Accessing Home and Community-Based Services:

A Guide for Self-Advocates

A Project of the Autism NOW Center and the Autistic Self Advocacy Network

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Introduction

CHAPTER 1

OUTLINE

- What is this?
- How to use this tool

[Above: an illustration by Ianthe MBD. A beige banner reading "Accessing Home & Community-Based Services" over the text "A Guide for Self-Advocates" on a purple background.]

What is this?

Accessing Home and Community-Based Services: A Guide for Self Advocates is a tool designed to help people with disabilities, our families, and friends find and use resources that are available to us. This may include family and friends, community-based services, state funded waivers and programs, and other resources to help empower people with disabilities to live as independently as possible and make our own choices about what we need.

This tool can help those using it become more self-sufficient and independent. It can also help spread awareness about resources that you may not have known about or been familiar with. It is a tool to inform about various resources and how to access them. It is also a reference about resources that, although you may not need or want them now, you can use in the future.

How to use this tool

Accessing Home and Community-Based Services: A Guide for Self Advocates is a tool designed to provide information about a wide range of resources available to people with

disabilities. You can read it from start to finish, or you can just read the chapters that are relevant to you. If you see a resource, or type of resource, that you think will be helpful, research that resource more thoroughly.

Each chapter in this tool focuses on one topic. **Chapter 1** is instructions on how to use this tool. **Chapter 2** discusses what it means to have a disability, and it has some useful facts that disabled people should keep in mind. **Chapter 3** explains what services HCBS provides. **Chapter 4** lists the benefits of HCBS. **Chapter 5** is an introduction to the housing program under HCBS. **Chapter 6** is on the subject of independent living. **Chapter 7** discusses what it means to have access to the community. **Chapter 8** explains how HCBS relates to employment. **Chapter 9** is instructions on how to deal with HCBS waivers. **Chapter 10** provides information on Medicaid and social security benefits. **Chapter 11** gives instructions on how to apply for HCBS benefits. **Chapter 12** explains what self-directed services are, and how they empower people with disabilities. **Chapter 13** discusses system alternatives with a focus on independent living options. **Chapter 14** is a description of the ideal daily life of a person with a disability receiving support through HCBS. **Chapter 15** contains links to sites with more in-depth information.

This tool will explain what kinds of things Home and Community-Based Services (or HCBS) can support, like housing and help with getting a job. It will also describe how Medicaid and Social Security are related to HCBS and teach you what an HCBS waiver is. There are also instructions that will show you how to apply for these benefits.

Not all states offer the same HCBS benefits, so sections of this tool will explain how these services may vary and how to determine if they are available to you. In case your state doesn't have any HCBS benefits you can use, this tool has a guide that can show you alternatives to traditional HCBS services that you can use to get the help you need without having to give up your chance at living independently. Some chapters will also have a "government funded options" and a "natural supports" section to tell you more about your options using HCBS and the options you have for other supports around you outside of HCBS.

You can use this tool in different ways. You can read it from beginning to end, or you can go right to the sections you want to know more about. Each section can stand on its own and will include its own overview, list of key terms, and summary of information. Because of this, you may see some of the same information in different sections.

In each chapter, you will see words or phrases that are **bold and green.** You can find definitions and explanations of these words and phrases in the Glossary section of Chapter 15.

I'm disabled – now what?

CHAPTER 2

[Above: an illustration by Jo M. A person standing with their hands on their hips. There is a thought bubble with a question mark above their head.]

OUTLINE

- Overview
- Key terms
- What is a developmental disability?
- Disability: a natural part of the human experience
- Rights
- Olmstead
- Self-determination
- Full participation
- Supports, accommodations, and other tools
- Conclusion/summary

Overview

The first section is called "What is a developmental disability?" and talks about what having a developmental disability means for you. Next is "Disability: a natural part of the human experience", which explains that disability and accommodations are a normal part of being a person.

The section "Rights" explains that disabled people have the same rights as non-disabled people. "Olmstead" is a very important legal case that means public services for people with disabilities need to be available in the community, instead of keeping people in institutions.

