

Adult Autism Waiver Program Participants:

The Office of Developmental Programs (ODP), Bureau of Supports for Autism and Special Populations (BSASP) has recently updated the **Adult Autism Waiver (AAW) Participant Handbook**.

If you have an earlier version of the AAW Participant Handbook, please replace it with this one.

The handbook is designed to provide you with important information about the AAW. Keep it in a safe place and refer to it if you have questions or concerns about your waiver services. Here are some topics that you will find in this handbook:

- What you should expect as a participant in the AAW;
- Your rights and responsibilities as a participant;
- Services available to you within the AAW; and
- Contact information for BSASP.

Please contact BSASP at 1-866-539-7689 or <u>ra-odpautismwaiver@pa.gov</u> if you have questions or concerns about the handbook or the AAW program.

Sincerely,

Bureau of Supports for Autism and Special Populations Office of Developmental Programs

ADULT AUTISM WAIVER PARTICIPANT HANDBOOK

Office of Developmental Programs



December 2023

Adult Autism Waiver Participant Handbook

This **Participant Handbook** gives you important information about the Adult Autism Waiver (AAW). You should keep it in a safe place so you can look back at it if you have questions or concerns about your waiver services. From time to time, you may get new information or forms that can be added to the handbook.

You will also find in this handbook:

- What you should expect as a participant in the AAW.
- Your rights and responsibilities.
- Contact information for the Bureau of Supports for Autism and Special Populations (BSASP), which is responsible for managing the AAW.

Please contact your Supports Coordinator or BSASP if you have questions or concerns about the AAW program using the contact information below:

Support Coordinator (SC) contact information:

SC provider agency/ contact name

SC contact phone number

Bureau of Supports for Autism and Special Populations (BSASP) contact information:

PHONE: 1-866-539-7689 EMAIL: ra-odpautismwaiver@pa.gov

Contents

Chapter 1: Overview of the Adult Autism Waiver	5
What is a Medical Assistance waiver?	5
What is the role of the DHS ODP in the AAW program?	5
What services does the AAW offer?	5
Chapter 2: Supports Coordination	6
What is Supports Coordination?	6
What are the functions of an SC?	6
How to choose a Supports Coordination Organization	7
Chapter 3: The Individual Support Plan (ISP)	10
What is an ISP?	10
Person-Centered Planning	10
You are entitled to:	10
The ISP Planning Process	11
What is in the ISP?	11
Chapter 4: Service Providers	14
Choosing a provider	14
What to expect when working with a provider?	15
What if you are not satisfied with a provider you chose?	15
Chapter 5: Incident Management	16
What events are considered to be "Reportable Incidents"?	16
The participant/family role in Incident Management	18
Chapter 6: Participant Rights & Responsibilities	20
Participant Rights	20
Additional Rights of a Participant Receiving Residential Habilitation (Community Homes or Life Sharing)	20
Exercising Your Rights	21
Participant Responsibilities	22
For Guardians of Participants:	24
Rights to Fair Hearing and Complaints	24
When can you ask for a fair hearing?	24
How do you file a request for fair hearing?	25
How do you make a complaint?	25
How long until a complaint is resolved by BSASP?	25
Rights regarding health information	25

Chapter 7: Additional Information and Resources	27
Autism Services, Education, Resources and Training (ASERT)	27
Participant directed service models	27
What are participant directed services?	27
Can I return to the Adult Autism Waiver if I try self-direction and find out it's not the best fit for me?	28
Self Advocates United as 1 (SAU1)	28
PA Family Network	28
Charting the LifeCourse	29
Housing Information	29
Independent Monitoring for Quality	30
Access to services	31
How do you contact BSASP?	31
Commonly used acronyms	33
Appendix A: Adult Autism Waiver Services	34
Appendix B: Notice of Privacy Practices	47

Chapter 1: Overview of the Adult Autism Waiver

What is a Medicaid or Medical Assistance waiver?

There are many Medical Assistance waiver programs. The Adult Autism Waiver (AAW) is a Home and Community-Based Services (HCBS) waiver. It is authorized under section 1915(c) of the federal Social Security Act. It allows adults who would need care in Intermediate Care Facilities to live in their home and community with the supports they need. Waivers let the state design programs especially for the people helped by each waiver.

What is the role of the Department of Human Services (DHS) Office of Developmental Programs (ODP) in the AAW program?

The Department of Human Services, Office of Developmental Programs, supports children and adults with autism through services and supports available in several different waiver programs. Within ODP is the Bureau of Supports for Autism and Special Populations (BSASP). BSASP is responsible for managing the AAW program. This is done in many ways. BSASP staff:

- Send out applications.
- Review and approve all Individual Support Plans (ISPs).
- Check the qualifications of all service providers.
- Enroll participants and providers into the AAW program.
- Monitor providers to make sure services are being provided according to the waiver.
- Train staff and providers, when needed.
- Occasionally make changes to the waiver and to policies that apply to providers and participants.

What services does the AAW offer?

The AAW offers a wide range of services to support individuals including in-home and community supports, behavior supports, residential services, employment services, therapies, assistive technology, transportation, and more. AAW also allows certain services to be delivered via teleservices if you so choose. Teleservices are services that are provided using remote technology that allows two-way live video communication, such as I-pads, smartphones or laptops (phone calls and texts are not acceptable). See Appendix A of this handbook for a full list of services and descriptions.

Chapter 2: Supports Coordination

What is Supports Coordination?

Supports Coordination, sometimes called case management, is one of the services provided under the AAW. Your Supports Coordinator's (SC) job is to find, coordinate, and monitor the supports and services you receive. The SC makes sure you get all the supports and services you need and that they are listed in your Individual Support Plan (ISP) (see Chapter 3 for more information about ISPs). Your SC does this by working with you, with someone else that you choose to help you (if you choose someone) and with providers of your supports and services. Your SC makes sure that you are healthy and safe and that the supports and services you receive are helping you the way they are supposed to help you.

What are the functions of an SC?

The SC has many jobs under the AAW. The major roles of the SC are:

ISP Development. To develop the ISP, the SC:

- Meets with you to do assessments.
- Schedules ISP team planning meetings.
- Explains all the services available through the AAW and helps you and your team decide which services you need.
- Makes sure that you and the people you choose are part of the ISP planning process and helps you to lead the person-centered planning process, as much as you want and are able to do (see Chapter 3 for more information on person-centered planning).

Locating Services. The SC is responsible for:

- Helping you pick people to be on your ISP team.
- Helping you choose providers for the services on your ISP. The SC also helps you choose a different provider if you want to change your provider.
- Making sure that each provider has a back-up plan ("contingency plan") in case services cannot be delivered as planned, such as if the provider's staff member is ill.
- Helping you find supports outside of the AAW program, if needed.

Coordinating Services and Supports. The SC is responsible for:

- Arranging for you to get the services included in your ISP. This includes services that are paid for through the AAW and supports that are not paid for through the AAW.
- Making sure that you get the services listed in your ISP and helping you with any problems that happen.

• Keeping members of the team, including providers of services, updated about any changes to the ISP, your situation, or other information they need to know.

Monitoring. The SC must:

- Contact you or visit you every month to ask you about your services and to check how you are doing.
- Meet with you in person at least once every three months.
- Meet with you at least once a year in your home and at least once a year in a location outside of your home where you receive services.
- Look at reports from providers to see your progress in reaching your goals.
- Work closely with your providers to make sure that all services are provided as described in your ISP.

Informing you of your rights. The SC will:

- Review your rights and responsibilities with you.
- Explain your right to keep your information confidential and only release it to people who you want to see it.
- Tell you how to tell someone if your rights are not followed or respected. The SC will tell you this when you start the waiver and every year after that.
- Ask you or your legal guardian to sign a paper stating that you have been given information about your rights and will keep it in your file.
- Explain when you can appeal a decision by BSASP and how you can file an appeal.
- Tell you that you can update your ISP at any time and what you need to do to have your ISP updated.

How to choose a Supports Coordination Organization

Using the Adult Autism Waiver Supports and Services Directory, you will need to review the list of Support Coordination providers and choose one who will be the best match for you. You can do this by contacting the Support Coordination Organization (SCO) by phone or email and asking them some questions that can give you an idea of how they do their jobs. It may be helpful to consider a few things that are most important to you. Let SCOs know what is important to you so they can help you to find a good match. Here are some questions you might want to consider.

Does your agency have a website? If so, what is the website address?

If the agency has a website, you may be able to find out information about how long the agency has been around and what the agency's mission statement is. You can look up information like an agency's service area and home office address. You may also be able to learn about the history of an agency.

What to look for: It may be helpful to be able to look at information visually at your own pace rather than listen to answers on a phone. Read the mission statement and consider whether it addresses what

is important to you.

• Where is the SC coming from? How far away from me is that?

An SC who works close to you may know more about what supports and services are in your area. Also, it may be easier for the SC to meet with you more often in person if you are close to where that SC normally works and travels. If you do not know where a place is in relation to where you live, it is OK to ask how far away it is from you.

What to look for: Most SCOs serve multiple counties from a single location. The SCO's main office may not be where the SC staff works. There is no rule about how far away from you an SC can be; it depends on what you are comfortable with.

What happens if I cannot reach my SC?

At some point, you may need your SC when you cannot reach him or her by phone. It is important to know the agency's policy about backup plans, which are also called contingency plans. Ask about short-term situations, such as if your SC is out of the office on a day you need him or her. Also ask about long-term situations, such as if your SC has a major injury or illness and cannot work for a while.

What to look for: Some agencies will offer a substitute staff if your assigned SC is not available. This means working with someone you may not know, but it also means you will have someone to help you if you need it. In case of long-term absences, it is important to know whether the agency could get a different SC to work with you or whether you would need to find a different SCO.

• Who supervises my SC? Is there someone I can contact if I am unhappy with my SC?

It is important for there to be someone you can contact if you are unhappy with services or need a problem to be fixed.

What to look for: AAW requires SCs to have a supervisor. Some agencies may have a supervisor who can also act as an SC.

• If I have a problem with my SC, can I have a different one from your agency? Would I have to go to a different agency to get a new SC?

People are not always a good match for each other. If you want a different SC, you can ask for a new SC. If the agency cannot offer you a different staff, and you and your SC cannot work out your differences, you may have to change to a different SCO of your choice.

