

What Do Individual Budgets Mean to Me?

- Having your own budget will give you more choice of what supports you receive, how you receive support and who will provide your support.
- You can look outside of the mental retardation system for people to provide some supports. After you find someone who can provide the supports you need, you can go to the county and ask them to contract with the new provider. Some agencies will work with you so that you can interview and hire people from the agency to provide your supports.
- You are not limited to your county when you are looking for supports and services. You can choose a qualified person or provider agency that is located in a county near your home if they are willing to provide the supports that you need.

Can I Hire Family Members and Pay Them With Waiver Funding?

- Siblings and other relatives, who do not live with you, can be paid with waiver funding to provide supports to you that are part of your Plan. Relatives who provide supports will have to meet certain qualifications. People cannot be paid with waiver funding to provide supports that they normally would provide for free.
- Parents, under specific conditions, can provide services to their own children (including minors) in the Consolidated Waiver. They must meet certain qualifications and carry out the individual's plan.



What Are Waivers And How Do They Help Me?

NOTE: In addition to the person needing supports, “you” also refers to the family member or friend who will assist him or her to get the needed supports and services.

What Is a Waiver?

- Waiver is a shortened term for the Medicaid Home and Community Based Waiver Program which provides funding for mental retardation supports and services to help you to live in your home and community rather than in an institution.
- The name Waiver comes from the fact that the federal government waives Medicaid rules for institutional care in order for the state to use the same funds to provide supports and services for people in the community. The state must make specific assurances to the federal government to substitute for the waived rules.
- Federal and state funds are combined in Medicaid Waivers. The federal and state shares are not the same in each state and they are adjusted each year. In Pennsylvania it is generally a 50/50 percent split.

Why Do Waivers Exist?

Katie Beckett spent three years in a pediatric intensive care unit of a hospital as the result of extensive health care needs that developed when she was six months old. Federal rules and

regulations prohibited her family from taking her home. Her parents advocated on her behalf to have the funding rules changed until Congress created the Home and Community Based Waiver program in 1981. Prior to creation of the waiver, children who lived in the family home and needed extensive care were unable to qualify for Medicaid because their parents' income or resources put them above the financial eligibility limit. However, if individuals received care in an institution, then the family's income would not be considered and Medicaid would fund the care.

Why Should I Apply for Waiver Funding?

Waivers are the primary funding source for mental retardation supports and services in Pennsylvania.

To Whom Do the Person/Family Directed Support Waiver (P/FDS) and the Consolidated Waiver Provide Funding?

- Both of these mental retardation waivers provide funding for supports and services to eligible persons with mental retardation who are age three and over so they can remain in their home and community. People can live in the home of their choice, such as their family home or an apartment or home of their own, with people they choose.
- Pennsylvania has set criteria to determine eligibility for mental retardation Medicaid waiver funding that is the same in all counties. Financial eligibility is based only on the income of the individual, not the income of parents.
- If you have questions about waiver eligibility, you can call your Supports Coordinator at the County Office of Mental Retardation.

- Another way to find out what is available in your community is to become a member of your county Independent Monitoring Team for Quality. Your Supports Coordinator can tell you whom to contact about this.

If I Have Person/Family Directed Support Waiver Funding and My Needs Increase, How Do I Get Additional Funding?

- The amount of funding you receive is based on your Needs Assessment and Plan of Care. Since your needs are different from those of other people, the amount of funding you receive will be different from the funding received by other people.
- The Person/Family Directed Support Waiver has an upper funding limit of \$21,225 per person approved by the Centers for Medicare and Medicaid Services (CMS). If there are changes in your life and it is determined that the services and supports you need cost more than this amount, then a new PUNS form will be completed and you may apply to enroll in the Consolidated Waiver. Your Supports Coordinator will complete this form with you.

Does the Consolidated Waiver Have an Upper Funding Limit?

- The Consolidated Waiver has no upper limit of funding for an individual. Funding is based on your Needs Assessment and Plan of Care. Since your needs are different from those of other people, the amount of funding you receive will be different from the funding received by other people.
- States must assure the federal government that, on an aggregate basis, the total costs for people receiving services in the Home and Community Based Waiver is less than the cost of services in an institution.

How Long Will It Take to Get the Supports and Services That I Need?

