customized education and training. These programs are administered through contracted partners, and fall into three broad categories: 1) workforce development programs including Employment Advancement & Retention Network (EARN), SNAP EARN, Work Ready, SNAP 50/50, and Contracted Partner Program; 2) education programs including Keystone Education Yields Success (KEYS), SNAP KEYS, Education Leading to Employment and Career Training (ELECT), and TANF Youth Development; and 3) supportive service programs including PA WorkWear, Allegheny Transportation Initiative, PLAN Legal Services and special allowances (SPALs). SPALS are available for persons or families for special needs such as transportation to medical appointments, or technology needed to participate in employment and training programs. BEP also manages the Commonwealth's Refugee Resettlement Program, which helps refugees successfully integrate into communities through public assistance and education and training activities. As of August 2022, this program is 100% federally funded.

Office of Long-Term Living (OLTL)

OLTL is committed to serving more people in communities rather than in facilities, giving them the opportunity to work, spend more time with their families, and experience an overall better quality of life.

Major program areas include:

- Managed Long-Term Services and Supports (MLTSS) provided through Pennsylvania's Community Health Choices (CHC) program·Nursing facilities services
- Medicaid-funded home and community-based services (HCBS)
- State-funded Act 150 HCBS Program
- Living Independently for the Elderly (LIFE), known nationally as the Program for All-Inclusive Care for the Elderly
- Personal Care Home and Assisted Living Residences licensing programs
- Adult Protective Services for those adults living with disabilities ages 18-59

OLTL is responsible for the statewide administration of Pennsylvania's Medicaid-funded long-term services and supports programs. As of April 2022, OLTL serves a population of 405,718 lives through its various LTSS programs to include OBRA, Act 150, LIFE, and CHC. BHSL's licensed facilities serve over 67,000 individuals across Pennsylvania. In addition, program responsibilities include assessing and improving the quality of services received by participants in various long-term living settings and monitoring fiscal and regulatory compliance.

Bureau of Fee for Service Programs – manages provider focused activities and functions in OLTL. The bureau is responsible for MA provider enrollment activities under provider code 03 and provider code 59 in coordination with the Office of Medical Assistance Programs; claims management in fee-for-service (FFS) programs such as the Act 150, as well as other waiver programs, manages the financial management contract, which provides payroll assistance to participants of the self-directed model of care; and manages and coordinates the ventilator dependent and durable medical equipment exception programs. The bureau also directs the Quality Management Efficiency Teams that audit and analyze the quality and efficiency of services delivered by providers who are participants in OLTL waivers and CHC MCO program to ensure compliance with state and federal regulations. BFFSP also manages the operations of seven field offices that conduct quarterly onsite clinical and financial reviews of nursing facilities enrolled in the MA program to ensure the utilization of MA services and reimbursements are appropriate and consistent with regulations and prepares statistical and other reports related to the utilization of MA services for senior management, consumer advocates, and other parties.

Bureau of Quality Assurance and Program Analytics – responsible for ensuring that valid statistical and procedural methodologies are used to collect and analyze quality control data to evaluate and improve service delivery and to ensure compliance with federal and state regulations. The bureau manages data analysis to measure the effectiveness of program design and operations, and ensures required reports are provided to CMS and other regulatory entities, supports OLTL management in the development and implementation of policies and procedures, directs the development and implementation of internal and external training to improve service delivery, oversees the analysis of data obtained through consumer satisfaction surveys and provider performance measures and oversees internal and external activities of OLTL Monthly Quality and Quarterly Quality Review meetings reviewing waiver assurance

Bureau of Finance – manages and monitors OLTL's appropriations and operating budget of approximately $ 13 billion. The bureau serves as liaison to the DHS budget office and the Governor's budget office. The bureau develops and manages related fiscal activities including managed care and fee-for-service rate setting, cost reporting, budget reporting and submissions, audits and fiscal management of grants and contracts.