What to look for: Some SCOs have several SC staff to pick from or at least have a different staff you can

pick if you would like to choose someone else. Keep in mind, however, that some SCOs are quite small, so it is normal to have only two or three different staff available. Many agencies will offer you a specific SC based on your location but may have other SCs who can help if that SC does not work out.

• How often will my SC expect to see me in person?

The AAW requires that your SC sees you for at least four quarterly monitoring visits a year and an annual ISP review meeting (which some SCs will include in one of the four quarterly visits). There may be times when more frequent contact is helpful and necessary. It is important that your needs and expectations match what the SCO is responsible to provide.

If you choose to do so, your SC may also do one of your four quarterly monitoring visits via teleservices. Teleservices are services that are provided using remote technology that allows two-way live video communication, such as I-pads, smartphones, or laptops (phone calls and texts are not acceptable).

What to look for: Let the SCO know how often you want to meet and ask whether they are willing and able to meet that request. Also, ask if the SC can meet with you more often if a crisis happens.

• How often will my SC talk with me?

The AAW requires that your SC communicate with you at least monthly. You may prefer to have more frequent contact with your SC.

What to look for: Let the SCO know what you prefer and ask whether that is something they can do. Keep reasonable expectations; most SCs are not able to talk with you daily or to talk for hours at a time regularly. You may also want to ask how quickly a SC returns phone calls, if this is important to you. This is also a good time to ask if the SC is willing to talk by text or by email, if you prefer those types of communication.

Would my SC know about county and state resources not offered through the AAW?

There are many resources and supports available that are not part of the AAW. It is important that your SC know and help you to get information about these resources and supports. Your SC should be able to help you with things like Social Security, the Office of Vocational Rehabilitation (OVR), Medical Assistance, and county services. Your SC should be able to answer basic questions and be able to refer you to an agency that can help with difficult questions.

What to look for: Your SC should be able to tell you about some community supports, such as activities or support groups, that meet in your county. Also, he or she should be familiar with your county mental health system and OVR.

Chapter 3: The Individual Support Plan (ISP)

What is an ISP?

An Individual Support Plan, or ISP, is a written plan of your goals, services, and other supports.

ISPs are developed by a planning team that includes you, your representative (if you have asked someone you know to help you as your representative), your SC, and anyone else that you choose to have involved. If you have a court-appointed legal guardian, that person is also part of your team. If you are receiving AAW services, you may ask current service providers to attend the planning team meeting.

Your SC will assist you with the process of developing your ISP. Your ISP is developed using a "person-centered planning" approach, which ensures you are the center of all planning that will affect your life in the present and future.

During the development of your ISP, a lot of information will be collected from you. This includes information about you, your goals, what is important to you, information about your health and medical information, and other kinds of information. This information will all go into your ISP and will be used by your ISP team to understand your needs and desires and plan for your services and supports.

The ISP also includes the services and supports (both waiver and non-waiver) that will best help you reach your goals. They will also include any special help or special arrangements for cultural considerations that you might need. The ISP includes a lot of information that is useful to know for people who provide services to you.

Your SC will write your ISP in clear and easily understandable language. If you find any of the language in your ISP confusing or not clear, you can always ask your SC to explain it to you.

Person-Centered Planning

All ISPs are developed using person-centered planning. Person-centered planning encourages you to lead in the planning of your services and supports by focusing on your interests and what you do well. It means that your ISP will be designed just for you and will be different from anyone else's plan. Person-centered planning is a way for you to say what is important to you and what is important for you in your life.

You are entitled to:

- Direct the ISP planning process as much as you want and ask for help from your SC to do so.
- Help develop and use your ISP. As the participant, you are at the center of planning for your future.

- Have the team meeting at a time and place that is easy for you to attend.
- Have your needs, likes, dislikes, goals and abilities put into your ISP.
- Request to change your ISP when your needs change or upon your request at any time.
- Have a representative and other people you identify help to develop your ISP, be part of your planning team, and support you as you use waiver services.
- Receive the services and supports listed in your ISP.
- Choose where, when, and how to get the services that are stated in your ISP.

The ISP Planning Process

Your ISP must be developed before you receive services through the AAW and must be updated every year. Before the ISP is developed or updated, your SC will do assessments to help you and your team understand your needs, what's working well for you, and how your services and supports need to be changed.

After assessments are completed, you and your ISP team will discuss the services and supports that may be a good fit for you based on your needs. You will decide what services and supports you want, and your SC will put them in your ISP. At the end of the ISP meeting, you and your SC will go over your ISP together. If you agree with what the ISP says, your SC will ask for your initials on the ISP Signature Form. If you don't agree, you should tell your SC why you don't agree. You, the SC and the ISP Team can keep working together until you agree and you want to sign the ISP Signature Form. The SC will send the ISP to BSASP. BSASP will review the ISP and either approve it or ask the SC to make changes to it. If changes are needed, the SC will discuss them with you and the rest of the ISP team. After the changes are made, the SC will send the changed ISP back to BSASP for review. Once BSASP approves the ISP, services included in the ISP can start or continue. You and your team will be given a copy of the approved ISP by your SC.

The ISP is usually written for a year of services. It is reviewed at least once every 12 months or whenever you request that updates be made to the ISP. During the review of your ISP, you and your ISP team can decide to keep the goals and services and supports the same or to change them. In addition, there are certain events that may happen, such as a crisis, that require the ISP team to meet more often to decide whether services need to be changed to better support you.

What is in the ISP?

ISPs contain the following sections:

Individual

- Demographics General information about you, like your age and gender.
- Address Your mailing address, place where you live, e-mail address and phone number.
- Insurance Information about your private insurance if you have it.

- Medicaid Information about your enrollment in the Medical Assistance Program.
- Diagnosis Includes your diagnosis of autism and any other conditions you may have.
- Contacts People you told the SC you would like to be contacted, if needed.

Individual Preferences

- Like and Admire What other people like and admire about you and what you like about yourself.
- Know and Do What kinds of activities you like to do and what is important to you.
- Desire Activities Activities you would like to continue doing, begin to do, or explore doing.
- Important To Things that are important to you.
- What Makes Sense What experiences do and do not make sense in your life RIGHT NOW.

Medical

- Medications/Supplements List of the medications that you regularly take.
- Allergies All of your known sensitivities and allergies.
- Health Evaluations Medical evaluations/appointments in the past 12 months.
- Medical Contacts Medical contacts such as doctors, dentists, etc.
- Current Health Status A summary of health issues that you have experienced in the past 12 months.
- Developmental Information Developmental milestones that happened prior to your 22nd birthday.
- Psychosocial Information Significant behavioral, mental health or psychiatric concerns.
- Physical Assessment Your long-term health history.
- Immunization/Booster List of immunizations and boosters that you have received.

Health and Safety

- General Health and Safety Risks Health and safety risks that you may have, such as not taking the correct medication.
- Fire Safety Your ability to react during a fire or fire drill.
- Traffic Whether you know how to be safe around traffic.
- Cooking/Appliance Use Your ability to safely use cooking and kitchen appliances, prepare meals, and knowledge of safe food storage.
- Outdoor Appliances Your ability to safely use a lawn mower, weed whacker, gas grill, etc.
- Water Safety Your understanding of water safety, including the danger of very hot or very cold water.
- Safety Precautions Your understanding of how to handle and store poisonous substances and ability to read danger signs or warning labels.
- Knowledge of Self-Identifying Information Your ability to give information such as your name, address and phone number.
- Stranger Awareness Your ability to interact with strangers safely.

- Sensory Concerns Whether any of your senses are very sensitive, such as sensitivity to light or sound.
- Meals/Eating Your needs and safety for eating, including whether you have a special diet or are at risk of choking, etc.
- Supervision Care Needs Your ability to be alone safely.
- Health Care Who is responsible for making your health care decisions.
- Health Promotions Any special information about your health care.

Functional Information

- Physical Development Your ability to move around by yourself, climb stairs, and do fine-motor tasks like assembling small objects.
- Adaptive/Self Help Your ability to take care of your personal hygiene and daily living needs.
- Learning/Cognition How you learn best and what supports you need to understand people.
- Communication How you express what you want to say.
- Social/Emotional Information How you deal with social interactions and feelings.
- Education/Vocational Information Your educational information if you are a student.
- Employment/Volunteer Information Your employment or volunteer organization.
- Understanding Communication Ways you communicate without words, such as that pacing may mean you feel anxious.
- Other Non-Medical Evaluations Additional information, such as vocational or counseling assessments.

Goals & Objectives

- Any number of goals may be included in your ISP. These goals can be short term or long term.
- Each goal is also linked to an objective. An objective is considered a "smaller step" to meet your goal. Your team will use the objective to help you to reach that goal.

Service Details

 This section of the ISP lists the services you have chosen to help you reach the goals included in the ISP. Your SC will review and explain the different services available to you through the AAW, including employment services. Each service included in the ISP must be used to help you reach at least one goal included in the ISP. A completed ISP outlines the ways you will achieve goals important to you by using both natural supports and paid services. The ISP will include services and supports that address all of your needs.

Your ISP will include the name of each provider that you have chosen to provide the services listed in the ISP as well as the goals they are going to be working on with you. It will also include how often and for how long you will receive each service.

Chapter 4: Service Providers

The Adult Autism Waiver (AAW) Supports and Services Directory is a list of all the agencies that provide services to AAW participants. It groups agencies according to the service they provide and lists which counties they serve. Your SC will give you a copy of the directory during your first meeting and every year during the review of your ISP. You may also ask your SC for a copy at any time. An electronic version of the Supports and Services Directory can be found here: <u>Adult Autism Programs General Information (myodp.org)</u>.

Providers of AAW services must complete training. The training required depends on the service they provide. The trainings help providers understand the needs of AAW participants and how to deliver good services.

BSASP checks some providers each year to make sure that staff are qualified and that they are following the rules of the AAW and Medical Assistance. BSASP also meets with some participants every year to ask them about their AAW services.

Choosing a provider

Here are some things to ask when choosing a provider:

• Does your agency have a website? If so, what is the website address?

If the provider has a website, you may be able to find out information about the agency's history and values.

What to look for: You should feel comfortable with everything you read on the website. If you do not like something you read on the website, ask follow-up questions or consider another provider.

Does the provider collaborate with community resources for employment and activities?

Some providers have good community networks that may help you to find things to do or employment. **What to look for:** Decide if the types of connections the provider describes are what are important to you.

• Am I able to meet with staff before I choose the provider?

You are more likely to benefit from your services if you like the staff. Meeting the staff will help you to decide how you feel about them.

