

# **Making Sure Your Health Care Needs Are Met After You Turn 21**

**Prepared by the Juvenile Law Center and the  
Disability Rights Network of Pennsylvania**

## **INTRODUCTION**

Most youth can't wait to turn 18 or 21 and have the rights and freedoms of an adult. Turning 21 can be really exciting, but being 21 also comes with a lot of responsibilities. One of the things that changes when you turn 21 is what is covered by your insurance if you receive Medical Assistance. It is important to educate yourself on what changes occur and how you can make sure you fill any gaps in treatment and care so you can stay healthy and active in the community.

**PLEASE NOTE: For information in alternative formats or a language other than English, contact DRN at 800-692-7443 Ext. 400, TDD: 877-375-7139, or [drnpa-hbg@drnpa.org](mailto:drnpa-hbg@drnpa.org).**

## **Why do youth under age 21 have pretty good insurance coverage when they are eligible for Medicaid (MA)?**

Under the federal law, children who receive MA receive any treatment that is medically necessary. This is called the EPSDT--Early Periodic Screening, Diagnosis, and Treatment--requirement. The requirement is intended to help ensure low income children and children with disabilities receive good care and also receive treatment that will prevent future illnesses if possible.

## **Do I have to re-apply for MA when I turn 21?**

Yes. And often the re-application must be done at age 19. Your insurance does not automatically renew itself, so you do need to re-apply.

## **What eligibility categories might I fit into?**

In addition to meeting the income eligibility criteria, you may be eligible in one of the following categories:

- If you are eligible for SSI, you will also receive MA
- If you are pregnant

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- If you have a temporary disability (often individuals fall into this category when they are awaiting an eligibility determination for SSI).

### **I have heard about a health insurance program called MAWD, what is it?**

MAWD is **M**edical **A**ssistance for **W**orkers with **D**isabilities. An individual may be eligible for MA under this category if she meets income requirement, has a disability that meets the requirements for SSI eligibility (although they do not need to be receiving SSI), and is working. This coverage is not free, but how much you pay per month depends upon your income from work, making it relatively affordable.

### **Does health insurance coverage change for individuals who receive MA when they reach age 21?**

Yes. When you turn 21, the EPSDT requirement no longer applies. You will have a health plan that covers a group of services and treatment that your insurance will pay for. There are some limits on the services and treatments that your insurer will pay for.

### **What are examples of services and treatments that I got when I was under age 21 and may not receive after becoming 21?**

- Hearing aids are not covered.
- You can only get one wheel chair every three years.
- Psychiatric hospitals are limited to 30 days a year.
- Therapeutic staff support services are not covered.
- Home health services, including nurses aids, physical, occupation, and speech therapists are limited to a combined total of 15 visits per month.

### **How am I supposed to meet my medical needs if my insurance stops covering things that I really need?**

There are a few things that you can do to make sure you get your needs met:

1. **Check if your HMO covers the service or treatment you need.** Depending on what county you live in you will have an HMO (Health Management Organization) that runs your medical plan under MA. Sometimes your HMO covers additional things that MA does not require.
2. **Request an exception to the limit in services.** If the denial of a service or treatment would jeopardize your life or result in the serious deterioration of your health, you may be able to get the service covered. Have your doctor write a letter to your HMO that explains why the service is so important and what will happen if you do not receive it.

3. **Appeal any denial of a service you need.** If your doctor requested a service for you in writing and it is denied, you should receive a denial notice in the mail explaining why it was denied and telling you how to file an appeal. Follow the instructions in the letter. If a service is being taken away from you, ask for an appeal right away – within ten days of the date the letter was put in the mail. If you need help you should call your local Legal Services Office, the Pennsylvania Health Law Project or the Disability Rights Network intake line (1-800-692-7443).
4. **Apply for a waiver.** Waivers provide funds for medical and non medical services that help an individual with particular disabilities function and be part of the community. There are many different waivers that you may be eligible for and they cover many of the services that you may have gotten when you were a child but are no longer covered now that you are an adult. Please see that attached information to find out more about the waivers that you may be eligible for.