The next section talks about the different parts and steps involved in "Self-determination" and why it is important for people with disabilities to be in charge of our own lives. "Full participation" explains our right to be included in every part of our communities and lives, and

how that right is protected. The section "Supports, accommodations, and other tools" talks about some of the ways you can find services in your community.

Key terms

- **Developmental disability**: A lifelong disability that can begin from ages 0-21.
- **Olmstead vs LC**: Ruling that mandated public organizations to provide community-based services to people with disabilities.
- **Americans with Disabilities Act (ADA)**: Civil rights law protecting people from being discriminated against on the basis of having a disability.
- **Self-determination**: Being in control of your own life and future.
- **Full participation**: A term used in the ADA to denote that people with disabilities have the right to join in their communities just like anybody else.

What is a developmental disability?

A **developmental disability** is a mild to severe disability that can begin from ages birth-21 years old, and is expected to last for rest of one's life. Developmental disabilities can affect a person's brain, body, or both.

While they are not always easy to see, these disabilities can result in a problems with learning, self-care, mobility, and being able to live or work on your own. About 5.4 million Americans have developmental disabilities, no matter what culture, family, or where you live.

Disability: a natural part of the human experience

A **disability** is a natural part of human experience. Having a disability does not change the right of individuals with developmental disabilities to live independently or in our communities, enjoy self-determination, make choices, be included in and belong to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational

mainstream of society. Disability is a part of human diversity just like any other aspect of a person's identity, such as race, ethnicity, sexual orientation, gender identity, or religion.

Rights

A person with a disability has the right to:

- be publicly educated in the same schools as non-disabled people
- be employed in the same workplaces as non-disabled people
- use transportation to get to places
- vote
- go to court
- get recreation
- get health care and social services
- come to town meetings
- join services, programs, and activities while giving them an equal opportunity to benefit from all these privileges like non-disabled people
- go to courses, movie theaters, shops, retail stores, restaurants, day care centers, private schools, funeral homes, zoos, sports stadiums, hotels, and anywhere else non-disabled people can go
- be treated like everybody else

Olmstead

A highly important legal case in disability rights is **Olmstead vs LC**. This case is usually just called Olmstead. The Olmstead case began with Lois Curtis and Elaine Wilson. These two women were voluntarily admitted into the

To learn more about Olmstead, see Appendix B: Resources by Chapter ***page 114.***

psychiatric unit in Georgia Regional Hospital. After receiving treatment, both were told by mental health professionals that they could be moved to a community-based program. Unfortunately, they were both kept for several years in the institution after the end of their treatments. Because of this, they filed a lawsuit under the **Americans with Disabilities Act (ADA)** for release from the hospital.

The important conclusions that the court reached still have a large impact today. On June 22, 1999, the court ruled in favor of Curtis and Wilson. This ruling mandated public organizations to provide **community-based services** to people with disabilities.

The only exceptions to this rule are:

- ➔ if community-based services are inappropriate
- ➔ if the affected persons oppose community-based treatment
- ➔ if community-based services cannot be reasonably accommodated

The transition is still incomplete and is ongoing on a state-by-state basis. This is part of the reason why HCBS services and availability may be different depending on what state you're in.

Self-determination

What is it?

Self-determination is controlling your own future. It means you are the one in charge of your life. If you need supports, as all people do, self-determination means you decide what those supports are and how you want to receive them.

Why is it important?

Many people with developmental disabilities are not expected or allowed to control our own lives. Other people decide where we will live, how we will spend our money, what we will do doing our days, who will work with us and who our friends are, and what we need. Self-determination says that this is wrong. Self-determination says that people with disabilities have the right and the ability to be in charge of our own lives.

To learn more about self-determination, see Appendix B: Resources by Chapter ***page 115.***

If a person with a disability is self-determined, we get to decide where we will live, what our job is, how we spend our days, who our staff is and what we want them to do, what help we need, and what we want to do. We get to make our own decisions and live the lives we want to live, just like everyone else.