What to look for: You should feel comfortable with the staff as a professional and recognize they are trained to balance personal and professional boundaries. This is very important to ensure the staff assists you in working towards the goals you set for yourself.

How does the agency handle suggestions, complaints and concerns? If I have a problem or concern, who will fix it?

Providers usually have supervisors and must have a complaint process. Even if you do not think you will have a problem, ask about this now in case something happens in the future.

What to look for: Write down the name and number of the person to contact if you have a concern or

complaint.

What to expect when working with a provider

As a participant in the AAW, you are entitled to:

- Choose a qualified provider who is ready and willing to provide your services.
- Change your service providers at any time.
- Have your providers educate and help you to make choices and understand your rights.
- Tell your provider, your SC or BSASP if you have problems or concerns about any of your providers, including the way your services are delivered.
- Choose where, when, and how you receive the services you need.
- Not participate in an activity or service.
- Have the provider make sure that you have people you want, like your family and friends, help you make choices and plan activities.
- Have your provider help you involve your family and friends in your life, unless you do not want those people in your life.

What if you are not satisfied with a provider you chose?

If at any time you are not happy with a service provider, you can tell your SC and they can help you to fix the problem or help you choose another provider. Your SC can also help you to file a complaint with the provider if you want to do so.

You do not need to tell the SC why you are unhappy, but if you do tell the SC why you are unhappy, it may help the SC decide what to do to help you. For example, if the SC knows that you are not happy with the person that provided services, but you are happy with the agency, you may be able to continue to get services from the same agency and work with a different staff person.

If you are unhappy with your SC or the organization that your SC works for, talk to your current SC about concerns you have, file a complaint with the Supports Coordination Organization (SCO) or ask your SC to change you to another SCO. You may also contact BSASP at 1-866-539-7689 or via e-mail at <u>ra-odpautismwaiver@pa.gov</u>. BSASP can tell you how to submit a complaint or help you switch SCOs.

Chapter 5: Incident Management

All AAW providers are required to make sure that you stay healthy and safe and that your rights are respected. To do this, providers must follow an "incident management" process. When you are involved in an event such as an accident or injury, there must be an immediate response to make sure that you, your staff and others involved are safe. If the event involves provider staff, the agency must try to make sure it does not happen again.

ODP has developed a family guide that is intended to help answer some basic questions and concerns and help in understanding what can be done and expected if someone they care about it involved in an incident. This guide is available on MyODP at <u>ODPs Incident Management Guide for Families</u>.

What events are considered to be "Reportable Incidents"?

- Someone abuses or mistreats you, physically or psychologically.
- You are restrained physically or prevented from leaving an area you want to leave (seclusion).
- You have a mental or behavioral crisis, such as going to the emergency room for a psychological evaluation, contact with crisis services, or contact with law enforcement for crisis support.
- You are admitted to a psychiatric hospital, voluntarily or involuntarily.
- You die (your family is required to report this).
- Someone uses your money or things without your permission or after forcing you to agree.
- You cannot find your medication (in case someone took it).
- If you live somewhere where you pay room and board and you are required to pay for something that should be covered by your board payment, such as utilities or standard furniture.
- You are required to do work without being paid for it.
- There is a fire at your home or somewhere you are visiting.
- You are arrested or are investigated by the police.
- You are missing and people do not know where to find you.
- Someone is supposed to give you medication and makes a mistake or does not give you your medication. These are both called medication errors.
- Someone else is responsible for taking care of you and does not do so or does not do so correctly.
- A staff person who is driving you somewhere gets pulled over by the police.
- Someone who is supposed to take care of you does not know how to take care of you properly or cannot give you the basic necessities, such as clothing and food, that you need.
- You are denied a civil right, such as voting, speaking freely, or using legal services if you want them.

- You need help communicating (or using an interpreter) and are not given that help.
- You are not educated about health (physical or behavioral) choices, or you are not given the right to make health care decisions.
- Your services are not provided as stated in your ISP, and this puts your health and safety at risk.
- You are not given the right to make changes to your services, or the ability to choose where, when and how your services happen.
- Anyone limits your ability to get what you want, takes away something you value, or forces you to do something without a specific plan ("restrictive procedure plan") with BSASP about how they will do this.
- You (or someone responsible for you) are not taking care of yourself and nobody is helping to make that better. This includes things like unsanitary conditions in your home, refusal to take prescribed medications, refusal to maintain hygiene, and refusing to accept services that are necessary to keep you safe.
- You are admitted to the hospital for medical reasons.
- You are hurt and need treatment beyond first aid, such as you need to see a doctor, nurse, or assessment or treatment by emergency services.
- You choke and need someone else to physically help you.
- You are injured accidentally, or you injure yourself on purpose.
- You have medical equipment that does not work properly, causing you to need medical help.
- You have ulcers or bedsores.
- Anyone has sexual contact with you against your will. This includes touching, verbal suggestions, and someone showing you body parts you do not want to see.
- Your staff has any sexual contact with you, with or without your agreement.
- Someone sends you sexual images you do not want or shows you sexual information you do not want to see.
- You pay to stay somewhere (like a residential habilitation or group home), and the place where you stay has to be closed temporarily or permanently.
- You attempt suicide.
- You need to be physically restrained in an emergency.

If you need more information about the types of incidents and what they mean, you can contact your SC or BSASP. You can also review the available trainings posted on MyODP at the links that are below.

Course: Abuse: Detection, Reporting and Prevention of Abuse, Suspected Abuse and Alleged Abuse (myodp.org)

Course: Addressing Day to Day Risks with the Team (myodp.org)

Course: Foundation of Incident Management and Risk Management (myodp.org)

Course: Understanding Incident Management (myodp.org)

Course: Human Rights and Restrictive Procedures: Human Rights in Depth (myodp.org)

Course: Human Rights and Restrictive Procedures – Making a Determination (myodp.org)

Service providers have been told by BSASP which events must be reported. Providers, Supports Coordination Organizations and BSASP have to report any incident to police where there is a possible crime. If you have been abused, neglected, or are the victim of a crime, your provider should refer you to a victim's assistance program.

Adult Protective Services (APS)

Your providers or your SC may also have to call Adult Protective Services (APS) as a result of some incidents, such as those that involved you being abused, neglected, or exploited. APS provides protective services to adults with disabilities between the ages of 18 and 59, and there are times when providers and SCs are required by law to report incidents to APS.

For more information on APS, visit the website, <u>Adult Protective Services (pa.gov)</u>. APS can also be reached by calling 1-800-490-8505.

The participant/family role in Incident Management

There are times when you or your family should report an event. If one of the events listed above happens and there is no provider staff present, you must contact your SC. For example, if there is an incident overnight at home or with your family over the weekend, you, your representative or a family member must tell the SC what happened as soon as possible.

If you, your representative or family member knows about an incident that happened while you were with provider staff, contact that provider agency. You can make sure that the provider knows about the incident and has reported it. If you, your representative or family member still has concerns about the incident or whether the incident was reported, you, your representative or family member may contact the SC or your regional BSASP office for help.

You and your family members are responsible to assist in reporting incidents that have happened to you by:

- Contacting the SC or provider and telling him or her of any incidents that have happened or any situations that affect your health and safety.
- Contacting BSASP if there are concerns related to incidents that may involve SC staff that cannot be solved by the Supports Coordination Organization.

You, your representative or family should never feel afraid to report anything that does not seem right to you, your

representative or your family. The SC and BSASP staff are always willing to talk about anything that may be a concern to you.

If you or your representative or family see or suspect concerns or someone doing something wrong, tell your provider or your SC. You can also call the BSASP Customer Service Line at 1-866-539-7689.

Chapter 6: Participant Rights & Responsibilities

Every participant receiving services through the AAW deserves to be, and is supposed to be, treated fairly. This means you have rights as a participant in the waiver, and you can use those rights to make sure you are being treated with dignity and equally to everyone else. Your rights may not be taken away or withheld at any time. Your rights are protected by the 55 Pa, Chapter 6100 regulations, specifically 6100.181 through 6100.186. If at any time you feel your rights have been violated, tell your SC, your provider, or someone at BSASP.

Participant Rights

- You may not be treated differently because of who you are, such as your skin color, your beliefs, your disability, your religion, your ancestry, if you are a man or woman, if you see yourself as a man or woman, who you are attracted to, what country you were born in, or how old you are.
- You have the right to civil and legal rights given by law, including the right to vote, the right to speak freely, and the right to follow the religion of your choice or follow no religion.
- You may not be treated badly, ignored or uncared for or abandoned. You may not be used or controlled.
- Your body may not be hurt for any reason.
- You have the right to be treated with dignity and respect.
- You have the right to make choices and take chances.
- You have the right to refuse to participate in an activity or service.
- You have the right to decide what activities you do each day and when you want to do these activities.
- You have the right to keep your body and the things you own private.
- You have the right for the things you own to be safe and to get them when you want.
- You have the right to choose a willing and qualified provider.
- You have the right to choose where, when and how to receive the services you need.
- You have the right to voice concerns about the services you receive.
- You have the right to items and services so you can always communicate with others.
- You have the right to participate in creating and carrying out your ISP.
- You or anyone you choose has the right to see and read your records.

Additional Rights of a Participant Receiving Residential Habilitation (Community Homes or Life Sharing)

• You have the right to meet with people who come to see you at planned and unplanned times and to

talk and meet in a private place at any time.

- You have the right to unlimited access to send and receive mail, email, text messages, and other types of communication, unopened, and unread by someone else.
- You have the right to share your contact information with people you choose.
- You have the right to unlimited and private access to phone calls.
- You have the right to control and have your money.
- You have the right to decide with whom you share a bedroom.
- You have the right to choose what furniture goes in your bedroom and how you would like your room to look. You may also help decide how other rooms in your house look.
- You have the right to lock your bedroom door.
 - A lock may be a key, access card, keypad code or other entry item available to you so that you can lock and unlock your door.
- People who work with you are allowed into your room only for an emergency or if you allow them.
- If needed, an item will be given to you that will help you open and close your door without help from someone else.
 - Any item used to lock your door must be easy for you to use and allow you and people who work with you fast entry and exit from your room in the case of an emergency.
- People who work with you will have a key or item that enables them to open your door.
- You have the right to have a key or other item that will lock and unlock the front door of your home.
- The lock on your front door will be easy for you to use and allow you and people who work with you a fast entry and exit in the case of an emergency.
- People who work with you must have a key to your front door.
- If needed, an item will be given to you to help you open and close the front door without help from someone else.
- You have the right to food at any time.
- You have the right to make choices about your healthcare.

