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# Self-Advocates and Health Care

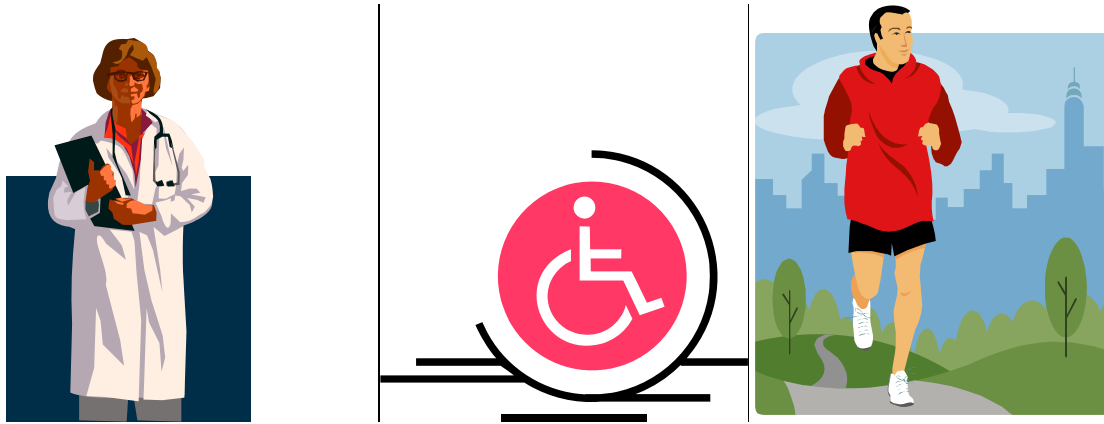
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# Health Care and Self-Advocacy



**Health Care is an important issue for self-advocates, both on an individual level and a group level. Self-advocates often need to:**

- Advocate for themselves to doctors and other people they deal with when obtaining health care.
- Deal with insurance companies and find people who can help them be sure they are getting access to all the care they need.
- Plan ahead for their futures and take control of their own medical decisions
- Learn about medicines and pills they take.
- Individual self-advocacy skills can be very useful when dealing with health care!
- Learn about the medical systems in the United States.
- Listen and share stories with self-advocates about issues in obtaining medical services, and work against barriers.
- Look at issues in local communities.
- Spread awareness to local doctors, and hospitals.
- Fight for more individualized funding sources, and better, more comprehensive care.

Makeover Medicaid: song to the tune of: If I had a Hammer....



If we had a hammer, we'd makeover Medicaid

Fix it for Freedom, all over this land

Money following people, people living in their own homes

Just like all their brothers and their sisters live

All over this land

Now we got a hammer, we'll makeover Medicaid

Fix it for Freedom, all over this land

Fix it with one loud voice working together

Money will follow people

Medicaid Moving forward

People living in their own homes

Lots of great direct support staff

Good Docs and Dentists too

People living in neighborhoods

All over this land

In all of our states

All over this land

From: Self Advocates of New York State Website: <http://www.sanys.org/songs/songlist.htm#mm>

## **Self-Advocates can learn to help advocate for their own medical care in the following ways:**



- **Ask questions when you don't understand what is being said**
  - Write down questions beforehand
  - Speak up about asking questions- if you don't understand ask again
  - Ask your doctor to explain all tests and their results
  - Make sure you know and communicate what you really want to your doctor
- **Be your own health care advocate**
  - Learn about your disability
  - Know warning signs for needing emergency help
  - Know who to call in emergency- have that information on you
  - Learn how to make appointments
- **Take charge of health care information**
  - Understand medicines you take
  - Know how to call your pharmacy and fill prescriptions
  - Keep lists and addresses of all of your doctors
  - Keep notebooks/ journals of doctor's reports, medicines, operations, and tests
  - Keep journals of symptoms, pain, etc.
  - Ask doctors for short written summaries of health conditions
  - Know how to order and care for any adaptive equipment you use
  - Bring an ally with you if you need support
- **Get to know rights regarding health care**
  - Learn about what type of services you have access to
  - Learn about your insurance coverage
  - Know what kind of care you are entitled to
  - Be wary of anyone who says "don't worry, you just don't understand"
  - Talk with others who have been through similar situations.