Self-determination is a right and a possibility for all people with disabilities. Some of us might need help figuring out what we want, understanding our options, and communicating our desires to other people. That's okay. With the right supports, everyone can be self-determined.

Full participation

What does it mean?

"**Full participation**" is a term used in the Americans with Disabilities Act (ADA) and has a specific legal meaning. The ADA helps people with disabilities to be able to have full participation in society.

Full participation is a part of inclusion. It refers not just refer to physical access, but also to the ability to access and participate in your community, workplace, and all areas of life just as a person without a disability would. In short, what it means is that just like a person with a disability can't be shut out of a business or public building altogether, it is also not okay for us to be shut out of specific parts of a building, event, or system.

Supports, accommodations, and other tools

People with disabilities might need different kinds of help or tools in order to do the things we want. We usually call this help "support" or "accommodations." We will talk a lot about different kinds of supports and services in some of this other chapters in this tool.

Finding individuals or organizations to provide assistance can seem difficult. There is help available in most communities. Connecting with resources and building relationships in your community is a good start.

A couple of good places to find resources are city halls or the local health offices. Most information now can be found on the internet, but you should still expect to have to make phone calls. Possible websites include:

- https://www.disability.gov/
- **Independent Living Research Utilization -** http://www.ilru.org/html/publications/directory/
- **Independent Living Institute** - http://www.independentliving.org/
- **Self Advocates Becoming Empowered** - http://www.sabeusa.org/
- **The Arc** - http://www.thearc.org/page.aspx?pid=2530
- The United Way
- Your state's website
- The official website of your city

Reaching out to family and friends can lead to them assisting you or helping you find assistance. School counselors and disability programs at schools can be great for helping students with disabilities. A trusted doctor could be a person to ask about organizations or programs that provide assistance.

You can also check **Chapter 14: Appendices** at the end of this tool. There is a section listing resources grouped by chapter and a section listing national resources with short descriptions for what each resource is.

Conclusion/summary

Everybody wants to be able to live their life the way that they choose. For people with disabilities, it might seem like a lot of work to figure out how to find supports and resources to help. The good thing is that there are a lot of choices and resources out there to help you live your life to the fullest. It might seem like a lot of work to find out about all of these supports, or you might be scared to try to figure it out all on your own. This tool was made to show you that you are not alone and that it is even easier than you think to learn about the choices you have. It will help you understand Home & Community-Based Services and make choices about your own life.

This chapter was an introduction to the basic framework of rights and protections we have as people with disabilities. Key terms in this chapter were "developmental disability," "Olmstead vs LC," the "Americans with Disabilities Act," "self-determination," and "full participation." The next chapter will provide an overview of the services that fall under the umbrella of "home and community-based services."

Services overview

CHAPTER 3

[Above: an illustration by Jo M. A postage stamp with a picture of the United States and the text "HCBS" across it.]

OUTLINE

- Overview
- Key terms
- What does HCBS cover?
- What HCBS is NOT
- The system at a glance
- Recent changes
- State differences
- Working outside the system
- Conclusion/summary

Overview

Working with government programs can be very confusing, but Home & Community-Based Services can help you live the life you want to. This tool can help you learn to use HCBS in a way that works for you. This chapter will help you understand the basics of Home & Community-Based Services. It will talk about what HCBS is and the ways that HCBS can help you.

The first section, "What does HCBS cover?", talks about what kind of supports the programs offer. "What HCBS is NOT" explains how HCBS is a specific program that only gives money for supports that help us participate in our communities. The next section explains the different parts of "The system at a glance" and some ways the HCBS programs prioritize our independence. "Recent changes" explains how the new health care system helps HCBS programs be better.

The next section talks about “State differences” in the way HCBS can help you. Last is “Working outside the system” which explains why you might not qualify for Medicaid HCBS and how this tool will talk about other ways you can get supports to live the way you want to.

