

MENTAL RETARDATION WAIVER SERVICES IN PENNSYLVANIA

In Pennsylvania, an array of in-home and community-based services and supports are available to individuals with mental retardation. Most of those services and supports are funded through Medical Assistance "waivers." Unfortunately, there is a great deal of confusion about waiver services which can limit the opportunities of individuals with mental retardation to access necessary services and supports. This booklet attempts to clarify some of the key questions concerning waiver services to assist individuals with mental retardation, their caregivers, and lay advocates. **PLEASE NOTE: THE INFORMATION IN THIS BOOKLET IS NOT INTENDED TO CONSTITUTE LEGAL ADVICE APPLICABLE TO SPECIFIC FACTUAL SITUATIONS.**

What Are Medical Assistance Waivers?

Most people with mental retardation are eligible for Medical Assistance, a program which pays for a range of health care services (such as physician visits, dental care, home health services, ICF/MR services, and nursing home services). Medical Assistance, however, generally does not fund a number of services that individuals with mental retardation need to stay in their own homes and communities, such as small group homes, day habilitation programs, vocational services, case management, and chore services. Other services that persons with mental retardation may need (such as physical, occupational, or speech therapies) may be available under Medical Assistance, but may be more limited than is needed. When the Medical Assistance statute was originally written, the primary mental retardation service available under the traditional Medical Assistance program was ICF/MR programs, which generally are provided in congregate, institutional settings.

In 1981, Congress decided that states should be encouraged to shift their Medical Assistance resources from institutional settings (like ICF/MR programs or nursing facilities) to more integrated community-based settings. Instead of mandating that states provide

home and community-based services, Congress gave states flexibility to create their own programs of home and community-based services. These programs are known as "home and community-based waivers."¹

Home and community-based waivers (which must be approved by the federal government) allow states to:

- ◆ specify the types of services that may be provided;
- ◆ provide services beyond those traditionally covered by Medical Assistance;
- ◆ cap the number of people who may receive services under the waiver;
- ◆ limit the services to people in one or more specific geographic regions;
- ◆ cap the amount of spending that any individual's services may cost.

In order to receive approval for a home and community-based waiver, a state must demonstrate that the waiver is "cost-neutral." This means that, on average, the cost of the home and community-based services cannot be greater than the cost of institutional services. In addition, the state may refuse to offer waiver services to any person for whom it expects the cost of waiver services to exceed the cost of institutional services. Since the cost of waiver services are, as a general matter, less than the cost of institutional services, few people (if anyone) should be rejected on "cost-neutrality" grounds.

Are There Waivers For People With Mental Retardation in Pennsylvania?

Pennsylvania has received federal approval for numerous home and community-based waivers to serve individuals with disabilities. There are waivers for people with physical disabilities; a waiver for people who have AIDS; a waiver for people who are technology-dependent; a waiver for people who are deaf and blind; a waiver for people who are elderly; and a waiver to provide early intervention services (including services for youngsters with mental retardation).

¹ Sometimes these waivers are called "HCB" waivers or "Section 2176" waivers or "Section 1396n(c)" waivers.

Pennsylvania also has received approval to provide services specifically for persons with mental retardation through several home and community-based waivers:

- ◆ In the mid-1980s, Pennsylvania created a waiver for persons with mental retardation that is now generally known as the "Consolidated" Mental Retardation Waiver. This Waiver remains in effect and is the largest of the mental retardation waivers in the Commonwealth in terms of the number of people served, the scope of services available, and the amount of funding available.
- ◆ In 1999, Pennsylvania created the "Person/Family Directed Support Waiver" or "P/FDS Waiver," which also provides services to persons with mental retardation.

What Are The Differences Between The Two MR Waivers?

