FAQ #2:

Intellectual Disability (ID) Waivers

Medicaid Home and Community Based Waiver Programs

Revised Spring 2013
**What is a Waiver?**

Waiver is a short way of saying “Medicaid Home and Community Based Waiver Program.” Waivers pay for supports and services that eligible people need to live in the community instead of an institution.

Waiver programs are funded by federal and state monies. The federal (Medicaid) portion of funding is matched by the state. In Pennsylvania, the ratio is approximately 54% federal to 46% state monies. Waiver services can be blended with natural supports and other community supports and resources or, in some cases, may provide for all of the support an individual needs.

**Why do we have Waivers?**

Katie Beckett was a young girl with significant health care needs. She lived for three years in a pediatric intensive care unit in a hospital. Her parents wanted to move her home. At the time, she was not eligible for Medicaid funding to pay for her care at home because her parents’ income and resources were above the financial eligibility limit. If she lived in the hospital or nursing home, their income was not considered.

Her parents advocated to have the federal rules changed, and in 1981, Congress created the Home and Community Based Waiver Program. This allowed services and supports to be provided in the community and to be paid for with Medicaid funds.

In a nutshell, we have Waivers so that people who receive Medicaid (also called “Medical Assistance” in Pennsylvania) funding can choose community based services in place of institutional or medical facility based care.

Waivers are designed to provide support for people to live and work in their communities. Waiver services can go hand-in-hand with the
supports that family, friends, schools and community organizations provide. Waiver services can be used to support people who live in their own homes, families’ homes, or in licensed and unlicensed residential settings, such as group homes, Community Living Arrangements, and supported living. People can receive a few or many services through the Waivers depending on what their needs are. For example, someone who gets all the support she needs in her home from her family and friends might need support to keep her job. The Waiver pays for a job coach to work with her a couple of hours a week. Someone who needs quite a bit of paid support might be a man who lives with his elderly mother. His mother is unable to provide all of his support, so a Waiver pays for his support to participate in social activities several days a week, to participate in some volunteer activities, and for someone to assist him on a daily basis with shopping, preparing food, personal care, laundry and cleaning his home.

**How does Pennsylvania get Waivers?**

For Waivers that support people with an intellectual disability, the Department of Public Welfare, Office of Developmental Programs (ODP) applies to the federal Centers for Medicare and Medicaid Services (CMS) to have Waivers approved. The State must outline eligibility criteria, types of services provided, and assurances about how the services will be delivered to recipients, including how the state will ensure the health and welfare of Waiver participants. Once a state’s Waiver application is approved, CMS will monitor the Waiver program to ensure compliance with federal rules. ODP must submit a renewal request 3 years after the initial approval and then every 5 years to continue receiving Waiver funding.

**What Waivers are available through the Office of Developmental Programs?**

The Office of Developmental Programs (ODP) in Pennsylvania offers two Waiver programs for people with an intellectual disability. One is the Person/Family Directed Support (P/FDS) Waiver and the other is the Consolidated Waiver. You must meet the eligibility criteria for the Waiver and be at least 3 years old to apply.

The Office of Developmental Programs also offers an Adult Autism Waiver. For more information on the Autism Waiver contact the Bureau of Autism Services at 1-866-539-7689

**The Person/Family Directed Support (P/FDS) Waiver:**

The P/FDS Waiver is known as the “small” Waiver because it has a cap of $30,000 per person each fiscal year. This funding can be used to get the support you need to participate in a wide range of activities in your community. With your Supports Coordinator, you will write an Individual Support Plan (ISP) that describes you, your life, your desired outcomes, and defines the supports and services you need to be successful. Your budget will be based on the needs identified through the planning process and in your approved Individual Support Plan (ISP). The ISP is authorized by your Administrative Entity (AE)/County. The P/FDS Waiver cannot pay for residential care in licensed or unlicensed residential settings but it can help provide the support you need to live in your own home or your family’s home.