Key terms

- **Activities of Daily Living (ADLs):** Daily self-care activities.
- **Community First Choice (CFC):** The "Community First Choice Option" lets States provide HCBS attendant services to Medicaid enrollees with disabilities under their State Plan.
- **Home and community-based services (HCBS):** Government-funded supports for people with disabilities delivered at home or in a community setting, instead of an institution.
- **Institution:** A long-term care facility that is segregated from the larger community.
- **Patient Protection and Affordable Care Act (PPACA):** Act enacted with the goals of increasing the quality and affordability of health insurance and expanding coverage.

What does HCBS cover?

Home and community-based services (HCBS) are government-funded supports for people with disabilities. HCBS helps people with disabilities to live in our own homes and to be integrated into the community, instead of living in institutional facilities.

States have a wide range of choices about what kinds of services they offer in their HCBS programs. Common benefits include:

- help with household chores and meal preparation
- modifications to homes for accessibility
- case management services
- transportation services

- ➔ supported employment services
- ➔ direct support services or attendant care
- ➔ particular kinds of therapy not funded in regular state Medicaid programs (like speech, hearing, physical, or occupational therapy).[1]

What HCBS is NOT

HCBS is not a general term

HCBS refers to a specific, government-funded program that is administered by each state. It does not refer generally to any service that you get in a home or community setting, because it is possible to work outside of the HCBS system to get services in these settings.

It is also important to remember that HCBS is not the same as therapeutic or rehabilitative services. It is not home health care (although medicine preparation and administration can be part of your **service plan**).

HCBS is not institutionalization

HCBS is not having to move to a group home or an **institution**. It is not segregation away from the community.

The rules regarding HCBS settings disqualify any location that has the "qualities of an institutional setting." Under this standard, if the setting has the effect of isolating individuals receiving Medicaid HCBS from the broader community, it is institutional.

The system at a glance

HCBS is a partnership. This partnership works to promote quality of life for people with disabilities. This includes independence and health. It is made up of:

- ➔ the national government

[1] http://www.nolo.com/legal-encyclopedia/medicaid-home-community-based-waiver-services-hcbs.html

- state governments
- people with disabilities
- advocates for people with disabilities
- service providers

Choice is an important part of HCBS. People with disabilities decide where we live and who we live with. We decide (within the limits of our program) who provides our services. We can include friends and supports to help us take full part in our communities.

Not only are HCBS programs highly individualized and customizable, the programs are actually less expensive, on average, than institutional care. The freedom to make lifestyle decisions, the lower cost, and the benefit of having individual needs met often make HCBS the preferred choice for support in living independently.

Standards for all HCBS settings

- **Integration with community:** The setting must support full access by the consumer to the greater community, "including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as [consumers] not receiving Medicaid HCBS."
- **Choice:** Consumers must have a choice among setting options, including settings that are not disability-specific.
- **Rights:** The setting must ensure consumer rights to privacy, dignity, and respect, and freedom from coercion and restraint.
- **Independence:** The setting must optimize a consumer's ability to make life choices, including choices relating to daily activities, the physical environment, and with whom to interact. Similarly, the setting must facilitate choice regarding services and supports and who provides them.[2]

[2] http://www.nsclc.org/wp-content/uploads/2014/04/Advocates-Guide-HCBS-Just-Like-Home-05.06.14-2.pdf

Recent Changes

With the new healthcare system, the **Patient Protection and Affordable Care Act (PPACA)**, there has been increased access to HCBS.

Here are some changes that may help people who could not get services previously:

The PPACA adds new services[3] to the original eight under the HCBS option:

- case management
- homemaker services
- home health aide services
- personal care services
- adult day health services
- psychosocial rehabilitation services
- clinic services for people with chronic mental illnesses

*To learn more about the PPACA, see Appendix B: Resources by Chapter **page 115**.*

Now states can no longer limit enrollment. They must make the coverage available statewide and states can give money to people with greater need, such as people with specific disabilities. The law also makes Medicaid benefits available to people with low incomes who meet their state's rules.