#### **If I am eligible for a waiver, will I automatically get it?**

No. Unlike the services that you received under the EPSDT requirement of MA as a child, waivers are not entitlements and have waiting lists. This is one of the reasons why it is important for you to know about the services provided by the waivers and the application process so you can put in your application as soon as possible. If you have been receiving shift nursing services and you are now over 18 years old, you should make sure your case-manager at your HMO has referred you to DPW for transition planning.

#### **Who do I contact to apply for the waivers if I live in Southeastern Pennsylvania?**

If you are applying for waivers having to do with physical health disabilities, such as the **OBRA, Independence, COMMCARE, Michael Dallas and Attendant Care Waivers**, you should contact:

**DPW's Office of Long Term Living**  
1-800-757-5042

If you are applying for the **Autism Waiver**, contact

**The Bureau of Autism Services**  
P.O. Box 2675  
Harrisburg, PA 17105.  
866-539-7689

If you are applying for waivers for individuals diagnosed with an **intellectual disability** (mental retardation), contact your **County Office of Mental Retardation**.

If you are applying for the **AIDS Waiver**, contact:

**AIDS Waiver Program**

PO Box 2675  
1401 N. 7<sup>th</sup> Street  
Harrisburg, PA  
1-800-922-9384 x 3

**What else can I do before I turn 21 to make sure the change in my insurance coverage goes smoothly and I stay healthy?**

- Meet with all your physical health, behavioral health, and any other treatment providers before you turn 21 to talk about the services and treatments that you will still need after you turn 21.
- Compare the list of the services you need to the list of services provided to adult MA recipients. If you anticipate that you will lose services that you need, you can start preparing documentation from your treatment providers to help meet the exceptions to the limits.
- If you are not already receiving services through a waiver, familiarize yourself with the waivers you may be eligible for and the services that it will cover, and contact the office that runs the waivers in your part of the state to get more information and to find out how to apply.
- Ask as many questions as you can think of to your doctors, managed care organization, advocacy groups, and peers to help you become prepared for the changes in coverage that occur at age 21.

## WAIVERS FOR INDIVIDUALS WITH PHYSICAL DISABILITIES

For Information and/or Complaints call the OLTL Hotline at 1-800-757-5042

### Attendant Care Waiver

**Financial Eligibility:** Up to \$2022 a month, up to \$8000 resources

**Functional Eligibility:** Severe physical disability, limitations of ADLs, require NF level of care, 18-59

**Services:** In-home personal assistance, community transition services, and personal Emergency Response services (PERS).

**Limitations and Special Features:** Right to hire, fire and supervise attendant if choose. Individuals with a lower level of need should ask about the Act 150 Attendant Care Program.

### Independence Waiver

**Financial Eligibility:** Up to \$2022 a month, up to \$8000 resources

**Functional Eligibility:** Severe physical disability, limitations of ADLs, require NF level of care, 18-59

**Services:** Assistive technology/specialized medical equipment and supplies, community integration services, community transition services, daily living services, education services, environmental adaptations, Personal Emergency Response Systems (PERS), respite services, service coordination, transportation services, and visiting nurse.

**Limitations and Special Features:** Right to hire, fire and supervise attendant if choose

### OBRA Waiver

**Financial Eligibility:** Up to \$2022 a month, up to \$8000 resources

**Functional Eligibility:** Severe physical developmental disability, need ICF level of care, limitations in ADLs, age 18-59

**Services:** Same services as Independence waiver PLUS prevocational services and supportive employment services

**Limitations and Special Features:** Serves some individuals with autism spectrum disorder, Right to hire, supervise, and fire attendant if choose.

## AIDS Waiver

**Financial Eligibility:** Up to \$2022 a month, Up to \$8000 resources

**Functional Eligibility:** 21 or older, symptomatic HIV or AIDS, Require skilled nursing or intermediate care facility level of care

**Services:** Homemaker services, home health visits, home health aide, specialized medical equipment /supplies, nutritional consultations, and transition services

**Limitations and Special Features:** Case management is not covered. Right to hire, supervise, and fire attendant if choose.