The cost of Supports Coordination does not count against the annual cap of $30,000.
The Consolidated Waiver:

The Consolidated Waiver is sometimes referred to as the “big” Waiver, residential Waiver, or the 2176 Waiver. There is no set dollar cap on your individual budget to purchase needed supports that you could receive on this Waiver. The amount of support you receive will be based on your assessed needs, as determined through the planning process and outlined in your Individual Support Plan (ISP). The ISP is authorized by your AE/County. This Waiver can provide the same supports and services available in the P/FDS Waiver, but also can include out-of-home residential care in the community. With both Waivers, your Individual Support Plan (ISP) and your supports should be updated at least once per year or any time your needs change significantly.

What supports and services are available through the Waiver?

Supports and services will vary from person to person. The Waiver supports you receive are based on your assessed needs and your Individual Support Plan (ISP). This plan should be written by you and your family with your Supports Coordinator and any other people in your life that care about you and support you. It could include your friends, your neighbors, your employer, your service providers and your teacher. As a team, you will develop a plan to help you meet your needs and reach your own individual dreams and desired outcomes.

As part of this planning process, you will participate in a standardized needs assessment. The Office of Developmental Programs has chosen the Supports Intensity Scale (SIS)™ and the PA Plus as the standardized needs assessment. In the planning process you will also write outcomes that will lay out what you want to happen in your life, action steps and the support and services you will need to reach your desired outcomes. Only supports and services outlined in Pennsylvania’s Intellectual Disability (ID) Waivers can be funded under these Waivers. You should review the descriptions of Waiver services to better understand what is available to you through the Waivers. Descriptions of the services can be found in the ISP Manual http://www.temple.edu/thetrainingpartnership/resources/isp/ and in Understanding the Office of Developmental Programs in Pennsylvania: Intellectual Disability and Autism Services (The Gold Book) http://www.temple.edu/thetrainingpartnership/pub/.

You can also request a copy of these materials by calling The Partnership’s toll free number 1-866-865-6170.

There may be things you need that are not covered under the Waiver. Your team can help you find other ways to meet these needs. These other ways can include natural supports, such as a neighbor or friend doing something free of charge. They can also include community supports and services available to all people in your community, like parks and recreation or local community organizations. All Waiver services outlined and approved in your ISP must be provided to you through the resources of the Waiver. If you are in the Person/Family Directed Support (P/FDS) Waiver, you are eligible to be funded up to the cap for services approved in your ISP. If you receive the Consolidated Waiver, there is no individual cap. Medicaid rules require that all services approved in your ISP to address your identified needs must be provided to you.

If needed services are denied, reduced, terminated, or suspended, you have the right to appeal. You should be given written notification whenever this happens. There is a formal Fair Hearings and Appeals process in place for you.
Supports and services available in the P/FDS and Consolidated Waivers include:

- Supports Coordination
- Companion Services
- Homemaker/Chore Services
- Assistive Technology
- Specialized Supplies
- Unlicensed Home and Community Habilitation
- Licensed Day Habilitation
- Supported Employment—Job Finding and Job Support
- Transitional Work Services
- Prevocational Work Services
- Home Accessibility Adaptations
- Vehicle Accessibility Adaptations
- Transportation
- Supports Broker Services
- Physical Therapy
- Occupational Therapy
- Speech/Language Therapy
- Nursing Services
- Behavior Therapy
- Behavioral Support
- Visual/Mobility Therapy
- Respite Services for the Care Giver
- Education Support Services

**What services are available in the Consolidated Waiver but not the P/FDS Waiver?**

Two services are available only in the Consolidated Waiver:

- Licensed Residential Habilitation
- Unlicensed Residential Habilitation

Licensed Residential Habilitation covers services provided in Community Living Arrangements (sometimes called group homes) and in licensed Lifesharing homes. Unlicensed Residential Habilitation covers services provided in provider-owned, rented, leased or operated homes or family living homes in which residents need a yearly average of 30 hours or less of direct staff contact per week per home.