Community First Choice

The new law establishes the **Community First Choice (CFC)** option under Medicaid. The purpose is to expand home and community-based services and supports under Medicaid.[4]

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[3] http://health.wolterskluwerlb.com/2012/05/expanded-home-and-community-based-care-under-ppaca/

[4] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Community-First-Choice-1915-k.html

The CFC option provides more money for states to use for home and community-based services. This can help people with disabilities because there are no caps on services, no waiting lists, and services must be given to people in all parts of a state. It allows states to provide home and community-based attendant supports and services to individuals who would otherwise be in an institution. Only a few states are currently using the Community First Choice option.

To learn more about Community First Choice, see Appendix B: Resources by Chapter ***page 116.***

Services include help with:

- **Activities of daily living (ADLs)**, such as:
  - eating, toileting, grooming, dressing, bathing, meal planning and preparation
  - managing finances
  - shopping for food, clothing, and other needs
  - household chores
  - using the phone and computer
  - traveling around and participating in the community
- Health-related tasks, such as nursing and other services under state law.

You can learn more about services HCBS can provide in the following chapters.

Among other provisions, the law requires:

- Services may be performed by a helper with assistance, supervision, or cueing.
- Services may also include assistance in learning skills.
- Transition costs may be covered, such as rent and utility deposits, some bill payments, and costs of outfitting a place to live.
- Services must be provided to anyone who needs them, and in a setting that is appropriate for the person.

State differences

At the moment, most states that offer HCBS will offer it for people with disabilities, but some states may make it easier for you to get them than others or might offer you more help.

For example, Colorado, Indiana, Maryland, and Wisconsin have waivers specifically addressing autism, but the waivers in question are specifically geared towards children and cannot be applied for after a certain age. However, most states consider autism to be a form of developmental disorder and can be covered by waivers related to intellectual and developmental disorders.

An easy way to compare the benefits of one state to another is to go to the following site and look up your state: http://medicaidwaiver.org/index.html

Working outside the system

If you do not qualify for your state's HCBS program, you still have many options available to you in the form of natural supports. Natural supports are alternatives to working through the HCBS system and can come in many forms, including help from friends and family, paying for services out-of-pocket, and other options that allow you to still have decision-making power in your everyday life.

Most of the chapters in this tool will include both a "government funded options" section and a "natural supports" section at the end. This will provide you with information about the options you have if you qualify for your state's HCBS program, and system alternative options if you don't.

The last chapter in this tool, Chapter 14, contains appendices with resources for you as you seek support services. Appendix B has resources organized by chapter and will help you learn more about your options and pursue alternatives to HCBS services. Appendix C is a list of national resources that will also aid you in navigating services outside of the HCBS system.