## Michael Dallas Waiver

**Financial Eligibility:** Up to \$2022 a month, Up to \$8000 resources

**Functional Eligibility:** Technology dependent, any age

**Services:** Attendant care, case management, specialized medical equipment and supplies, private duty nursing, respite care, and transition services

**Limitations and Special Features:** Right to hire, supervise, and fire attendant if choose.

## COMMCARE Waiver

**Financial Eligibility:** Up to \$2022 a month, up to \$8000 resources

**Functional Eligibility:** Individuals with traumatic brain injuries

**Services:** Service coordination, personal care services, respite care, prevocational services, supported employment, habilitation and support, educational services, environmental adaptations, non-medical transportation, specialized medical equipment/supplies and assistive technology, chore services, Personal Emergency Response Systems (PERS), extended state plan services, coaching/cueing, night supervision, structured day program, behavioral specialist consultant, cognitive therapy, counseling (consumer and/or family), community integration, and community transition services.

**Limitations and Special Features:** Right to hire, supervise, and fire attendant if choose.

## **WAIVERS FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY (MENTAL RETARDATION) AND AUTISM**

Consolidated Waiver for Individuals with Mental Retardation AND Person/Family Directed Support Waiver

**Financial Eligibility:** Up to \$2022 a month, up to \$8000 resources

**Functional Eligibility:** ICF/MR level of care needed, 3 or older, diagnosis of MR

**Services:** Assistive technology, behavior support services, companion services, educational support services, environmental accessibility adaptations, family living, financial management services, home and community habilitation, home finding, homemaker/chore services, job finding/job support, day habilitation, nursing services, prevocational services, residential habilitation, respite, specialized supplies, supported employment services, supports broker services, supports coordination, therapy services, transitional work services, and transportation.

**Limitations and Special Features:** Waiting list exists, waivers distributed based on prioritization of need as determined by the PUNS.

### Autism Waiver

**Financial Eligibility:** Up to \$2022 a month, Up to \$8000 resources.

**Functional Eligibility:** Diagnosed w/autism spectrum disorder, 21 or older, need ICF level of care

**Services:** Assistive technology, behavioral specialist services, community inclusion, community transition services, counseling, day habilitation, environmental modifications, family counseling family training, job assessment and finding nutritional consultation occupational therapy, residential habilitation respite, speech/language therapy, supported employment, supports coordination, temporary crisis services, and transitional work services

**Limitations and Special Features:** 200 available, individuals not receiving any other waiver services are prioritized. IQ is not considered. Some individuals w/autism are served through the OBRA waiver. Chester County residents may be eligible for the Adult Community Autism Program (ACAP).

## **What an 18 Year Old Should Know About Supplemental Security Income (SSI)**

Supplemental Security Income is a cash assistance benefit for individuals who are very low income and have a disability. To be eligible as an 18 year old, you need to show that your disability prevents you from working in the mainstream economy. Below are some of the highlights you need to know as an 18 year old about SSI.

### **If I have received SSI as a child, what will happen when I turn age 18?**

If you have been receiving SSI as a child, your case will be re-evaluated again based on the adult standard, which is related to work. You will need to submit information such as medical records to document your condition and treatment, a vocational evaluation, and other information that help document your condition and your ability to work.

### **When I turn 18, whose income is looked at to determine if I am income eligible for SSI?**

When you were under 18, your parents' income counted towards determining if you were income eligible for SSI. After you turn 18, it is your income that determines if you are eligible even if you are still living with your parents. You can be working and still receive SSI. For more information on receiving benefits while you work, go to the Workshop on Work Incentives or review their materials in your binder.

### **Is my eligibility affected by where I live and who I live with?**

In most cases, no. Your eligibility for SSI is usually not affected by where you live, however, the amount of your benefit does depend on your living arrangements. The Social Security Administration will look at where you live, if you pay rent, and whether others contribute to your care to determine the amount of SSI you will receive.