Descriptions of each support or service are written in the Waivers and in the ISP Manual. Please note that some services have limitations on when and where you receive services, and how much of the service you can receive. A summary of the services and their definitions is available in *Understanding the Office of Developmental Programs in Pennsylvania: Intellectual Disability and Autism Services*, often referred to as *The Gold Book*. (Please see resource listing at the end of this booklet for more information.) Copies of the complete Waivers, *The Gold Book* and the ISP Manual are also available on The Partnership website, www.TheTrainingPartnership.org.

**Can I choose who provides services?**

Yes, you have a right to choose who provides your Waiver services and supports. Federal rules require that a person receiving supports has the opportunity to choose any willing and qualified Medicaid Waiver provider whose costs are within reasonable limits.
The Office of Developmental Program’s policy dictates that all individuals have choice, control, community, relationships, authority, responsibility and the other values set forth in the *Everyday Lives* doctrine. The principles of Everyday Lives are statewide policy as outlined in ODP Bulletin 00-03-05.

Your Administrative Entity (AE)/County can provide you with a list of qualified Medicaid Providers. You can also get one on-line through the Provider Profiles page. Please see the back of this booklet for the link to that website.

If you choose, you should have the opportunity to direct your own supports. Ask your Supports Coordinator for information about Participant-Directed Services. One way to have more control over your services is to use Financial Management Services (FMS). An FMS is an organization which will help you with some of the employer responsibilities. This will give you the freedom to choose your support service workers (SSWs) and design your services to meet your specific needs. Every AE/County is required to have FMS available for you. Once your budget is created and approved by you and your AE/County, you can use an FMS to exercise the authority to manage your SSWs to best meet your needs.

**How do I apply for a Waiver?**

You can apply for Waivers at your County Mental Health/Intellectual Disability (MH/ID) Office. Waiver applications are separate and apart from registration for Intellectual Disability (ID) services. You must be registered and eligible for ID services to even apply for an ID Waiver. If you are eligible for ID services and you receive Medical Assistance (MA), your Supports Coordinator will assist you in completing the application for the Waiver. You will do this by filling out the Waiver Application and Service Delivery Preference form (DP 457). Using the DP 457, you will select whether you want your services provided in an Intermediate Care Facility for People with an Intellectual Disability (ICF/ID) or in a home and community-based setting. If you choose to receive your services in home and community-based settings, you will also formally apply for the Waiver using this form.

To be eligible for an Intellectual Disability Waiver you must meet the following criteria:

1. You need to meet the requirements for ID services in Pennsylvania (have a diagnosis of ID).
2. You must need the same level of care provided in an Intermediate Care Facility for People with an Intellectual Disability (ICF/ID). This is determined by a Qualified Intellectual Disability Professional (QIDP) and a medical evaluation.
3. You must need active treatment (means you need at least one on-going waiver service).
4. Your income can not exceed 300% of SSI ($2130 per month—2013 figures) and there are limits on the value of your assets. However, you can own a home, a car and a burial space. Questions about financial eligibility can be answered by the local County Assistance Office (CAO).

After you apply, you will be notified in writing within 30 days if you are eligible for an ID Waiver. The decision will say that you are “likely” to be eligible for the waiver. This is a preliminary decision. When funding is available for you to be enrolled in a Waiver, the AE/County program will verify that you meet all of the conditions to be on an ID Waiver. If you are not eligible for any reason, you may appeal that decision.
**Am I entitled to apply for Waiver funding?**

Yes. If you are 3 years old or older and eligible for Intellectual Disability (ID) services, you are entitled to apply for Waiver. The Waiver application only determines your preliminary eligibility to receive Waiver funding. It does not mean you will be enrolled and get Waiver funding. If you believe you are denied the opportunity to apply or are denied eligibility for any reason, you have the right to appeal.

**What if I am eligible, but they have no money for me?**

If you are preliminarily eligible for a Waiver, but there is no funding available for you, you will be added to the Waiting List. Anyone who will need supports and services in the next five years should complete a Prioritization of Urgency of Need for Services (PUNS) form with their Supports Coordinator (SC). This form is used by the AE/County and the state to track how many people are waiting for support, and what types of support are needed.