- You are always entitled to a second opinion
- Your physician is a paid consultant

*Adapted from: Medical Home Portal-Self Advocacy*  
<http://www.medicalhomeportal.org/living-with-child/transition-issues/transition-to-adulthood/self-advocacy>

## Medicines/ Prescription Medications:



Some medicines we get from the doctor and some we get at a local drug store. Some make us feel better right away, and some help for long term care. Some are important for things like diabetes or epilepsy because they help keep conditions under control. Some medicines might have serious side effects, and may make us feel worse. **So what are a person's rights when it comes to medicines?**

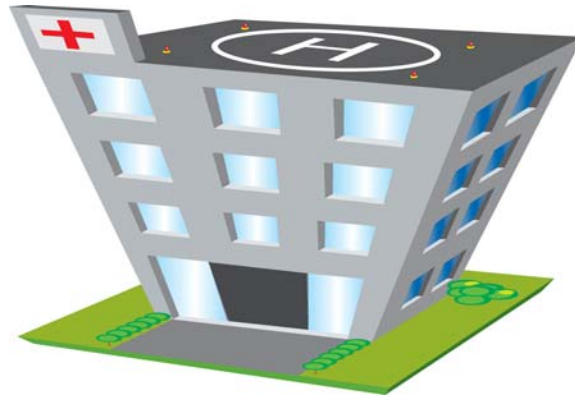
When you take medicines, you have the right to know:

- What it's for
- What it's called
- What side-effects it may have
- How often, for how long, and in what amount it should be taken
- Whether its effects should be reviewed periodically.

*You should always try to understand and learn about your medicines. If there is medicine you don't understand and don't know why you are taking, you should talk more with loved ones and doctors about the medicine and whether it is the right choice for you after you have an understanding of what it is for. There may be a difference in a pill for a medical condition than a pill to "control behavior".*

**Adapted from:** Atkinson, D. et. al (1996) *Work Book 2: Speaking out for Equal Rights*.  
 Dorchester, Dorset: The Dorset Press.

## Health Care Policies and Systems:



*As we speak, Congress is deliberating on vast and important changes to the system of health care in the United States. This issue is one of crucial importance to all Americans, but of particular interest to those Americans who interact with public health insurance more than almost any other group -- people with disabilities. Ranging from veterans with disabilities who receive care through the Veteran's Administration health care system to the many low-income disabled adults who are eligible for Medicaid, the disability community interacts with the public health care infrastructure in the United States in a wide variety of ways.*

From: Ari Ne'eman, president of the Autistic Self Advocacy Network in Health Care Reform and the Disability Community, Huffington Post. [http://www.huffingtonpost.com/ari-neeman/health-care-reform-and-th\\_b\\_206492.html](http://www.huffingtonpost.com/ari-neeman/health-care-reform-and-th_b_206492.html)

## **Medicaid:**



Medicaid is a program for people who can't afford to pay for other types of medical care, or who may have higher medical needs. Individuals who are U.S. citizens may qualify if they:

- Have high medical bills.
- Have qualified for Federal Supplemental Security Income (SSI).
- Meet certain income, resource, age, and disability requirements.

## **The Medicaid Waiver:**



Medicaid Waivers were created by the Federal Social Security Administration (SSA) to let States manage some specialized Medicaid programs with greater flexibility. Medicaid waivers have helped self-advocates get more individualized services in many ways.

- The Medicaid waiver helps people live in the community, instead of living in a more institutionalized setting.

- The *Home and Community Based Services Waivers* provide services and supports to children and adults with long-term needs and their families to enable them to remain at home and in the community.
- Waiver services are designed for people who would need a lot of care, and would otherwise have been given care in a long term facility.
- Some other services that the waiver will pay for include; *case management, therapeutic recreation, respite, and home adaptations.*

## Medicare



Medicare is the largest health insurance program and comes from the Federal Social Security Administration.

There are two parts to Medicare: Hospital Insurance (Part A) and Medical Insurance (Part B).

All individuals have to pay, to some degree, for Part B.

*A person under age 65* can qualify for Part A without paying if

- They received Social Security Disability (SSDI) or Railroad Retirement Board Disability Benefits for a period of 24 months. So self-advocates may be eligible for Medicare services, under Part A.