Exercising Your Rights

- Your choices may not limit another person and their choices.
- You cannot be treated badly or punished for using your rights.
- Your rights will be limited if a judge orders, in writing, that your rights be limited.
- If you have a court appointed guardian, that person may exercise rights and make decisions for you in the way that the judge wrote the order. As much as you are able and the court order allows, you have the right to contribute in making decisions about your services.
- You have the right to file an appeal when:
 - You are not given a choice between home and community-based services and institutional services.
 - Your request for new or more services is not approved (denied).

- Your choice of a willing and qualified provider is not approved (denied).
- Your current waiver services are not approved (denied), put on hold (suspended), lowered (reduced) or ended (terminated).

Participant Responsibilities

The following is a list of your responsibilities as a participant in the AAW. If you fail to meet these responsibilities, you might lose your services.

Requests from BSASP

BSASP is responsible for making sure you are healthy and safe, you are happy with the services you have, and you get your services the way your ISP says.

If BSASP calls you, sends you an e-mail or letter, or asks to meet with you, you are responsible for responding to BSASP or meeting with BSASP.

Remaining Eligible

You are responsible for making sure that you continue to be eligible for Medical Assistance and the AAW.

You must contact your County Assistance Office (CAO) as well as the Social Security Administration if you get Supplemental Security Income (SSI) if your financial situation or address changes.

You must give your CAO any required documentation if the CAO asks for it.

If you have questions about Medical Assistance, ask your SC for help.

Every year BSASP determines that you continue to be eligible for the AAW by reviewing your assessments and ISP.

If you do not have a SC, ODP staff will assist you in finding a new SC.

SC Monitoring

You are responsible for cooperating with your SC's monitoring activities by:

- Answering calls or returning calls from your SC.
- Keeping your appointments with your SC.
- If you are not able to keep your appointment, you must call your SC to cancel with as much notice as possible. If you cancel your appointment, you must reschedule the appointment. Tell your SC another time when you can meet.

You must meet or talk with your SC to review and monitor your services at least once a month either in person or by telephone.

Monthly contacts with your SC are important to:

- Make sure you are healthy and safe.
- Make sure you are satisfied with the services you receive.
- Make sure your services are being provided the way your ISP says.

You must meet with your SC in person at least quarterly, unless you choose to meet with your SC via teleservices. If you choose to do so, your SC may meet with you once per year via teleservices. Teleservices are services that are provided using remote technology that allows two-way live video communication, such as I-pads, smartphones, or laptops (phone calls and texts are not acceptable).

You must meet with your SC once a year in your home and once a year at a place where you are receiving waiver services outside your home, if you get waiver services outside your home.

You are responsible to report to your SC whether your services are being provided as written in your ISP. This can be done during monthly contact with the SC. You can also call your SC at any time to talk about your services.

ISP Development

You are responsible for:

- Participating in an ISP meeting with your SC every year. You should participate as actively as you can because the services listed in your ISP will be provided to help you meet your needs.
- Participating in required assessments every year to determine your strengths and needs. This information will be used by you and your ISP team to develop an ISP that meets your needs and goals.
- Working toward the goals in your ISP.
- Contacting your SC if you want your services changed in any way, at any time.
- Giving verbal permission to your SC if you want your services changed in any way.
- Giving written permission to your SC no more than 14 calendar days after BSASP approves a change to your ISP.

Providers and Service Delivery

You are responsible for cooperating with your service providers by:

- Keeping in contact with your provider. For example, answering and returning calls, texts, and emails.
- Keeping your appointments and being ready when staff arrives to provide services.
- Calling your service provider to cancel any appointment you cannot keep with as much notice as possible.
- Rescheduling any appointment you cancel. Give your service provider another time when you can meet.
- Treating your staff with respect. You and the people you live with should not yell at, curse or threaten your staff.

Incidents

You are responsible for telling your SC if something happens that is considered a reportable incident in Chapter 5.

You must tell your SC when an incident occurs, even if it happens when you are not getting a wavier service.

For Guardians of Participants:

If you are the Legal Guardian, all responsibilities listed in this section are your responsibilities. Remember that the participant is at the center of the ISP team.

The participant's preferences and needs should drive the service planning process. As much as they are able, participants have the right to contribute to decisions affecting their life. The guardian should let the participant take an active role in planning services and supports. Without the participant's acceptance, services will not be effective.

Right to Fair Hearing and Complaints

Understanding Fair Hearings and Complaints

You have the right to ask the Department of Human Services (DHS) Bureau of Hearings and Appeals to review a determination or decision made by BSASP when you disagree with the decision. This is called requesting a fair hearing or filing an appeal.

A complaint refers to a disagreement or dissatisfaction with the way that a provider is delivering waiver services, including Supports Coordination services. Complaints can include concerns about service quality, services not being provided on time and other topics related to the AAW program.

If you or your representative is unsure whether to file a request for fair hearing or a complaint, you or your representative may talk about any concerns with your SC or BSASP. Your SC or BSASP can give you more information on what to do.

When can you ask for a fair hearing?

You can ask for a fair hearing when BSASP:

- Denies a request to include a new service in your ISP.
- Approves fewer hours of a service that you had been receiving or requested.
- Denies a request to increase the number of hours for a service you are getting.
- Stops a service that you are currently receiving.
- Denies the provider of your choice.
- Ends your waiver enrollment.

Your SC will discuss with you your right to a fair hearing every year when your ISP is reviewed or changed.

How do you file a request for fair hearing?

The request for fair hearing (appeal) must be made in writing and mailed to the address below within 30 calendar days of the date of the letter that tells you about the decision that you want to appeal.

If the decision is to reduce or stop services that you are currently getting and you want those services to continue while you wait for your appeal to be decided, your written request for a fair hearing must be made within 10 calendar days of the date of the letter that tells you about the decision that you want to appeal. BSASP will send the fair hearing request to the DHS Bureau of Hearings and Appeals.

By mail: Department of Human Services, Office of Developmental Programs Attn: Stephanie Maldonado Forum Place, 8th Floor, ODP Suite PO Box 2675 Harrisburg PA 17105-2675

How do you make a complaint?

Waiver Providers are required by the 55 Pa Code Chapter 6100 Regulations (6100.51. Complaints) to have their own process in place to respond to your complaints. The provider should tell you about their process when you select that provider. You can make a complaint about a provider using the provider's complaint process before telling BSASP about the complaint.

You can file your complaint with BSASP by calling BSASP's toll free general information line at 1-866-539-7689. Please leave a message with a daytime phone number, and someone will return your call. You can also file a complaint by sending an email to BSASP at <u>ra-odpautismwaiver@pa.gov</u> or by sending a letter to your BSASP Regional Office. Complaints do not need to be made in writing. Filing a complaint is not needed before requesting a fair hearing, nor does it take the place of a fair hearing.

How long until a complaint is resolved by BSASP?

If you file a complaint with BSASP, it is sent to a BSASP staff person for resolution. BSASP will resolve your complaint within 30 calendar days of getting it and will let you know in writing the complaint's resolution.

Please see "Appendix F: Participant Rights" in the approved waiver at <u>www.dhs.pa.gov</u> for a description of the grievance and complaint processes.

Rights regarding health information

The "Notice of Privacy Practices," which has been included as Appendix B in this manual for your reference, includes important information about the privacy of your medical information. Please review and pay special attention to the "What Are My Rights Regarding My Health Information?" section. It discusses important information about how your medical information may be used and given out and how you may see your health information.

Chapter 7: Additional Information and Resources

Autism Services, Education, Resources and Training (ASERT)

ASERT (Autism Services, Education, Resources and Training) is a partnership of medical centers, centers of autism research and services, universities, and other providers involved in the treatment and care of individuals of all ages with autism and their families. ASERT was developed to bring together resources locally, regionally and statewide.

ASERT is funded at the state level through the Office of Developmental Programs. This partnership allows ASERT to support the mission and values of ODP, while also connecting with the larger autism community across the state.

ASERT supports the autism community throughout Pennsylvania by providing up to date and accurate information and resources through their statewide resource center. ASERT helps individuals with autism and their families learn more about services and resources available and assists them with using the service system in Pennsylvania.

The ASERT Statewide Resource Center can be contacted by phone or email at: 1-877-231-4244 info@paautism.org

Contact ASERT en Español 1-877-231-4244 <u>ASERTespanol@paautism.org</u>

Participant directed service models

ODP offers participant directed services, known as PDS or self-direction, in order to provide people with more choice and control over their services and supports. Participant directed service models let the participant direct the delivery of waiver services which are delivered by support service professionals chosen by the participant.

What are participant directed services?

In the self-direction models, you control how waiver services are provided, which includes doing things like:

- Selecting and hiring your own workers, including family and friends.
- Training the workers to provide services how you want them to be provided.
- Creating your workers' schedules.
- Supervising your workers.
- Dismissing your workers from employment.

There are two ways you can self-direct your services. The option you choose depends on how much responsibility

you want to have. You can also self-direct some services and use a provider agency for other services.

The option to self-direct services is not currently offered in the Adult Autism Waiver (AAW). ODP has set aside openings in the Consolidated, Person/Family Directed Support, and Community Living Waivers for a small number of people currently served in the AAW who want to self-direct their services. If you want to self-direct your services, you would leave the AAW and, if found eligible, would transfer to either the Consolidated, Person/Family Directed Support, or Community Living Waiver.

These openings are given on a first-come, first-served basis. Therefore, depending upon the number of people interested, you may have to wait for an available opening.

The services in the Consolidated, Person/Family Directed Support, and Community Living Waivers have different names, but the kinds of services offered are similar or equal to the services offered by the AAW.

Can I return to the Adult Autism Waiver if I try self-direction and find out it's not the best fit for me?

Once you choose to self-direct services in the Consolidated, Person/Family Directed Support or Community Living Waiver, you will be disenrolled from the AAW and enrolled in one of the other three waivers. Once this happens, you will not be able to return to the AAW. If you want to re-enroll in the AAW, you will be considered a new applicant and may be put on a waiting list.

If you feel self-direction may be right for you, you should discuss your options with your AAW SC, who can give you more information about self-direction.