Unfortunately, there are many people across the state waiting for supports and services. There are some things you can do while you wait. You can use community supports, such as YMCA, church groups, advocacy agencies, and other groups that may have volunteers or programs to meet some of your needs. You can also try to build your natural support network. The Partnership has trainings for family members that were written to help people think about new ways to expand their natural support. Additionally, some counties have limited Base funding or Family Driven Support Services (FDSS) funding that may help meet some of your needs. These services and supports should be outlined in an Individual Support Plan (ISP). You should discuss available resources with your SC while you are waiting for Waiver enrollment. An honest discussion of your needs is critical to obtaining resources. Be honest about what you need and why you need it. You will not be “at the table” when funding decisions are made at the AE/County and state offices, so your SC must have a good understanding of your needs to effectively advocate on your behalf.

**When I am enrolled on a Waiver, am I entitled to services?**

Yes. If you are found eligible for a Waiver and you begin receiving Waiver services, then you are entitled to all of the services you need that are offered in that Waiver, as per your authorized Individual Support Plan (ISP).

**What happens if I request a service and my supports coordinator or someone else on my support team tells me I cannot get that service?**

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

The Waiver Service Request form is a formal request in which you will state what service you need, how much of it you need, and why you need it. Your SC should submit this form to the AE/County program within 10 days and the AE/County program should give you a formal approval or denial of your request within 20 calendar days of when they receive the form.
**Some services have limits to how much I can use. Are there exceptions to these limits on waiver services?**

Yes, there are some exceptions to service limitations for respite and assistive technology.

*The established service limits:* For respite (15 minute increments), the waiver limit is 480 units (120 hours) per fiscal year and for respite (24 hour increments) the waiver limit is 30 days per fiscal year. For assistive technology the waiver limit is $10,000 per lifetime. (This lifetime limit began July 1, 2012.)

*The request for exception process:* You and your Individual Support Plan (ISP) team meet to discuss the needs of your caregiver regarding an exception request for respite or to discuss your needs regarding an exception request for assistive technology. The same form is used for both respite and assistive technology. The form is the DP 1023. The Supports Coordinator (SC) completes the DP 1023 form which contains your needs as discussed with the Individual Support Plan (ISP) team as well as additional information depending on the exception requested. The DP 1023 form is forwarded by the Supports Coordination Organization (SCO) to the Administrative Entity (AE). The AE reviews and forwards the DP 1023 form plus a recommendation on the request to the Office of Developmental Programs (ODP) Regional Office Regional Program Manager.

Emergency respite has an exception process in place when a need for respite has to be provided in a location that is not a waiver-funded residential location. Emergency respite has a specific process that utilizes form DP 1037.

Additional information can be found in ODP Communication Number: Packet 067-12 and Packet 066-12. A copy of DP 1023 can be found in *The Gold Book 2013*, beginning on page 146.

**Is it possible to lose my Waiver after I am enrolled?**

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

- **Eligibility for Intellectual Disability services**
- **Intermediate Care Facility for People with an Intellectual Disability (ICF/ID) Eligibility** – This means that you need the same level of care as someone who would otherwise receive services in an institution. You must also continue to need “Active Treatment.” This means that you need at least one on-going service that is covered under the Waiver every month. If you go into a hospital or rehabilitation care facility while you are receiving Waiver services, and you do not come out in time to receive a Waiver service during that month, the Office of Developmental Programs will hold your place in the Waiver for up to 180 days to ensure you can come back to the Waiver once you get out of the hospital or rehabilitation care facility.

- **Financial Eligibility** – There are income and asset limitations to qualify for a Waiver. If you are working, be sure to remember those limits. Contact a Benefits Counseling Program (formerly known as Work Incentive Planning Assistance offices or “WIPAs”) if you anticipate increases in wages.