Although the Consolidated and P/FDS Waivers both serve people with mental retardation, there are significant differences between them. Those differences include:

- ◆ Eligibility Criteria
 - ◇ Non-Financial
 - Consolidated Waiver -- The applicant must have mental retardation sufficient to qualify for an ICF/MR level of care.
 - P/FDS Waiver -- The applicant must: (1) have mental retardation sufficient to qualify for an ICF/MR level of care; (2) be over age three; and (3) not presently reside in a licensed community or family living home
 - ◇ Financial
 - Consolidated Waiver -- Generally, people who receive Medical Assistance are eligible. Additionally, people who are not

currently Medical Assistance recipients but whose income is within 300% of the SSI federal benefit are eligible for services.²

- P/FDS Waiver -- The same financial eligibility standards described above are applicable to the P/FDS Waiver. In addition, persons may be eligible for services under the P/FDS Waiver if they are deemed to be "medically needy," which for single individuals means that they have income of no more than about \$2,600 in a six-month period and assets worth no more than about \$2,400.

◆ Cap on the Number of Persons Eligible

- ◇ Consolidated Waiver -- As of June 30, 2000, services under this Waiver were limited to 12,292 persons.
- ◇ P/FDS Waiver -- As of June 30, 2000, services under this Waiver were limited to 3,382 persons.

◆ Cost of Services

- ◇ Consolidated Waiver -- There is no limit on the cost of service other than the general cost-neutrality limits discussed previously.
- ◇ P/FDS Waiver -- The cost of Waiver services cannot exceed \$20,000 per year for an individual.

◆ Types of Services

- ◇ Consolidated Waiver
 - Case management
 - Residential programs

² Effective January 1, 2001, the federal benefit will be \$530 for an individual and \$796 for a couple. Thus, a person who is not otherwise eligible for Medical Assistance but whose income is no greater than \$1,590 per month (or \$2,388 for a couple) would be eligible for services under the Consolidated Waiver.

- Day habilitation
- Pre-vocational services
- Supported employment services
- Educational services
- Chore services
- Private duty nursing
- Specialized therapy
- Permanency planning for children and youth
- Respite care
- Environmental accessibility adaptations
- Transportation

◇ P/FDS Waiver

- Residential programs
- Day habilitation
- Pre-vocational services
- Supported employment services
- Chore services
- Respite care
- Environmental accessibility adaptations
- Transportation
- Expanded therapy services (that is, therapy beyond that allowed under traditional Medical Assistance benefits);
- Adaptive appliances and equipment
- Visual/mobility therapy
- Behavior therapy
- Visiting nurse

Can I Receive Services Under Both MR Waivers?

An individual cannot receive services under both MR Waivers at the same time. This should not, however, preclude an individual from moving from one Waiver to the other.

Are All People With Mental Retardation Entitled To Services Under The MR Waivers?

Each home and community-based waiver identifies a specific number of persons who DPW intends to serve under the MR Waivers during each year. Once the cap on the Waiver is reached, DPW need not provide services under the Waiver to any additional persons who might otherwise be eligible. DPW has taken the position that it has no obligation to provide services under its home and community-based waivers to the number of people it identifies. Some courts, however, have indicated that there is an entitlement to services under home and community-based waivers for the number of people who states say they will serve during any given year. This issue has not yet been conclusively resolved.

How Do I Apply For Services Under The MR Waivers?

DPW implements both the Consolidated Waiver and P/FDS Waiver through its county MH/MR programs. Accordingly, case managers or other persons in the county MH/MR program should be familiar with both the Consolidated and P/FDS Waivers and provide assistance in the application process.

Individuals need not await an invitation to apply for either Waiver. Attachment 1 to this booklet is the Application form that is used to begin the application process. Individuals can complete it and send it to their county MH/MR program.

How Is Eligibility for Waiver Services Determined?

After an individual submits an application for Waiver services, the county MH/MR program must determine whether he or she is eligible. The county may ask for psychological, social, and medical information to make this determination. The county

subsequently will refer the individual to a qualified mental retardation professional for a formal assessment. This process must generally be completed within 45 days.

If the individual is found to be eligible and there is funding available, the county must offer the individual a choice between receiving Waiver services and receiving ICF/MR services. The individual (or, in the case of persons age 18 and under, his/her parent or legal guardian) will be asked to complete a "Service Preference Form" to choose between Waiver and ICF/MR services. If an adult is unable to signify a preference between ICF/MR and Waiver services by initialing or making a mark on the Service Preference Form, the individual's preference must be determined with the assistance by an independent qualified mental retardation professional.