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. More information about SAU1 can be found by visiting their webpage at <u>Self</u> <u>Advocates United as 1 (sau1.org)</u>

PA Family Network

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. More information about the PA Family Network can be found by visiting their webpage at <u>PA Family Network - Vision For Equality</u>.

Charting the LifeCourse ¹

The Charting the LifeCourse Framework includes a toolkit of resources called the LifeCourse tools. The LifeCourse Framework and tools were created to help people to develop a vision for a good life. They are designed to help you to think about what you need for you to have the life you want. You can use the LifeCourse tools to think about things you can do in your life right now to ensure that you are planning for and moving toward your vision for the future.

The core belief of the LifeCourse Framework is that all people have the right to live, love, work, play and pursue their dreams in the community. This is another way to say that all people and their families have the right to live Everyday Lives.

Your SC can give the LifeCourse tools to you. You can also find them online at:

www.lifecoursetools.com

If you already use the LifeCourse tools, tell your SC. If you feel comfortable doing so, share the tools you completed with your SC and providers. You should tell your SC if you feel you have a good life now and what supports you think you need to have a good life. You can share your LifeCourse tools with anyone you want.

Housing Information

You have the right to choose where to live. Some people choose to move away from their parents or caregivers to live on their own. If you want to live on you own or with roommates, the AAW can give you services to help you to be successful with that choice.

Choosing to live away from family can be difficult. However, there are also many ways to make it easier. Some things that help can be:

- Natural supports (family, friends, neighbors, community members, employers, and more). Everyone needs help from other people.
- Community services (rent and utility discount services, food support such as food banks and food stamps, volunteer organizations, and more). Many people who do not get waiver services also get help from these services.
- AAW services (staff who come to your home to help you, special devices and tools to make your life easier or more successful, and your SC). You can get more services if you need them.

There are also creative solutions to some reasons you may think you cannot live alone. You, your family, and your ISP team can think of what stops you from living alone. Then, you can think about what would make living alone possible for you. Here are some example problems and solutions:

¹Charting the LifeCourse[™] and LifeCourseTools.com is a project of the University of Missouri–Kansas City Institute for Human Development, Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services

• PROBLEM: You do not feel safe alone overnight.

SOLUTIONS: Work with your SC and your ISP team to make goals that help you to learn to be safe alone for longer and longer periods overnight. Make a list of people you can call, and their phone numbers, if you need help in the night. Talk about what tools, such as an emergency call button or motion sensors, would help you to be and feel safe when you are alone.

- PROBLEM: You do not know how to be safe in an emergency, such as if there is a fire in your home.
 SOLUTIONS: Practice safe emergency responses with your family or support staff. Make a list of emergencies that may happen and then make a plan what you would do for each situation. Think about tools, such as an emergency response bracelet, that you could use if an emergency did happen.
- PROBLEM: You cannot afford to live alone.

SOLUTIONS: You can work with your community and your SC to find a roommate. You and your roommate can share the costs of rent and utilities. Talk with your family to see if they would be willing to help you with the cost of living alone. Think about finding a job or asking for more hours if you already have a job. Ask your SC to find information about programs that may help your rent or utilities to cost less.

• PROBLEM: You need help with daily living activities, such as remembering to shower regularly, cooking meals safely, and paying bills correctly.

SOLUTIONS: Work with your SC and ISP team to decide which of these skills are most important. Then, make goals to work on getting better at them. Remember that you can have staff with you most of the time, so you can also plan these activities during times when you have staff to help. If you need more time with staff support, you can ask your SC for more service time.

• PROBLEM: You have no transportation.

SOLUTIONS: Talk with your SC about tools and services that may help you to travel more independently on public transportation. There are also community-based services that help you to get where you need to be. Work with your ISP team to practice using public transportation if it is available in your community.

Independent Monitoring for Quality

Independent Monitoring for Quality (IM4Q) is a way to collect important and helpful information from people receiving services in Pennsylvania. This information is used to improve the lives of people receiving services through ODP.

As a participant in the AAW, you may be asked to participate in an interview to collect IM4Q information. The

interview is done face-to-face by an independent team, which means the people on the team are not from ODP, BSASP or a provider.

The IM4Q team may also conduct a telephone interview with a family member, friend, or guardian. The information gathered from the interviews is used to make improvements in services statewide.

If you are selected for an IM4Q interview, you will receive a letter about it. The interview is voluntary. You will be asked by the IM4Q team member if you would like to participate, and it is your choice if you want to do so. BSASP highly encourages all AAW participants and their representatives to participate in the IM4Q interviews because it is important that your voice be heard to improve services for all Pennsylvanians. This is your chance to bring your point of view about your experiences with the system and your overall quality of life and satisfaction with the services you receive to inform change.

Access to services

Free translation and interpretation services are available for participants with Limited English Proficiency or for participants who are D/deaf.

All written materials for waiver participants and the public are available in both English and Spanish. Written waiver materials can also be translated at no cost into another language as needed. Forms also include a statement in five languages – Spanish, Chinese, Cambodian, Vietnamese and Russian – that tells participants who do not prefer English that they may have the document translated free of charge. If an interpreter is needed, BSASP can use a telephone or virtual interpreter service that has translators for many languages in Pennsylvania, including languages which are less common. Translation and interpretation services can be provided by phone, in writing or in person.

BSASP's toll-free number, 1-866-539-7689, provides instructions for Spanish-speaking callers. Messages can also be left in any voice mailbox in any language, and BSASP will have the message translated. BSASP will return the call with the help of a telephone translator. Participants who prefer written communication can email BSASP at <u>ra-odpautismwaiver@pa.gov</u>.

Supports Coordination Organizations and other AAW providers must make sure participants have access to translation and interpretation services. It is the responsibility of the service provider to notify participants that these services are available for free to participants. Providers may contact BSASP if they need help.

How to Contact BSASP:

BSASP Statewide Toll-Free Number: 1-866-539-7689

Central Region: PO Box 2675 Harrisburg, PA 17105 These are the counties in Central Region:

Adams	Dauphin	Mifflin
Bedford	Franklin	Montour
Blair	Fulton	Northumberland
Cambria	Huntington	Perry
Centre	Juniata	Snyder
Clinton	Lancaster	Somerset
Columbia	Lebanon	Union
Cumberland	Lycoming	York

Western Region:

Piatt Place, Room 490, 301 Fifth Avenue Pittsburgh, PA 15222

These are the counties in the Western Region:

Allegheny	Erie	Potter
Armstrong	Fayette	Venango
Beaver	Forest	Warren
Butler	Greene	Washington
Cameron	Indiana	Westmoreland
Clarion	Jefferson	
Clearfield	Lawrence	
Crawford	McKean	
Elk	Mercer	

Eastern Region:

801 Market Street, Suite 5071 Philadelphia, PA 19107

These are the counties in the Eastern Region:

Berks	Lehigh	Schuylkill
Bucks	Luzerne	Sullivan
Bradford	Monroe	Susquehanna
Carbon	Montgomery	Tioga
Chester	Northampton	Wayne
Delaware	Philadelphia	Wyoming
Lackawanna	Pike	

Autism Waiver Email Address for questions about AAW services: <u>ra-odpautismwaiver@pa.gov</u> Website: <u>Autism Services (pa.gov)</u>

32

Commonly used acronyms

These are common acronyms you may see when reading about services.

AAW	Adult Autism Waiver
ABA	Applied Behavioral Analysis
ADLs	Activities of Daily Living
APS	Adult Protective Services
ASD	Autism Spectrum Disorder
BHA	Bureau of Hearings and Appeals
BSASP	Bureau of Supports for Autism and Special Populations
BSP	Behavioral Support Plan
BSS	Behavioral Specialist Services
CAO	County Assistance Office
CS	Community Support
DHS	Department of Human Services
EIM	Enterprise Incident Management
FBA	Functional Behavior Assessment
HCSIS	Home and Community Information System
ISP	Individual Support Plan
LEP	Limited English Proficiency
MA	Medical Assistance (also called Medicaid)
ODP	Office of Developmental Programs
PDS	Participant Directed Services
PRE	Periodic Risk Evaluation
RO	Regional Office
SC	Supports Coordinator
SBS	Skill Building Specialist
SSB	Systematic Skill Building
SSI	Supplemental Security Income or Social Security Income
SSDI	Social Security Disability Income
SBP	Skill Building Plan

Appendix A: Adult Autism Waiver Services

This appendix describes the services available through the AAW. Please see "Appendix C: Participant Services" at <u>Adult Autism Waiver (AAW) (pa.gov)</u> for the full text of the service definitions and limitations to the services in the approved AAW. If you have questions about any of the services you can get through AAW, you can ask your SC or call BSASP for help.

Service	Page
Assistive Technology	35
Career Planning	35
Vocational Assessment	35
Job Finding	35
Community Transition Services	36
Day Habilitation	36
Family Support	36
Home Modifications	37
Nutritional Consultation	38
Remote Supports	38
Residential Habilitation	38
Community Home	39
Life Sharing	39
Respite	40
Small Group Employment	40
Specialized Skill Development	40
Behavioral Specialist Service	40
Systematic Skill Building	41
Community Support	42
Supported Employment	42
Intensive Job Coaching	43
Extended Employment Supports	43
Supports Coordination	44
Temporary Supplemental Services	44
Therapies	44
Speech/Language Therapy	44
Counseling	44
Transportation	44
Vehicle Modifications	45

Assistive Technology: This service pays for items that you can use to help you be more independent in your daily life. It includes helping you, as well as your representative and informal care network, choose, learn how to use, and care for the item. It also includes fitting the chosen item, if needed. If you are interested in this service talk to your SC. Your SC will help you to request this service.

Some examples of Assistive Technology are iPads, application software, special cooking and eating tools, special computer keyboards, medication dispensers, and equipment that creates speech.

Career Planning: This service helps you identify a career direction and come up with a plan for getting a job. The job you get must pay you at or above the minimum wage and must be integrated (which means a job where you are working alongside people without disabilities). This service can also be used to help you start self-employment.

Career Planning has two parts: Vocational Assessment and Job Finding

Vocational Assessment is used to develop a plan (called a Vocational Profile) to identify a career direction that meets your goals, needs and abilities. The Vocational Profile includes what you need to do or learn to get the job you want.