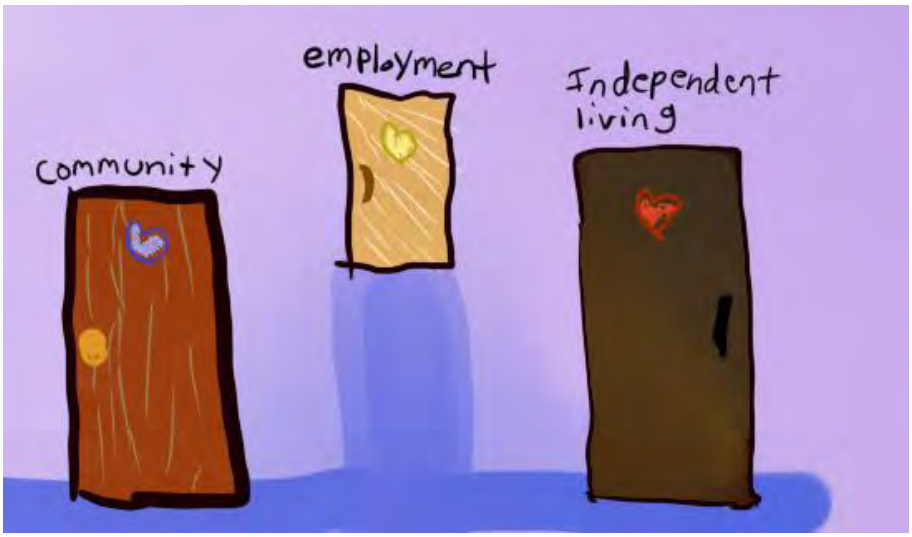
Conclusion/summary

This chapter provided an overview of the HCBS system and introduced the concept of working outside of the system if you don't qualify for your state's program. It also explained that HCBS refers to a specific set of government-funded support programs and is not a general term for any service in a home or community setting. Key terms in this chapter were "activities of daily living," "Community First Choice," "home and community-based services,"

"institutions," and the "Affordable Care Act." The next chapter will go into more detail about what areas HCBS can provide support in for a person with a disability.

What can HCBS do for me?

CHAPTER 4



[Above: an illustration by Corbin K. There are three doors with hearts on them, each labeled "community," "employment," and "independent living."]

OUTLINE

- Overview
- Key terms
- Supporting independent living
- Accessing the community
- Accessing employment
- An everyday life
- Conclusion/summary

Overview

Home and Community-Based Services can be very helpful in a lot of different ways. This chapter explains some of the main ways that it can help you. This chapter will also help you navigate this tool if you want more information about any of the sections right now.

First, "Supporting independent living" talks about ways HCBS can help you live independently. The next section talks about what "Accessing the community" means and about your rights to make decisions and fully participate. The next section explains what "Accessing employment" means and some of the ways HCBS can help you. The point of HCBS is to help people with disabilities live "An everyday life" in the way that we want.

Key terms

- **Case manager/coordinator:** Person who helps someone with a disability to coordinate their Medicaid support services.
- **Home and community-based services (HCBS):** Government-funded supports for people with disabilities delivered at home or in a community setting, instead of an institution.
- **Natural supports:** Supports that you get from the relationships you have in your everyday life, as opposed to paid/hired assistance.

Supporting independent living

Home and Community-Based Services (HCBS) supports people with disabilities to live independently in our own homes.

It is possible to get services in the areas of:

- individual, group, or center-based day supports
- residential, community, and/or day habilitation
- homemaker and chore services
- live-in caregiver or adult companion
- physical, occupational, and speech therapy
- behavioral supports and stabilization
- transportation and vehicle modification
- supported employment
- specialized medical equipment and assistive technology
- housing modifications
- respite
- family training and peer support

- individual goods and services
- activities that are used to help youth move from high school to either employment or college

***Chapter 6** has more information about independent living.*

Accessing the community

Accessing the community means being able to attend community events, build relationships, come and go, have hobbies, and generally interact with the community. Being disabled should not mean that you cannot do these things. Furthermore, you have the right to decide for yourself how and when to access your community.

***Chapter 7** has more information about accessing the community.*

Accessing employment

Accessing employment means people with disabilities working together with people who are not disabled. It means doing the same jobs. It means receiving the same compensation for work.

However, to ensure success in your job, you will have access to several helpful resources, such as **vocational rehabilitation** and **supported employment**.

Vocational rehabilitation provides vocational and rehabilitative services to individuals with disabilities to help them prepare for, secure, regain or retain employment.[5]

[5] http://dds.dc.gov/service/vocational-rehabilitation-services-rsa

Supported employment programs provide employment specialists who will:

- ➔ help you find a job that matches your needs and interests.
- ➔ help you identify the need for training and work with your employer to provide.
- ➔ help you and your employer adapt the work site so that you can do the job.
- ➔ help you and your employer design the supports needed to do the job well.
- ➔ provide the support you and your employer need for as long as it is needed.

***Chapter 8** has more information about accessing employment.*

An everyday life

The purpose of HCBS is to provide the support people with disabilities need to live an ordinary life in our communities. Services and supports will allow people to work, live independently, and participate in recreational activities. People with disabilities want to be part of the community, and with the right supports in place it is possible.