Bureau of Policy Development and Communication Management – supports the strategic policy and communication goals across all bureaus and the Deputy Secretary's Office. The bureau plans, coordinates, evaluates, and develops policies and procedures across the OLTL, and coordinates internal and external communication with stakeholders. The bureau serves as a liaison with other DHS programs and policy offices and other commonwealth agencies, supports all bureaus in the development of consistent policy, evaluating impact, and improving strategic directions. The bureau also serves as the liaison with DHS's right-to-know law office and submits the state plan and waiver documents to the federal government's Centers for Medicare and Medicaid Services (CMS).

Bureau of Human Services Licensing – responsible for the overall management and coordination of Personal Care Home and Assisted Living Residences licensing programs administered by the Department of Human Services (department) in the Central, Northeast, Southeast and Northwest, and Northeast regions. Responsibilities include the management, planning, direction, oversight, design, development, and administration of licensing statutes, licensing regulations and policy, licensing enforcement policy, licensing training, licensing research, and licensing data systems for more than 1,100 out-of-home care settings licensed by the department serving over 67,000 adults with mental illness, developmental disabilities, physical disabilities, behavioral, and/or cognitive disorders.

Bureau of Coordinated and Integrated Services – responsible for the administration and oversight of the Community Health Choices (CHC) Managed Care Organizations (MCO) that provide managed long-term services and supports to eligible participants. The Bureau is also responsible for the development and management of the Living Independence for the Elderly (LIFE) managed care program. BCIS oversees the Medicare Improvements for Patients and Providers Act (MIPPA) Agreements with Medicare Advantage Plans and Dual Special Needs plans including enforcement of MIPPA requirements to promote the effective coordination of Medicare, Medicaid, and Behavior Health services. This Bureau is also responsible for the oversight of the IEB (independent enrollment broker), incident management, complex case management and of the Independent Assessment Entity (IAE) contract.

Office of Medical Assistance Programs (OMAP)

OMAP's mission is to promote whole-person health for all Pennsylvanians served by Medicaid and CHIP by modernizing systems and programs, ensuring access to the highest value healthcare available, and dismantling institutional and systemic barriers to equity and wellness.

OMAP administers Pennsylvania's Medicaid program, which is the joint state and federal Medical Assistance program that provides coverage for health care for eligible Pennsylvania residents. Medical Assistance provides coverage for health care services through a fee-for-service program as well as through the managed care program that is administered by contracted Managed Care Organizations. OMAP is also responsible for enrolling providers, processing provider claims, establishing rates and fees, contracting, and monitoring of managed care organizations, and detecting and deterring providers and recipients' fraud and abuse.

OMAP Programs:

- Medical Assistance (Medicaid) – Medicaid is a joint federal-state program that provides health care coverage to an estimated 3.1 million Pennsylvanians.
- oTwo delivery systems: fee-for-service and managed care.
- Children's Health and Insurance Program (CHIP) – joint federal-state program established to provide coverage to uninsured children in families whose incomes are too high to qualify for Medicaid.
- Medical Assistance Transportation Program (MATP) – non-emergency medical transportation is a required Medicaid benefit designed to provide transportation to and from medical appointments for enrollees who have no other means of transportation.

- PA eHealth Partnership Program – responsible for establishing and operating the state's electronic health information exchange, known in Pennsylvania as the PA Patient & Provider Network.

Bureau of Data and Claims Management – responsible for activities related to Medical Assistance invoice processing and payments to providers. All claims processing issues that involve the claims processing contractor, the Office of Information Systems, other OMAP bureaus, and other DHS organizations are coordinated and approved by this bureau.

Bureau of Fee-For-Service Programs – responsible for the operational components of OMAP's Fee-for-Service healthcare delivery program.

Bureau of Fiscal Management – responsible for the administration and oversight of fiscal operations for both Fee-for-Service and Physical Health Managed Care delivery systems.

Bureau of Managed Care Operations – responsible for the administration and oversight of mandatory managed care program known as HealthChoices that provides Medical Assistance benefits to eligible recipients in Pennsylvania.

Bureau of Policy, Analysis, and Planning – responsible for the policy and program development for all inpatient, outpatient, and ancillary Medical Assistance services in both the fee-for-service and managed care delivery systems, as well as managing the functions of planning and data analysis for OMAP.