The Vocational Assessment includes:

- Discovery, or figuring out your likes, interests, skills and abilities. If you choose this service, you will be asked what kind of workplace you would like, how you could get to work, and what support you might need to do the job you want. It also includes reviewing your work history.
- Talking to natural supports (such as family, friends or neighbors), with your permission, who can provide more information about you that may be helpful.
- Helping you to participate in job-related programs such as the Ticket to Work program through the Social Security Administration and work incentives programs that might make it easier to get a job.
- Assistance with finding a certified benefits counselor who can explain to you how working will affect your ability to keep your benefits. This includes Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), or the Supplemental Nutrition Assistance Program (SNAP).
- Determining the kinds of jobs that match your skills, abilities, and interests.
- Short job tryouts to allow you to see if you have the ability to do a certain job or if you are interested in a certain job.

Job Finding helps you find a job with people in the general public that pays minimum wage or more. The job should match you and your employer's needs. It should also be a job that you want. Job Finding includes:

- Looking for jobs that fit your Vocational Profile.
- Working with your natural supports to find contacts and possible jobs.
- Searching for a job.
- Supporting you to start your own business, including finding potential business opportunities, helping you make a business plan, and looking for ongoing supports to run the business.

- Identifying and developing customized jobs, such as working with an employer to create a job that does not exist yet or doing part of an existing job for an employer.
- Setting up informational interviews with potential employers where you can talk to someone working in a job of interest to you so that you can learn more about it.
- Helping you find and schedule job interviews.
- Helping you negotiate reasonable accommodations and supports from the employer to help you do a job.

In some instances, you must be referred to the Office of Vocational Rehabilitation (OVR) before you can receive AAW Career Planning services. Your SC may ask you if you have ever been referred to OVR in the past. Providing the name of your current or former OVR counselor along with any paperwork you have from OVR will help your SC with the next steps to have Career Planning added to your ISP.

An example of Career Planning services is evaluating you for different job skills. This service may also include looking at your interests or experience that might help you to do a job.

Community Transition Services: This service helps you move from an institution to a home in the community by helping to pay for some items and services. You must have lived in the institution for at least 90 days in a row. Institutions include State Hospitals, State Centers, nursing facilities and psychiatric hospitals.

An example of Community Transition Services is paying a security deposit or paying for dishes and glassware for you to move from a State Center to an apartment of your own in the community.

Day Habilitation: This service helps you become more independent. This service also helps you to build and keep social roles and relationships that are important to you. To do this, the day habilitation service must offer you opportunities and needed support to participate in community activities that you choose.

Day Habilitation can also be used to help you gain daily living skills (dressing, eating, and using the toilet) and instrumental activities of daily living skills (communicating, cooking, managing money and time).

If you choose this service, you will usually be at the Day Habilitation facility or out in the community with the Day Habilitation provider for no more than 6 hours per day, 5 days a week.

An example of Day Habilitation services is participating in a choice of scheduled activities with peers.

Family Support: This service provides support for your unpaid family and informal network (such as friends or neighbors) to help develop and maintain healthy relationships among all members of your family, informal network and with you. This service also teaches your family and informal care network skills that they can use to help you reach the goals in your ISP.

The major purpose of this service is to teach your family and members of your informal network skills by building on their strengths. You do not need to be there when this service is provided.

An example of Family Support is teaching family members ways to help you calm down when you are upset and explaining how autism may make it difficult for you to understand why others may be getting upset.

Home Modifications: These are physical changes made to the home where you live, including a home that is owned or rented by your parents, relatives, or someone else with whom you live. If you are getting Residential Habilitation services in a life sharing home, Home Modification services can be used to pay for physical changes to your host family's home if it is privately owned or rented. The changes must be needed for you to remain safe and/or live with more independence.

Some examples of what Home Modifications services can pay for:

- Alarms and motion detectors on doors, windows, or fences.
- Brackets for appliances.
- Locks.
- Changes that need to be made to a home that helps with special sensitivity to sound, light, or other environmental conditions.
- Outdoor gates and fences.
- Installing a shatterproof or break resistant material to replace glass windowpanes.
- Moving electrical switches and sockets lower or higher.
- Widening a doorway, hallway, or landing.
- Modifying bathrooms.

Home Modifications services include the cost to install, repair, and maintain the changes and the cost of warranties for the changes. It also includes, when required by a rental agreement, the cost of returning the property to its original condition.

Home Modification services do not include:

- Home modifications that are for the benefit of the public at large, staff, significant others, or family members.
- General maintenance of the home.
- Adaptations that add to the total square footage of the home.
- Building a new room.
- Building a new home.
- Durable medical equipment.
- Modifications in a home that is owned, rented or leased by a provider agency.
- Modifications that a family or caregiver would be expected to make for a person without a disability.
- Anything that is covered under the Medical Assistance State Plan.

If you are interested in the Home Modification service, talk to your SC. Your SC will walk you through the steps to

get this service if you need it.

An example of Home Modifications services is, if you are sensitive to light, changing the lighting in your home to make it more pleasant for you.

Nutritional Consultation: This service can help you and your family or informal network plan a diet and meals. It can also include learning how to make healthy food choices.

A nutritionist will evaluate your needs and determine how often these services are needed. The nutritionist can work with the other members of your ISP team to help you learn how to eat healthy.

This service does not include buying food.

An example of Nutritional Consultation services is a professional helping you to plan meals. Another example is providing advice on how to help you eat a larger variety of foods.

Remote Supports: This service is designed to use technology to help you live with more independence and privacy in your own home. There are two parts of Remote Supports: the equipment that has two-way real-time communication in your home or community, and the staff that is monitoring (paying attention to) the equipment to see if you need help with your health and safety needs.

The Remote Supports service can pay for things like fall detectors or door sensors that real people pay attention to. If you left home but accidentally left the door to your apartment open, they could contact you to let you know that your door is open and to check that you are OK.

Video cameras and two-way speakers are included as part of the technology that might be available to you, depending on your needs. There are very strict rules about how these cameras and speakers can be used. These rules are there to protect your privacy and the privacy of other people in your home.

There are other rules about how this service can work and how it cannot be used. Your SC can explain these differences to you. If you live in a Residential Habilitation home, your provider can offer you the remote supports you need to live with more independence if they fit in your service plan. This is another situation that your SC can explain to you.

An example of Remote Supports: You like to cook your own dinner, but sometimes you forget to turn off the stove. A stove monitor can be placed on your stove that is connected to your Remote Supports provider. If the monitor detects that the stove has been on for too long, it will send an alarm to the Remote Supports provider, who will then call you to remind you to turn off the stove.

Residential Habilitation: If you need services or support all or most of the time, including overnight, you may want to use this service, but this service should only be used when other services cannot meet your health and safety needs. Residential Habilitation may not be used in place of regular housing. The purpose of this service is to teach

you the skills you need to be able to live with less help so that you would no longer need Residential Habilitation services. If you do not need help all or most of the time, you should use other waiver services to learn skills that will help you live independently.

The goal of Residential Habilitation services is to teach you the skills necessary to live successfully in the community as independently as possible.

Residential Habilitation services can be used to help with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs and IADLs may include bathing, dressing, eating, doing housework, managing money, and cooking. The goal of Residential Habilitation services is to improve your ability to do ADLs and IADL on your own.

The Residential Habilitation service can help you learn communication skills and teach you how to make decisions and how to ask for help when you need it.

Residential Habilitation provides transportation to and from community activities.

Residential Habilitation services will not pay for room and board. You must pay the cost of your housing and food (known as room and board). You must pay the amount it says in your room and board contract. You and your Residential Habilitation provider must both sign a room and board contract every year.

If you were to get this service, you would live in a home in the community, usually with other people who are also receiving services. There are two different types of places where Residential Habilitation services can be provided:

- Community Home: A home that is licensed by ODP and owned, rented or leased by a provider agency. This is sometimes called a "group home." Community homes may not have more than four people living there. The provider agency employs staff who work in the home to provide services to you to help you become more independent.
- Life Sharing: This is when you live with and become a part of a family, often called a "host family" to develop relationships with family members and participate in the community with the family as well as on your own. No more than two people can get Residential Habilitation services at the same time in a Life Sharing Home.

Before Residential Habilitation services are provided, the SC and ISP team must explain to BSASP why your needs cannot be met with services and supports in a different setting. Residential Habilitation should only be considered when all other options have been looked at or tried and will not meet your needs.

An example of a time that Residential Habilitation may be needed is when you need "around the clock" support. This may be because it is not safe at your current home and you need to develop more skills before you can live on your own. This may be due to things such as challenging behaviors, (for example, self-harm and threatening others), needing assistance with Activities of Daily Living (i.e. showering and grooming), or other complex needs that require

a staff person to be with you 24 hours a day.

Respite: This service gives your caregiver a short break if they need one. It is for circumstances when your caregiver is not available at a time when your caregiver would usually be available to support you, such as a long weekend away or vacation. Respite can be provided in your home, or some Respite providers have homes you can go to away from your own home.

An example of a time where Respite services can be used is when a caregiver has jury duty and must be out of the house for a few hours when the caregiver would usually be home.

Small Group Employment: This service gives you the chance to work in your community alongside other people with disabilities. This service helps you to get ready for competitive integrated employment, which is a job paying minimum wage or more than minimum wage at a job site where you work alongside people without disabilities. This service should be used when you need to gain work skills and are interested in working in one of the situations included with this service (see below).

Small Group Employment includes:

- Mobile work force: This uses teams of workers who do their work away from the physical location of the agency or facility. This includes work such as maintenance, lawn care, janitorial services and other similar tasks.
- Work station in industry: This involves individual or group training at an industry site. Training is slowly ended as you develop the skills needed to do the job and meet production standards.
- Affirmative industry: This is a business that sells products or services where people with and without disabilities work together on the same job tasks.
- Enclave: This is a business model where people with disabilities are hired by a business or industry to perform specific tasks while working alongside people without disabilities.

Small Group Employment may be provided without a referral to OVR.

An example of Small Group Employment is participating in a mobile work force team to learn job skills that could be used to help you get a job in the future. Job skills learned can include the importance of being on time, how to take direction from a supervisor and specific skills like yard maintenance.

Specialized Skill Development: This service is used to teach you skills to help with challenges you may have. Specialized Skill Development includes three kinds of services: Behavioral Specialist Services, Systematic Skill Building and Community Support.

Behavioral Specialist Services (BSS) is used to help you with behaviors that interfere with how you want to live your life. This may include disruptive or destructive behaviors, which may make it hard to be active in your community or live at home. BSS includes the development of a Behavioral Support Plan (BSP).

A Behavioral Specialist provides the Behavioral Specialist Service.