### **Do I automatically become my own payee when I turn 18?**

In most cases, yes. As an adult, it will be assumed that you can manage your own money and be your own payee. If you are your own payee, you can decide whether you want to receive the check directly or whether you want it directly deposited in a bank account. You will also be the one to budget your money so that your benefit lasts throughout the month.

Depending on your disability, the Social Security Administration may ask that you have a payee appointed for you. If this is the case, and you think that you have the ability to be your own payee, you should let SSA know. Sometimes they will grant your request to be your own payee on the spot. In other situations, they may ask that you have a doctor document that you are able to manage your own money.

## **Who can be a payee?**

A payee should be someone who you trust to be concerned about your wellbeing and health and helps you understand your benefits and financial situation. Sometimes agencies or case managers will help you find a payee if you cannot think of one. Usually, the following are concerned good candidates for payees.

- Someone who is concerned with your welfare, usually a parent, close relative, guardian, or friend
- An institution or health care provider
- A public or nonprofit agency
- Case managers

## **If I live in a hospital or nursing home, can I still receive SSI?**

If you are living in a hospital or institution for more than 90 days, you will only receive about \$30 a month of your benefit. This is because in most cases Medicaid will be paying for your room and board.

## **What is the student earned income exclusion?**

In some cases receiving income for work can affect the amount of SSI that you get. If you are under 22 years old and are regularly attending school—whether it is high school, college, vocational training, etc—you can make up to \$1640 a month and up to \$6600 a year and it will not affect the amount of SSI you receive.

## **What should I do if my application for SSI is denied?**

If your application is denied, you should appeal the denial as soon as you can. You are given 60 days to appeal. After you send in the appeal forms you can try to see if a legal services attorney can represent you at the appeal.

## Housing Resources You Should Know

*As everyone gets older, they want more independence and freedom, but sometimes you still need some support to make sure you can be as independent and productive as possible. Below are some resources to consider if you are looking for housing or living settings in the community. There are many sources for information about housing. The list below is just a sampling.*

- **Domiciliary Care (“dom care”)** is for individuals who are 18 or older who have a disability, and who need some help with activities of daily living, but do not need 24 hour care. There is a dom care program in every county and it is run by the Office on Aging. In dom care you live in someone’s home. The homeowner provides you some support and care as well as meals. You create House Rules with the dom care provider to make sure there is agreement about things such as going in and out of the house, having visitors, etc. You have rights in the dom care program that have to be respected and you are able to file grievances if you feel you are not treated well. The cost of dom care is usually provided by your SSI benefit and a state supplement.
  
- **Supportive Housing through the Office of Behavioral Health and/or Your behavioral health managed care organization (MCO):** If you have a behavioral health impairment that prevents you from living completely on your own, you may be eligible for a supportive housing arrangement either through the county office of behavioral health or through your MCO (such as CBH or Magellan). The options may be different in each county so it is good to do a little investigation as you get close to 18 or 21. Check out the Pennsylvania Housing Choices website to find out more information about different housing models and residential settings for individuals with behavioral health impairments:  
<http://www.pahousingchoices.org/about.html>
  - **The PATH Program:** Projects for assistance in Transition from Homelessness (PATH) provides states with funding to provide community-based services, including supportive housing, for individuals with mental illness as well as co-occurring substance abuse disorders who are homeless or at risk of becoming homeless. To find out if your county uses any of its PATH funds for housing arrangements that you may be eligible for, contact the state PATH coordinator at the Department of Public Welfare, Amanda Pearson, at 717-346-0752.
  
  - **Fairweather Lodges:** Fairweather Lodges provide housing and employment for individuals with behavioral health impairments. Individuals in the program have significant independence, decide on the house rules together, and run the operations of the home (budgeting, paying bills, such as utilities). Residents pay a subsidized rent. This housing model uses peer support as a

key motivator. While not many Fairweather Lodges have yet been developed in Pennsylvania, there is at least one in the South East. Call David Young at Elwyn at 215-895-5663 if you are interested in learning more about this program.