Office of Mental Health and Substance Abuse Services (OMHSAS)

OMHSAS' goal is to transform the children's behavioral health system to a system that is family and youth guided, implement services and policies to support recovery and resiliency in the adult behavioral health system, and assure that behavioral health services and supports recognize and accommodate the unique needs of older adults. Every individual served by the Mental Health and Substance Abuse Service system will have the opportunity for growth, recovery, and inclusion in the community, have access to culturally competent services and supports of their choice and enjoy a quality of life that includes family members and friends.

Bureau of Children's Behavioral Health Services – promotes the emotional wellbeing of children and works to ensure that children with emotional and behavioral challenges live, learn, work, and thrive in their communities. The bureau supports the objective of OMHSAS that is specifically related to the behavioral health needs of children and adolescents: to transform the children's behavioral health system to a system that is trauma informed, family driven, and youth guided.

Bureau of Community and Hospital Operations – responsible for the oversight of county mental health programs, contract oversight of HealthChoices managed behavioral health program, and operation and oversight for the state hospitals and South Mountain Restoration Center.

Bureau of Financial Management and Administration – responsible for the development, implementation, oversight, and continual improvement of all OMHSAS administrative, financial, budgetary and personnel policies, procedures, regulations and performance standards. Specific activities include budget planning, allocation, and monitoring; HealthChoices behavioral health capitation rate setting, analysis, and negotiation; capitation contract development and negotiation; management of the Medical Assistance fee-for-service program; personnel management, including labor relations; contract management and procurement; coordination of statewide training activities. The Bureau Director is a member of the OMHSAS Executive Staff Council.

Bureau of Policy, Planning, and Program Development – responsible for performing a full range of behavioral health system and service planning as well as grant-funded program management functions. This includes managed care design and development, service system design and development, policy and program development, state and county planning and human resource development. Commonly identified as "OMHSAS Policy," the bureau coordinates legislative analysis, bulletin creation, regulation development and the issuance of regulatory waivers of mental health program licensing regulations and bulletins.

Bureau of Quality Management and Data Review – supports the Department's goal of public accountability. By using proven methodologies and evidenced based practices, the bureau works to ensure that adults and children with mental illness and/or substance use disorders, and their families receive high quality services from the Department of Human Services. Additionally, the bureau works to ensure that those in our care are provided a voice in the oversight of the services they receive.

Appendix H

Resources

Pennsylvania County Assistance Offices

Call Center: 1-877-395-8930 COMPASS HHS Home (state.pa.us)

Adams County Assistance Office	717)-334-6241
Allegheny County Headquarters	412-565-2146
Allegheny County Alle-Kiski District	(724) 339-6800
Allegheny County - Liberty District	(412) 565-2652
Allegheny - Three Rivers District	(412) 565-7755
Allegheny County Southeast District	412) 664-6800 or 6801
Allegheny County Southern District	(412) 565-2232
Allegheny County Greater Pittsburgh East District	(412) 645-7400 or 7401
Armstrong County	724-543-1651
Beaver	724-773-7300
Bedford	814-623-6127
Blair	1-866-812-3341
Bradford	570-265-9186
Bucks	215-781-3300
Butler	724-284-8844
Cambria	814-533-2491
Cameron	814-486-3757
Carbon	610-577-9020
Centre	814-863-6571
Chester	610-466-1000
Clarion	814-226-1700
Clearfield	814-765-7591
Clinton	570-748-2971
Columbia	570-387-4200
Crawford	1-800-527-7861
Cumberland	717-240-2700
Dauphin	717-787-2324
Delaware Crosby District	610-447-5500
Delaware Darby District	610-461-3800
Elk County	814-776-1101
Erie	814-461-2000