- The Behavioral Specialist first gathers information from you and other people who know you, with your permission, to complete an assessment called a Functional Behavior Assessment (FBA). The FBA is done to understand your behavior concerns and the causes of the behaviors.
- The Behavioral Specialist then uses the information from the FBA to write your Behavioral Support Plan (BSP), which includes specific strategies for the team to use when working with you.
- The Behavioral Specialist also has team members collect information (data) on each of the goals in order to determine if progress is being made. This helps the Behavioral Specialist know if the BSP is working or if revisions need to be made.
- After the BSP is developed, the Behavioral Specialist and SC meet with you and the people who support you to explain the BSP and data sheet and answer questions about the plan.
- People learn skills faster and better when they are helped in the same way by everyone who helps them. For that reason, the BSP tells everyone who is in regular contact with you what they should do to help you learn skills.
- BSS includes explaining the BSP to you. It also includes training your family members, people who have regular contact with you like friends and neighbors, and providers so that they understand the BSP and can help you learn the skills that you need to be more independent and to reach your goals.
- The Behavioral Specialist works with the SC to make sure that all of your waiver services follow the BSP. The Behavioral Specialist will ask providers to collect information (data) to see if the BSP is working well or needs to be changed.
- The Behavioral Specialist also develops a Crisis Intervention Plan (CIP). The CIP explains what can be done to help you avoid a crisis. It also explains how to help you if there is a crisis.
- The BSS agency must have someone available 24 hours per day, 7 days per week to help if you have a crisis. This number should be given to you by the Behavioral Specialist in case you would need to use it for emergency purposes.
- The Behavioral Specialist will check to see how well the BSP and CIP are working. If the BSP and CIP are not working well and need to be changed, the Behavioral Specialist will discuss the need for changes with you.

An example of the Behavioral Specialist Service is when you struggle with handling situations that are upsetting. The Behavioral Specialist will develop a plan that is specifically written to provide strategies to help you if you are upset or angry.

Systematic Skill Building helps you learn skills that increase your independence and participation in your home or community. These skills are not behavioral in focus. They include skills like cooking, using public transportation or keeping your home neat.

A Skill Building Specialist provides the Systematic Skill Building service.

• This service works together with other services (such as Community Support) by developing strategies for the team to use to assist you in meeting your goal faster.

- The Skill Building Specialist develops a Skill Building Plan (SBP), which includes specific strategies for the team to use when working with you.
- The Skill Building Specialist also has team members collect information (data) on each of the goals in order to determine if progress is being made. This helps the Skill Building Specialist know if the Skill Building plans (SBPs) are working or if revisions need to be made.
- After the SBP is developed, the Skill Building Specialist and SC meet with you and the people who support you to explain the SBP and data sheet and answer questions about the plan.
- With your permission, the SBP tells everyone who is in regular contact with you what they should do to help you learn skills. Systematic Skill Building includes training family members and providers so that they understand the plan and can help you learn the skills you need. Systematic Skill Building can also include training other people who have regular contact with you (like friends and neighbors) how to use the SBP to help you learn the skills you need to be more independent and to reach your goals.
- The Skill Building Specialist will check to see how well the SBP is working. If the SBP is not working well and needs to be changed, the Skill Building Specialist will discuss the need for changes with you.

An example of the Systematic Skill Building service is when you are receiving the Community Support service, Systematic Skill Building would be added to your plan to support the Community Support staff. The Systematic Skill Building service provider would develop a specific plan for each of your goals and teach you how to use the plan. The Community Support staff would also use the plan to help you reach your goals.

Community Support helps you to gain, keep, and improve skills needed to live in the community. The goal of this service is for you to be more independent.

Community Support services includes helping you to improve the skills you need to be active in the community. This includes helping you meet people, attend social events and develop social relationships. You may also use this service to help you get to know your neighborhood and community where you live, take part in community activities and be involved in hobbies. You may go shopping, volunteer or attend events.

Community Support services can be used to assist you with self-care activities that are usually done at home, such as bathing, dressing, eating, housework, managing money, or cooking.

Community Support can also be used to attend an outing or event with other people also receiving AAW services. If this is something you are interested in, you should talk to your SC. Your SC can help you set this up.

Some examples of Community Support services are helping you use public transportation, make new friends, and handle money. Community Support services can also be used to help you with personal hygiene, cooking, grocery shopping, or following a daily schedule.

Supported Employment: This service is used if you need support to keep a job. If you get this service, you must have competitive, integrated employment. That means a job paying at least minimum wage where you are working alongside people without disabilities. The Supported Employment service may also be used to support you if you

are self-employed.

Supported Employment has two parts: Intensive Job Coaching and Extended Employment Supports.

Intensive Job Coaching provides on-the-job training and support to help you learn how to do a new job for an employer or for a self-employment situation, when you are new to the job or when the job duties have changed, and you need more support.

Intensive Job Coaching includes:

- Providing onsite job training and skills development.
- Assisting you with working with natural supports, such as coworkers and your supervisor, in the workplace.
- Coordinating with employers, coworkers and supervisors, as necessary, either with you or, with your permission, without you present.
- Training you on how to use public transportation to and from the place of employment.

You could use this service if you need a lot of on-the-job support to keep your job. Intensive Job Coaching should be used when you need services for more than 20% of your work week. For example, if you work 20 hours a week, Intensive Job Coaching would be used to provide support for more than 4 hours per week and up to 20 hours per week. When you receive Intensive Job Coaching, you should need less support over time as you learn the job and your supervisor and co-workers become more familiar with you. After Intensive Job Coaching services are no longer needed, Extended Employment Supports can be used instead, if needed.

The Extended Employment Supports service is used if you need some help to keep your job but are mostly able to do your job without support. Extended Employment Supports should be used when you need services for 20% or less of your work week. For example, if you work 20 hours a week, Extended Employment Supports could be used to provide support for less than 4 hours per week.

Extended Employment Supports includes:

- Reminding you of good workplace practices.
- Reinforcing skills learned prior to employment or during the period of Intensive Job Coaching.
- Coordinating with employers, employees and coworkers (including maintaining coworker supports), either with you or, with your permission, without you present.

In some instances, you must be referred to the Office of Vocational Rehabilitation (OVR) before you can receive AAW Supported Employment services. Your SC may ask you if you have ever been referred to OVR in the past. Providing the name of your current or former OVR counselor along with any paperwork you have from OVR will help your SC with the next steps to have Supported Employment added to your ISP.

An example of Supported Employment services is when a staff person goes with you to work until you have learned the routine of your workplace.

Supports Coordination: Please see Chapter 2: Supports Coordination for information on Supports Coordination.

Temporary Supplemental Services: This service provides extra staff for a short time when there is a concern about your health and welfare. This service is for times when something happens that has a negative effect on you and makes it more difficult for you to get through your normal day-to-day activities.

An example of Temporary Supplemental Service is providing extra support after you had an unexpected family crisis that you are having difficulty coping with, such as the loss of a loved one.

Therapies: These services are provided by healthcare professionals.

Therapies provided through the AAW include:

- Speech/Language Therapy: This service is provided by a licensed speech therapist or certified audiologist. It needs to be recommended by a certified or certification-eligible audiologist or a licensed speech therapist.
- Counseling: This service is provided by a licensed psychologist or licensed psychiatrist. It may also be provided by a licensed social worker, licensed marriage and family therapist or licensed professional counselor. It is provided directly to you.

You must have reached the limits included in your Medical Assistance State Plan before getting therapy services through the AAW.

An example of therapies is a licensed professional counselor meeting with you privately once a week to talk about ways to think about and work through anxiety.

Transportation: The transportation service provides you with options to get to and from services, work and activities specified in your ISP. There is an annual limit on the amount of Transportation that is paid by the waiver. The transportation service offers two options:

- Public transportation: This option pays for your use of public transportation, such as a bus, subway, or ride sharing services like Uber or Lyft.
- Transportation-Trip: This option pays for you to get to and from your home, a waiver service, activity in the community or work. If it is used to get to work, the job must be competitive integrated employment which is a job paying minimum wage or more than minimum wage at a job site that includes people without disabilities doing the same or similar work. Transportation-Trip may be provided by a friend or family member, but this must first be arranged with your SC because there are certain steps that have to be taken before the waiver can pay someone for this service.

An example of when transportation would be used is to help you to get to an event with a friend without staff support to work on a socialization goal in your ISP.

Vehicle Modifications: Vehicle Modifications are changes to an automobile or van. The vehicle must be your main form of transportation. The changes must be needed for your health, welfare and safety and must be for the purpose of helping you live more fully in the community.

If you need Vehicle Modifications, they must be for one of the following things:

- Vehicular lifts
- Interior changes to seats, head and leg rests, and belts
- Customized devices necessary for you to be transported safely in the community, including driver control devices
- Changes needed to help you with a special sensitivity to sound, light or other environmental conditions
- Raising the roof or lowering the floor so that a wheelchair will fit in the automobile or van

Vehicle Modification services do not include the following:

- Changes to the vehicle that are not of direct medical or remedial help to you
- Regularly scheduled upkeep of a vehicle, except upkeep and maintenance of changes that were made as part of Vehicle Modification services
- Changes to a vehicle owned or rented by a provider

Vehicle Modifications cannot be used to buy or lease vehicles for you.

There are some financial limitations to this service. If you think you are interested in pursuing a vehicle modification, talk to your SC to find out about those limitations.

An example of a Vehicle Modification is adding a lift to a van to help you if you are in a wheelchair.