- **Affordable Housing Locator Websites:** There are at least 2 website that help you find affordable housing in PA. These websites allow you to search for units that are subsidized as well as units that have special accessibility accommodations. Unfortunately, affordable housing is far too rare in Pennsylvania so starting the search early is a good idea.

1. **Pennsylvania Affordable Apartment Locator**  
<http://pal.phfa.org>

2. **Columbia Property Management Home Finder**  
<http://www.cpmhomefinder.com>

- **Local Housing Option Teams (L-HOTS):** If you have a behavioral health impairment, your local L-HOT will be a great source of information regarding supportive housing options. The role of L-HOTS is to expand housing opportunities and to seek long term solutions to the housing needs of people with mental illness and co-occurring disorders. Not all counties have L-HOTS, but below is the contact information for the L-HOTS in the South East.

1. Bucks County  
Deborah Perry-Neidhardt  
215-442-0760  
[dpneidhardt@co.bucks.pa.us](mailto:dpneidhardt@co.bucks.pa.us)

2. Chester County  
Catherine Freidman  
610-518-6242  
[cfriedman@residentiallivingoptions.org](mailto:cfriedman@residentiallivingoptions.org)

3. Delaware County  
Catherine Freidman  
610-518-6242  
[cfriedman@residentiallivingoptions.org](mailto:cfriedman@residentiallivingoptions.org)

4. Montgomery County  
Pam Howard  
610-278-3625  
[phoward@mail.montcopa.org](mailto:phoward@mail.montcopa.org)

- **Housing Vouchers:** Housing vouchers provide rental assistance to individuals or families who meet certain income criteria. In most cases when people talk about vouchers they are talking about vouchers provided by the federal government—section 8, for example. Sometimes these vouchers are targeted at particular groups who may face barriers to finding and maintaining stable, accessible, and affordable housing. Below are some of the voucher programs targeted at individuals with disabilities:

1. **Section 811 Supportive Housing for People with Disabilities:** In this program, funds are provided to housing developers or service providers to develop housing for disabled individuals and to cover rental subsidies.
2. **Permanency Supportive Housing for Homeless Individuals with Disabilities and Shelter Plus Care:** While these funds are targeted at individuals with disabilities, eligible persons must also be homeless.

Some vouchers are distributed through your county housing authority while other are distributed through specific programs in the county. You may need to contact your housing authority as well programs like Liberty Resources to determine if any vouchers are available in your county and how they are distributed.

- **Centers for Independent Living (CILs)**

Centers for Independent Living are advocacy organizations of and for people with disabilities. They usually offer housing counseling, advocacy and resource information. In Southeast Pennsylvania the CIL is:

**Liberty Resources**

714 Market Street, Suite 100  
Philadelphia, PA 19106  
215-634-2000  
fax: 215-634-6628  
tdd: 215-634-6630  
toll free: 888-634-2155  
email: [LRinc@libertyresources.org](mailto:LRinc@libertyresources.org)

## CONTACT INFORMATION

If you need more information or need help, please contact

- **Juvenile Law Center (JLC)** at 1-800-875-8887 or email JLC at [info@jlc.org](mailto:info@jlc.org).
- **Disability Rights Network of Pennsylvania (DRN)** at 800-692-7443 (voice) or 877-375-7139 (TDD). DRN's email address is: [intake@drnpa.org](mailto:intake@drnpa.org).

The mission of **Juvenile Law Center (JLC)** is to advocate on behalf of youth who come into contact with the juvenile justice and child welfare systems to ensure that they are treated fairly and are given the support they need to grow into healthy and productive adults. JLC works for positive change in these child serving systems through strategies such as impact litigation, legislative advocacy, and public education.

The mission of the **Disability Rights Network of Pennsylvania (DRN)** is to advance, protect, and advocate for the human, civil, and legal rights of Pennsylvanians with disabilities. Due to our limited resources, DRN cannot provide individual services to every person with advocacy and legal issues. DRN prioritizes cases that have the potential to result in widespread, systemic changes to benefit persons with disabilities. While we cannot provide assistance to everyone, we do seek to provide every individual with information and referral options.

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