Fayette	724-439-7015
Forest	814-755-3552
Franklin	717-264-6121
Fulton	717-485-3151
Greene	724- 627-8171
Huntingdon	814-643-1170
Indiana	724-357-2900
Jefferson	814-938-2990
Juniata	717-436-2158
Lackawanna	570-963-4525
Lancaster	717-299-7411
Lawrence	724-656-3000
Lebanon	717-270-3600
Lehigh	610-821-6509
Luzerne Wilkes-Barre District	570-826-2100
Luzerne Hazleton District	570-459-3800
Lycoming	570-327-3300
McKean	814-362-4671
Mercer	724-983-5000
Mifflin	717-248-6746
Monroe	570-424-3030
Montgomery Norristown District	610-270-3500
Montgomery Pottstown District	610-327-4280
Montour	570-275-7430
Northampton	610-250-1700
Northumberland	570-988-5900
Perry	717-582-2127
Philadelphia Headquarters	215-560-7226
Philadelphia Boulevard District	215-560-6500
Philadelphia Chelten District	215-560-5200
Philadelphia Delancey District	215-560-3700
Philadelphia Elmwood District	215-560-3800
Philadelphia Glendale District	215-560-4600

Philadelphia Liberty District	215-560-4000
Philadelphia Somerset District	215-560-5400
Philadelphia South District	215-560-4400
Philadelphia Unity District	215-560-6400
Philadelphia West District	215-560-6100
Pike	570-296-6114
Potter	814-274-4900
Schuylkill	570-621-3000
Snyder	570-374-8126
Somerset	814-443-3681
Sullivan	570-946-7174
Susquehanna	570-278-3891
Tioga	570-724-4051
Union	570-524-2201
Venango	814-437-4341/4342
Warren	814-723-6330
Washington	724-223-4300
Washington Valley District	724-379-1500
Wayne	570-253-7100
Westmoreland	724-832-5200
Westmoreland Donora/Valley District	724-379-1500
Wyoming	570-836-5171
York	717-771-1100

PA Intellectual/Developmental Disabilities/Autism Offices

ODP Customer Service Line: 1-888-565-9435

RA-customerservice@pa.gov

York/Adams	(717) 771-9618
Allegheny	412-253-1399
Armstrong	(724) 548-3451
Beaver	(724) 847-6225
Bedford/Somerset	(814) 443-4891
Berks	(610) 478-3271
Blair	814) 693-3023
Bradford/Sullivan	(570) 265-1760
Bucks	(215) 442-0760
Butler	(724) 284-5114
Cambria	(814) 534-2800
Cambria/Elk	(814) 772-8016
Carbon/Monroe/Pike	(570) 421-2901
Centre	(814) 355-6782
Chester	(610) 344-6265
Clarion	(814) 226-1080
Clearfield/Jefferson	(814) 371-5100
Lycoming/Clinton	(570) 326-7895
Columbia/Montour/Snyder/Union	(570) 275-5422
Crawford	(814) 724-8380
Cumberland/Perry	(717) 240-6325
Dauphin	(717) 780-7050
Delaware	(610) 713-2400
Erie	(814) 451-6800
Fayette	(724) 430-1370
Forest/Warren	(814) 726-2100
Franklin/Fulton	(717) 264-5387
Greene	(724) 852-5276

Huntingdon/Mifflin/Juniata	(717) 242-6467
Lackawanna/Susquehanna	(570) 346-5741
Lancaster	(717) 299-8021
Lawrence	(724) 658-2538
Lebanon	(717) 274-3415
Lehigh	(610) 782-3551
Luzerne/Wyoming	(570) 825-9441
McKean	(814) 887-3357
Mercer	(724) 662-1550
Montgomery	(610) 278-3642
Northampton	(610) 974-7500
Northumberland	570) 988-4187
Philadelphia	(215) 685-5460
Potter	(814) 544-7315
Schuylkill	(570) 621-2890
Somerset	(814) 443-4891
Tioga	(570) 724-5766
Venango	(814) 432-9753
Washington	(724) 228-6832
Wayne	(570) 253-4262
Westmoreland	(724) 830-3617

ASERT & Aid in PA
1-877-231-4244

Temple Institute on Disabilities
(215) 204-1356

PA Family Network
1-844-723-2645

Disability Rights Pennsylvania
1-800-692-7443 (Intake number)