- The primary factor that determines when you receive services is whether funding is available in your county and the urgency of your need. Each county gets an annual allocation of state and federal funds from the Department of Public Welfare. Counties must prioritize people in the emergency and critical categories and enroll them in services up to the limit of their allocation.
- Another factor is your urgency of need for services as determined from your completed Prioritization of Urgency of Need for Services (PUNS) form. “Emergency Need” means you need support immediately. “Critical Need” means you need support within one year. “Planning for Need” is when your need for supports or service is more than a year away. The number of people on “Emergency” and “Critical” lists ahead of you also influences how long you will have to wait for services. (See Frequently Asked Questions, No. 1 for detailed information on the PUNS.)
- This is why completing a PUNS from annually is important; it establishes your need and enables the county and state to prepare a budget request for expansion. There has been service expansion every year for the past decade.

What Should I Be Doing While I Wait for Supports?

- You can use this time to become familiar with the supports and services that are available in your community.
- You can set up appointments to visit places where you might receive supports. If you need help with this, your Supports Coordinator should be able to assist you.

- If you have access to a computer, you can get more information about Pennsylvania mental retardation waivers on the Department of Public Welfare, Office of Mental Retardation Web site. Here are the steps to follow:
 - Go to the Web site: **www.dpw.state.pa.us**. (Pennsylvania Department of Public Welfare)
 - Near the bottom of the screen, click on “Enter DPW”
 - On the left side of the next screen under “DPW Services,” click on “Home and Community Based Services”
 - On the next screen, scroll down and click on “Consolidated Waiver for Individuals with Mental Retardation.”
 - “Person/Family Directed Support Waiver” follows “Consolidated Waiver” on the Web site. If you want to go directly to the Person/Family Directed Support Waiver, you can click on it instead of “Consolidated Waiver” in step four.
- You can also get information about mental retardation waivers by calling the Pennsylvania Self-Determination Consumer and Family Group at 1-800-459-1838.

How Did the Department of Public Welfare, Office of Mental Retardation Get These Waivers?

- The Department of Public Welfare, Office of Mental Retardation (OMR) must apply to the Centers for Medicare and Medicaid Services (CMS) to have waivers approved and they are then monitored by this federal agency. Waivers are approved for an initial period of 3 years and are renewed for 5 year periods.

- Before a waiver ends, OMR must reapply to the Centers for Medicare and Medicaid Services in order to continue to receive waiver funding. When the Office of Mental Retardation renews a waiver they must look at the current requirements set forth by the Centers for Medicare and Medicaid Services and respond as to how they will meet those requirements in Pennsylvania. At the same time, Pennsylvania can also seek approval for services that will be included in waivers in the state that are not part of the current Pennsylvania mental retardation waivers.

What Do Waivers Mean to Me?

- Waivers can provide funding for the supports and services that you need, in order for you to remain in your home and community.
- You will have a choice of the kinds of supports and services you receive in order to meet your needs. These needs are identified when you do person centered planning that looks at your total life.
- You will have a choice of qualified people or agencies that provide the supports or services that you need.
- Your health and safety will be assured.
- Supports and services will be monitored for quality. You will decide if you are receiving quality supports and services. If you are not satisfied with the quality, then you need to talk with the person or agency that provides your supports about improving the quality. Monitoring is also done by your Supports Coordinator and other people including the Independent Monitoring Team for Quality in your county.

How Can I Use Waiver Funding?

- Both of these waivers can provide modifications to your home to make it accessible such as ramps, widening of doorways and bathroom modifications. They also can provide day services such as a support person to assist you in participating in a wide range of activities in the community. Job coaching with someone to help you on the job either long or short term, can also be funded by the waivers. In addition, waivers can be used for transportation, respite care and physical, occupational and speech therapy. This is not a complete list of things that can be paid for with waiver funding. You can check with your Supports Coordinator to see if other things you need are eligible to be funded under the waiver.
- Residential services are available only under the Consolidated Waiver.

Am I Entitled to Waiver Funding?

If you are three years old or over, you are entitled to fill out an application for waiver funding. This only determines your eligibility to receive waiver funding for supports and services. It does not mean that you will be enrolled and get waiver funding.

After I Apply for Waiver Funding, What Happens Next?

- If you are approved for waiver funding for supports and services, you will be placed on a waiting list.
- Your county will determine your place on the waiting list based upon the Prioritization of Urgency of Need for Services (PUNS) form that you complete with your Supports Coordinator. (See Frequently Asked Questions No. 1.)