HCBS services are self-directed, and personalized. Usually, you have a **case manager** who knows what your individual needs are, and how to help. You should also be included in the decision making team, and have a say in what services you receive.

Conclusion/summary

HCBS services have the potential to provide much support and assistance to people with disabilities. ASAN and Autism NOW have teamed up to help educate and increase access to such services. HCBS has the potential to help a broad range of people living with disabilities, including those living with developmental disabilities.

This chapter described in more detail the areas that HCBS services can provide support for a person with a disability: independent living, accessing the community, and accessing employment. Key terms in this chapter were "case manager/coordinator," "home and community-based services," and "natural supports." The next chapter will tell you about your options for housing, either through HCBS funding or outside of the system.

Housing

CHAPTER 5

[Above: an illustration by Jo M. Three houses around a cul-de-sac. The house in the middle is colorful and the two on either side are grey.]

OUTLINE

- Overview
- Key terms
- Rights
- Independent living: what can it look like?
- Government funded options: housing waivers
- Natural supports
- Conclusion/summary

Overview

As a person with a disability, you may have found that there are many obstacles in your way when trying to find housing. HCBS can be very confusing and hard to navigate. The purpose of this section is to help you use HCBS in order to find and obtain the type of housing you want.

In the “Rights” subsection, you will learn what your rights are as a disabled person with regard to housing, including information about housing vouchers and community living.

In “Independent Living”, you will learn about Centers for Independent Living and how they can help you find supports and services within the community.

Alternatively, in the subsection “Shared Living” you can find out about living with someone else. If you need programs that provide housing services, then turn to the section “Supported Housing.”

Key terms

- **Americans with Disabilities Act (ADA):** Civil rights law protecting people from being discriminated against on the basis of having a disability.
- **Fair Housing Act:** Legislation that protects you from being discriminated against because of a disability when seeking housing.
- **Housing vouchers:** Government-provided assistance for people with disabilities to have more choice as to where we live.
- **Natural supports:** Supports that you get from the relationships you have in your everyday life, as opposed to paid/hired assistance.

Rights

- Landlord-tenant protections
- Lockable doors
- Choice of roommates
- Freedom to furnish and decorate
- Control over schedule
- Access to food anytime
- Visitors anytime
- Physical accessibility[6]

Every kind of housing is open to people with disabilities. Because of the **Fair Housing Act**, no landlord or seller can refuse to rent or sell to someone because of a disability.

[6] http://www.nsclc.org/wp-content/uploads/2014/04/Advocates-Guide-HCBS-Just-Like-Home-05.06.14-2.pdf

Landlords or sellers have to change their rules to make their living spaces work for people with disabilities due to the **Americans with Disabilities Act**. A place that doesn't allow pets would have to allow a guide dog for a person who is blind. A place where wheelchairs don't fit would have to allow changes to their building to adjust to someone who uses a wheelchair. The landlord or seller wouldn't have to pay for the changes, though. New buildings with four or more apartments must be built so someone in a wheelchair could use the space. Other reasonable changes would also be allowed.

*If a landlord or seller doesn't rent or sell to you because of your disability, or if they won't change the living space or rules to meet your needs, you can file a complaint by calling **1-800-669-9777** or **TTY 1-800-927-9275.***

Housing Vouchers

The voucher program now available to disabled, elderly, and low income people is commonly called **Section 8**. Public Section 8 housing is provided by **housing authorities**. Local housing authorities use federal funds to make housing affordable. A person using Section 8 would pay only 30% of their income on rent and utilities. The housing authority would pay the rest of the rent for a safe, sanitary, moderately-priced house or apartment. There is a waiting list for Section 8 vouchers.

ADAPT is a disability rights organization which supports a plan called Access Across America. This plan hopes to give housing vouchers (something like coupons) to people in nursing homes, or to people that might soon need a nursing home, to help the people afford a home in the community.

Community living

Equal access of the community is a right. You deserve to pursue your goals and have the same opportunities as anyone. You have the right to develop relationships. Most importantly, if you are an adult, you have the right to decide where and with whom you will live.