NOTE: The Notice of Privacy Practices document in Appendix B can also be accessed online at: <u>https://www.dhs.pa.gov/providers/Providers/Documents/MA/s_001608.pdf</u>

Appendix B: Notice of Privacy Practices

NOTICE OF PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

Este aviso contiene información importante acerca de la privacidad de su información médica. Si necesita este aviso en otro dioma o alguien para que interprete, comuniquese con la Oficina de Asistencia de su Condado. La asistencia bilingüe serà gratuita.	Данное уведомление содержит важные сведения относительно конфидонциальности вашей мидицинской информации. Если вам нужно данное уведомление на другом языке или вам нужны услуги устигот переводчика, обращайтесь в Бюро помощи вашего округа (County Assistance Office). Переводческие услуги предоставляются бесплатно
此通知包括关于您的医疗信息的个人降私方面的重要资料。 如果您需要此通知译成其它语言或需要有人替您翻译, 请联系您所在地区的都且援助办事处。可提供免费语言协助。	Thông bảo này gồm những thông tin quan trọng về việc bảo mật các chỉ tiết y tế cả nhân của quí vị. Nếu cần có thông bảo này hàng một ngôn ngữ khác hay người để thông dịch, xin quí vị liên lạc với Văn Phỏng Trơ Cấp Địa Phương. Trợ giúp ngôn ngữ về được cung cấp miền phí.
សមត្រូវនេះមានផលិលដល់នេះដល់លេះរហូបវានាសម្លាល់ដ្រះលើមានអេស្ប របស់លោកស្មង។ ហើលការបុរស្សដ្ឋាយសមត្ថកូននេះ ជាជាសារឲ្យសេទ្យ។ ឲ្យក្នុងការស្មានដែរអ្វីបានដំបូ សូមសាធិរាសារិយាលីហើស៊ីនដែលការដូច។ សំអូមេខាច អាសាធិរាស្តាល់សោយជាមកតាន់វាត់ក្នុ។	يحتوي هذا الإخطار على معلومات هامة حول خصوصية المعلومات الطبية المتطقة بك. إذا كنت بحاجة إلى هذا الإخطار بلغة أخرى أو إلى شخص ما لترجمته لك، فيرجى الاتصال بمكتم معونة المقاطعة المحلي. وستقدم المساعدة اللغوية مجانًا.

The Department of Human Services (DHS) provides and pays for many types of benefits and social services. We also determine an individual's eligibility to receive benefits and services. To do these things, we have to collect personal and health information about you and/or your family. The information we collect about you and/or your family is private. We call this information "protected health information."

DHS does not use or disclose DHS health information unless it is permitted or required by law. DHS is required by law to maintain the privacy of protected health information, to provide individuals with notice of its legal duties and privacy practices concerning protected health information and to notify affected individuals in the case of a breach of unsecured protected health information. As a "covered entity," DHS must follow applicable laws protecting the privacy of your protected health information which include the Health Insurance Portability and Accountability Act (HIPAA) privacy rules. Under HIPAA, Medicaid agencies, certain health plans and health care providers are examples of covered entities that must comply with HIPAA. Other laws that may apply include rules concerning confidential information about Medical Assistance, other benefits, behavioral health, substance abuse/ treatment and HIV/AIDS. When we use or disclose protected health information, we make every reasonable effort to limit its use or disclosure to the minimum necessary to accomplish the intended purpose. This notice explains your right to privacy of your protected health information on DHS privacy or Complaints" section on the last page of this notice.

We are required by law to follow the terms of this notice. We reserve the right to change the terms of this notice and to make the new notice provisions effective for all protected health information we maintain. If we make an important change in our privacy policies or procedures, we will post a revised copy of the notice on our website and/or provide you with a new privacy notice by mail or in person. You may request and receive a paper copy of this notice at any time.

What is protected health information?

Protected health information is information about you that relates to a past, present or future physical or mental health condition, treatment or payment for treatment, and that can be used to identify you. This information includes any information, whether verbal or recorded in any form, that is created or received by DHS or persons or organizations that contract with DHS. This includes electronic information and information in any other form or medium that could identify you, for example:

Your name (or names of your children) Address Date of birth Admission/discharge date Diagnostic code Telephone number DHS case number Social Security number Medical procedure code

PA 1805 7/17

Who sees and shares my health information?

DHS professionals (such as caseworkers and other county assistance office and program staff) and people outside of DHS (such as our contractors, health maintenance organization (HMO) staff, nurses, doctors, therapists, social workers and administrators) may see and use your health information to determine your eligibility for benefits, treatment, payment or for other required or permitted reasons. Sharing your health information may relate to services and benefits you had before, receive now, or may receive later. DHS will not use or share genetic information about you when deciding if you are eligible for Medicaid.

Why is my protected health information used and disclosed by DHS?

There are different reasons why we may use or disclose your protected health information. The law says that we may use or disclose information without your consent or authorization for the reasons described below.

For Treatment: We may use or disclose information so that you can receive medical treatment or services. For example, we may disclose information your doctor, hospital or therapist needs to know to give you quality care and to coordinate your treatment with others helping with your care.

For Payment: We may use or disclose information to pay for your treatment and other services. For example, we may exchange information about you with your doctor, hospital, nursing home, or another government agency to pay the bills for your treatment and services.

For Operating Our Programs: We may use or disclose information in the course of our ordinary business as we manage our various programs. For example, we may use your health information to contact you to provide information about appointments, health-related information and benefits and services. We may also review information we receive from your doctor, hospital, nursing home and other health care providers to review how our programs are working or to review the need for and quality of health care services provided to you and/or your family.

For Public Health Activities: We report public health information to other government agencies concerning such things as contagious diseases, immunization information, and the tracking of some diseases such as cancer.

For Law Enforcement Purposes and As Required by Legal Proceedings: We will disclose information to the police or other law enforcement authorities as required by court order.

For Government Programs: We may disclose information to a provider, government agency or other organization that needs to know if you are enrolled in one of our programs or receiving benefits under other programs such as the Workers' Compensation Program.

For National Security: We may disclose information requested by the federal government when they are investigating something important to protect our country.

For Public Health and Safety: We may disclose information to prevent serious threats to health or safety of a person or the public.

<u>For Research</u>: We may disclose information for permitted research purposes and to develop reports. These reports do not identify specific people.

For Coroners, Funeral Directors and Organ Donation: We may disclose information to a coroner or medical examiner for identification purposes, cause of death determinations, organ donation and related reasons. We may also disclose information to funeral directors to carry out funeral-related duties.

For Reasons Otherwise Required By Law: DHS may use or disclose your protected health information to the extent that the use or disclosure is otherwise required by law. The use or disclosure is made in compliance with the law and is limited to the requirements of the law.

Do other laws also protect certain health information about me?

DHS also follows other federal and state laws that provide additional privacy protections for the use and disclosure of information about you. For example, if we have HIV or substance abuse information, with a few exceptions, we may not release it without special, signed written permission that complies with the law. In some situations, the law also requires us to obtain written permission before we use or release information concerning mental health or intellectual disabilities and certain other information.

Can I ask DHS to use or disclose my health information?

Sometimes, you may need or want to have your protected health information sent or otherwise disclosed to someone or somewhere for reasons other than treatment, payment, operating our programs, or other permitted or required purpose not needing your written authorization. If so, you may be asked to sign an authorization form, allowing us to send or otherwise disclose your protected health care information as you request.

The authorization form tells us what, where and to whom the information will be sent or otherwise disclosed. You may revoke your authorization or limit the amount of information to be disclosed at any time by letting us know in writing, except to the extent that DHS has already taken action in reliance upon the authorization.

If you are younger than 18 years old and, by law, you are able to consent for your own health care, then you will have control of that health information. You may ask to have your health information sent to any person who is helping you with your health care.

Except as described in this Notice, we will not use or disclose your health information without your written authorization. For example, HIPAA generally requires written authorization before a covered entity may use or disclose an individual's psychotherapy notes. In most cases, HIPAA also requires written authorization before a covered entity may use or disclose protected health information for marketing purposes or before it sells it.

What are my rights regarding my health information?

As a DHS client, you have the following rights regarding your protected health information that we use and disclose:

<u>Right to See and Copy Your Health Information</u>: You have the right to see most of your protected health information and to receive a copy of it. If you want copies of information you have a right to see, you may be charged a small fee. However, generally, you may not see or receive a copy of: (1) psychotherapy notes; or (2) information that may not be released to you under federal law.

If we deny your request for protected health information, we will provide you a written explanation for the denial and your rights regarding the denial.

DHS does not receive or keep a file of all of your protected health information. Doctors, hospitals, nursing homes and other health care providers (including an HMO, if you are enrolled in one) may also have your protected health information. You also have a right to your health information through your doctor or other provider who has these records.

<u>Right to Correct or Add Information</u>: If you think some of the protected health information we have is wrong, you may ask us in writing to correct or add new information. You may ask us to send the corrected or new information to others who have received your health information from us. In certain cases, we may deny your request to correct or add information. If we deny your request, we will provide you a written explanation of why we denied your request. We will also explain what you can do if you disagree with our decision.

<u>Right to Receive a List of Disclosures</u>: You have the right to receive a list of where your protected health information has been sent, unless it was sent for purposes relating to treatment, payment, operating our programs, or if the law says we are not required to add the disclosure to the list. For example, the law does not require us to add to the list any disclosures we may have made to you, to family or persons involved in your care, to others you have authorized us to disclose to, or for information disclosed before April 14, 2003.

<u>Right to Request Restrictions on Use and Disclosure</u>: You have the right to ask us to restrict the use and disclosure of your protected health information. We may not be able to agree to your request. In fact, in some situations, we are not permitted to restrict the use or disclosure of the information. If we cannot comply with your request, we will tell you why. Except as otherwise required by law, we must grant your request to restrict disclosure to a health plan if the purpose of disclosure is not for treatment and the medical services to which the request applies have been paid out-of-pocket in full.

<u>Right to Request Confidential Communication</u>: You may ask us to communicate with you in a certain way or at a certain location. For example, you may ask us to contact you only by mail.

Right to Receive Notification of a Breach: You have the right to receive notification if there is a breach of your unsecured protected health information

Whom do I contact about my rights or to ask questions about this notice?

You can contact the DHS HIPAA helpline, toll-free at 800-692-7462 to discuss your rights or to ask questions about this notice. You can also contact your caseworker or health care provider or write to DHS's Privacy Office, 3rd Floor West, Health and Welfare Building, 7th and Forster Streets, Harrisburg, PA 17120.

You can receive important information or updates to this notice by visiting DHS's Web site at www.dhs.pa.gov.

How do I file a complaint?

You may contact either office listed below if you want to file a complaint about how DHS has used or disclosed information about you. There is no penalty for filing a complaint. Your benefits will not be affected or changed if you file a complaint. DHS and its employees and contractors cannot and will not retaliate against you for filing a complaint.

PENNSYLVANIA DEPARTMENT OF HUMAN SERVICES PRIVACY OFFICE 3RD FLOOR WEST, HEALTH AND WELFARE BUILDING 7TH AND FORSTER STREETS HARRISBURG, PA 17120

REGION III U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES OFFICE FOR CIVIL RIGHTS 150 S. INDEPENDENCE MALL WEST - SUITE 372 PHILADELPHIA, PA 19106-9111

Effective: April, 2003 – Revised July 28, 2015



PA 1806 7/17