*Adapted From:* [www.healthytransitionsny.com](http://www.healthytransitionsny.com)

## What about the United Nations Law?



### Here are some of what the new law says about health care rights (paraphrased):

- We should have the same health care as others.
- Our care should be as good as others' and not cost more.
- We should not have to travel farther than others to get care.
- Insurance companies must treat us equally.
- Medical workers must treat us equally.
- Health is more than health care.
- These make us less healthy: being poor, poor schooling, poor housing.
- These help us be well: enough money, enough education, enough for a good life.
- Society must reach for the top: the best well-being for each person.

*Not everyone in America thinks that all Americans are receiving the care they should. Self-advocates and people with disabilities often do not get good enough health care. Understanding what the United Nations and the rest of the world sets as the standards may help self-advocates fight for a better health care system in the United States.*

Adapted from Advocating for Change together memo:  
<http://www.selfadvocacy.org/programs/sarn/memos2009/jan14.htm>

## What self-advocacy groups can do?



- Have discussions about health awareness
- Speak out about health issues that they face individually and collectively
- Have a say in what goes on in local health services
- Fight for increased funding for Medicaid, and universal health care
- Fight against insurance companies who discriminate against people with disabilities and turn down people with disabilities.
- Fight to get access to health care information in accessible formats
- Fight for information brochures to be in plain language and easy to follow
- Support legislative bills such as the Community Choice Act: several disability rights organizations have sent a [joint letter to Secretary Sebelius](#) urging that the Community Choice Act, which would eliminate the institutional bias in Medicaid and enable people with disabilities to live in the community, be included in health care reform legislation. Send a similar letter!
- Fight for more individualized and community based health care services!

## Resources



### **Florida Developmental Disabilities Council: Health Care Transition Training Program:**

<http://hctransitions.ichp.ufl.edu/ddcouncil/>

Health care transition is a process that takes time and planning. This site has been developed as a learning resource for people like yourself who are either in the process of transition, or about to be. The website provides both training and resources in Florida.

### **Florida Medicaid** <http://medicaidresource.com/>

Provides resources about Medicaid specific to Florida.

### **Florida Medicaid Waiver:** <http://www.wphf.org/pubs/briefpdfs/Medicaid5.pdf>.

Information on Florida's Medicaid Waiver system.

### **Handbook for people who self- or family manage Medicaid Waiver Services:**

<http://www.dail.state.vt.us/DSwebsite/docs/ds/ddasSelfManagedHandbook.pdf>

A handbook for individuals who wish to self- or family-manage their developmental services. Copy of the appendices for the handbook can be found on the Developmental Services webpage under Publications or by contacting the Division of Disability and Aging Services - 802-241-2614.

### **Health Insurance, Appeals and Medicare Resources for Self Advocacy**

<http://www.nationalmssociety.org/download.aspx?id=10498>:

Although focused on MS, this has really good general information on self advocacy and the Medicare system.

### **Healthy Transitions:** <http://www.healthytransitionsny.org/>

This is a highly accessible site including activities, videos and other resources to provide information focusing on youth with developmental disabilities and self-advocates within the health care system. An excellent resource.

### **Kids as Self Advocates (KASA):** <http://www.fvkasa.org/resources/health.html>

Has a variety of resources and fact sheets on health related issues.

**Kids Health:** <http://kidshealth.org/kid/>

A plethora of information on health care and interactive activities, focused on providing information to youth. Have areas for parents, teens, and kids to investigate.

**Medical Home Portal:** <http://www.medicalhomeportal.org/living-with-child/transition-issues/transition-to-adulthood/self-advocacy>

Here we aim to help parents and other family members learn about caring for children with chronic and complex conditions and to become effective partners in their care with physicians and other health care professionals. Including a really great Care Notebook Resource.

**Self- Advocacy Online:**

[http://www.selfadvocacyonline.org/learningcenter/sao\\_lesson.asp?lessonid=2&pagenumber=1](http://www.selfadvocacyonline.org/learningcenter/sao_lesson.asp?lessonid=2&pagenumber=1)

The self-advocacy online site has a spoken and video module about living a healthy life.

**The Boulevard:** <http://www.blvd.com/>

A Disability Resource Directory of Products and Services for the Physically Challenged, Elderly, Caregivers and Healthcare Professionals

**TSAlliance:** <http://www.tsalliance.org/pages.aspx?content=64>

Self-Advocacy page has a range of tips for getting appropriate medical care. The *Home and Community Based Services Waivers* provide services and supports to children and adults with long-term needs and their families to enable them to remain at home and in the community.