If the individual chooses Waiver services **and the county has funds available** to serve the person, the county will establish a tentative start date for services and forward a form to the individual's County Assistance Office to determine whether the individual is in one of the Medical Assistance financial categories for eligibility for Waiver services. (For most people with mental retardation, this will be a mere formality.) Once the County Assistance Office confirms Medical Assistance eligibility for Waiver services, the county will develop a program plan that identifies what services are to be provided and which providers are responsible for the services.

If the individual chooses Waiver services but the county does not have funds available to serve him or her, the county must notify the individual that there will be a delay in service and then complete (if it has not previously done so) the PUNS form (discussed below) which is used to determine service priority.

How Is Priority For Services Under The MR Waivers Determined?

Since both MR Waivers serve only a limited number of people, counties are required to give preference to those applicants who have the greatest need for the services. The

counties must compare applicants' service needs using the "PUNS" (Priority of Urgency of Need for Services) assessments.

PUNS assessments are performed by the county for every person who receives or applies for any mental retardation services. PUNS assessments categorize persons into three categories: those whose service needs are considered an "emergency"; those whose service needs are considered "critical"; and those whose service needs are in the "planning" stage. Counties must give service preference under the MR Waivers to applicants whose PUNS assessments have categorized them as having "emergency" needs.

Once Accepted Into An MR Waiver, What Are An Individual's Service Choices?

After an individual has chosen and been approved for Waiver services, the county must develop an individualized program plan. In doing so, the individual has the right to choose among service providers. **It is up to the individual to choose their case manager and any other providers.** The individual can switch providers if she or he is dissatisfied at any time.

Counties may not limit individuals' ability to choose among qualified providers. The county is only authorized to deny an individual's choice of a provider if:

- ◆ The provider is not qualified to provide the particular services in accordance with the Waiver. Each Waiver establishes various provider qualifications for particular services. For example, physical therapy under the P/FDS Waiver can only be provided by a state-licensed physical therapist or a state-registered physical therapy assistant.
- ◆ The provider is unwilling to sign a provider agreement with DPW and agree to offer cost-effective services in accordance with state regulations.

- ◆ The provider is not willing to provide the services. The provider can refuse to offer services for due cause (such as a conflict of interest or a determination that the provider cannot meet the person's needs).
- ◆ The provider fails to comply with its obligations under state law, its agreement with the county, or the county's agreement with DPW.
- ◆ The provider's rates are higher than necessary and reasonable, as determined by the county.
- ◆ The provider has failed to deliver services in accordance with the individual's program plan.

Can I Appeal Decisions Concerning MR Waiver Services?

An individual has a right to appeal to DPW virtually any negative decisions by the county concerning Waiver services. He or she may appeal:

- ◆ A determination by the qualified mental retardation professional that the individual does not have mental retardation or does not require an ICF/MR level of care.
- ◆ A failure by the county to give the individual the opportunity to choose between ICF/MR and Waiver services or a denial by the county of the individual's service preference.
- ◆ A denial by the county of the individual's Waiver services of choice on his/her program plan, including challenges to the amount, duration, or scope of services offered and denials of the individual's choice of providers.
- ◆ A decision by the county to refuse, suspend, reduce, or terminate Waiver services after the county has authorized those services.
- ◆ A failure by the county to provide services with reasonable promptness. This includes not only a failure to provide services under an approved individual program plan promptly, but also a failure by the county to provide Waiver services with reasonable promptness due to insufficient allocations from DPW or due to an incorrect PUNS assessment.

An appeal may be filed even if the individual has agreed to and is receiving services in the individual program plan if, for example, she or he wants to challenge the amount of services provided or a refusal to allow a choice among providers.

The appeal must be filed within thirty (30) days of the challenged decision. The county should provide written notice about the reasons for the decision which also explains appeal rights (including, how to file an appeal, where to file the appeal, how the appeal is conducted). If the decision would reduce or terminate the individual's current MR Waiver

services, the individual must receive written notice at least ten days prior to the date the action is take effect and **has a right to maintain his or her present level of services as long as he or she files an appeal before the date the action is to take effect.** A copy of DPW's Fair Hearing Request Form is Attachment 2 to this Booklet.

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