The County Assistance Office (CAO) does an annual financial eligibility re-determination that covers both your Medical Assistance and Waiver. They will look at your income and any assets you have and make sure that you still qualify. Annually, the AE/County will ask you to have a medical evaluation by your physician regarding
your disability to ensure that you still meet the Intellectual Disability and ICF/ID eligibility standards. Your physician can use the form MA-51 to document that you still need home and community-based services. The MA-51 form can be found on the Partnership website: http://www.temple.edu/thetrainingpartnership/resources/odpForms.shtml

**What do I do if I have a Problem?**

You have a few options to address specific problems. You can set up a meeting with your Supports Coordinator, the Supports Coordinator Supervisor, and/or the Administrative Entity (AE)/County. You should document all meetings and phone calls. All decisions concerning Intellectual Disability (ID) services should be put in writing to you. If you have not received written documentation regarding ID services, request the documentation from your AE/County. You could also contact your Regional ODP Manager, or call the ODP toll free customer service number—1-888-565-9435. Advocacy organizations may be able to help you or offer specific information about your situation.

If you are enrolled in a Waiver, you have the right to Fair Hearings and Appeals for certain issues. You should receive a copy of all your rights at your annual meeting, and any time you request a copy. If your services are denied, reduced, suspended, or terminated, the AE/County must notify you in writing. It is important to act quickly if you disagree with a change in your services. If you file the appeal within the 10 day window, services that are on-going will continue. One-time services or services that have not started do not need to be provided. When you file for Fair Hearing, you will automatically have a “Service Review.” Service Review is a 15-day process in which your situation is reviewed by the Regional ODP Office in an attempt to reach a quick resolution. If you disagree with this review, you will proceed to Fair Hearing and Appeal. ODP Bulletin 00-08-05 Due Process and Fair Hearing for Individuals with Intellectual Disability explains all of your rights as a Waiver participant.

**Where do I go if I need help?**

The Pennsylvania Training Partnership for People with Disabilities and Families (The Partnership) can provide you with a copy of Understanding Office of Developmental Programs in Pennsylvania: Intellectual Disability and Autism Services. Known as The Gold Book, this publication contains the following: detailed information about the Intellectual Disability system; copies of important forms; descriptions of the services available through the Waivers; advocacy group contact information; and checklists for families to use as they navigate the system. It is free to people with disabilities and their families. Please contact The Partnership at 1-866-865-6170 for a copy. It is also available on The Partnership website, www.TheTrainingPartnership.org.

The State Office of Developmental Programs has a toll free phone number for you to call if you have questions about the Waiver programs, the services available, or the choices you have in directing your own supports. ODP’s toll free number is 1-888-565-9435. Additionally, The Partnership and its participating agencies can answer questions and offer assistance to individuals or their families.
The State Office of Developmental Programs has a toll free phone number for you to call if you have questions about Waivers. Additionally, The Partnership and its participating agencies can answer questions and offer assistance to individuals or their families.

Office of Developmental Programs
1-888-565-9435

The Partnership
1-866-865-6170
www.TheTrainingPartnership.org

ODP Regional Point
People:
(as of Spring 2013)

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Northeast
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570-963-4749
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Southeast
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215-560-2242
vstillmant@pa.gov

Western
Michele O’Toole
412-565-5144
micotoole@pa.gov

The Partners:

Achieva
412-995-5000
toll free: 1-888-272-7229
www.achieva.info

Mentors for Self Determination
814-547-1577
www.mentors4sd.org

Self-Advocates United as 1
Eastern 215-923-3349 x132
Western 724-877-3984
toll free: 1-877-304-7730
www.sau1.org

Vision for Equality
Philadelphia: 215-923-3349
Harrisburg: 717-233-2424
www.visionforequality.org

Institute on Disabilities at Temple University
215-204-7556
toll free: 1-866-865-6170
www.disabilities.temple.edu

Links to Resources
ISP Manual (includes descriptions of all Waiver services)
http://www.temple.edu/thetrainingpartnership/resources/isp/

Provider Profiles
http://www.dpw.state.pa.us/foradults/intellectualdisabilityservices/howtochooseanintllctldsbltsprovider/index.htm
THE PARTNERSHIP
THE PENNSYLVANIA TRAINING PARTNERSHIP FOR PEOPLE WITH DISABILITIES AND FAMILIES

- Achieva
- Institute on Disabilities
- Mentors for Self Determination
- Self-Advocates United as 1
- Vision for Equality

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This information is available in alternate formats, upon request.

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