Community living consists of living in a safe and decent home of your choice, whether that be an apartment or house with roommates, or a place of your own. The bottom line is, you choose the neighborhood, you choose the setting—it is not chosen for you. And once you move into that community, you are just as much an active part of it as everyone else living in it.

Independent living: what can it look like?

Independent living is a person being in control of their environment and making choices on their own as much as possible. This is different for different people, depending on their needs and want. This section explains four different ways independent living can happen. After some thought, you can decide which type of independent living will work best for your life and needs.

You may live on your own with paid support. You may choose shared living. Perhaps all you need is supported housing or maybe you use supported housing along with paid supports. You may be quite independent in your home, using only natural supports.

Living on your own with paid support

You can choose to live in your own home with a paid **Personal Care Assistant (PCA)** to help you with things like cooking and cleaning or even bathing. A PCA might provide transportation around the community. You may also have other help like a speech therapist.

*You can learn more about the kinds of staff you might have in **Chapter 12**, under "Employer authority & managing staff."*

Shared living

Shared living is a situation where the person with a disability lives in a home with at least one other person who provides needed support. This person is called the "**shared living provider**." You might decide to live with a single roommate, a couple, or a family.

You each pay your share of the rent, utilities, and other bills. State agencies may pay the provider a monthly amount for their services, or the provider might provide support in exchange for rent.

You and the provider are equals who have chosen to share your lives. The other person is your roommate, and will also provide whatever supports you need to help you with activities of daily living and activities around the home.

Supported Housing

Supported housing is government-funded, permanent housing for people with disabilities. People receiving supported housing live on their own in their own apartments and have a comprehensive array of supports and services to enable us to live in our homes and participate in the community. Residents control the services, and all services are community integrated and focused on promoting independence and enabling people with disabilities to live in our communities.

Living on your own with natural supports

Natural or informal supports are the kind of supports you get from people that you know. These are supports that you don't have to pay for and come from friends, family, or other people.

A major natural support for housing comes from living with other people. These people can give you many kinds of support to help you live a comfortable life. They might remind you when bills or rent are due, or they could help you to make your home more accessible for you.

There is more information on this option under the "Natural Supports" section for this chapter.

Government funded options: housing vouchers

One way that the government is helping people with disabilities to choose where and with whom we live is with housing vouchers. With a housing voucher, you can find your own housing, including single-family homes, townhouses, and apartments. As long as the house meets the requirements of the program, you are free to live anywhere you wish.

In order to apply, you will need to contact your local **Public Housing Agency (PHA)**, which can be found at the following web address:

http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/pha/contacts

When you apply, the PHA will collect information on income, assets, and disability. Once the information is verified, you will either be offered housing assistance immediately or put on the waiting list to receive it. Unfortunately, in most areas, the demand for housing assistance exceeds the resources provided by the government.

Natural Supports

Roommates

Living with others is a great opportunity to get natural support. Roommates live with you, so they are around most of the time. You can share chores with roommates, and ask them to do the chores that you have difficulty doing yourself. It is also possible to ask roommates to remind you to do tasks, like pay the bills. If your roommate is trustworthy, you could ask them for advice or help with taxes, medical issues, or other concerns.

Paying out-of-pocket

If you have too many financial resources (such as a trust fund or money from earlier work or disability insurance) to qualify for Medicaid and HCBS, you can use your money to pay for services that will let you stay in the community you choose. You can hire your own caregivers and therapists. You will not need to worry about using only providers covered by Medicaid, so you will have a lot of freedom. In choosing providers, it is helpful to ask friends and family about their experiences and for recommendations.

Conclusion/summary

This chapter provided information about our housing rights as people with disabilities, as well as a vision for independent living and options for support. Key terms this chapter were the "Americans with Disabilities Act," the "Fair Housing Act," "housing vouchers," and "natural supports." The next chapter will explain in more detail what independent living is and how supports can enable us to live healthy, independent lives.

Independent living

CHAPTER 6

[Above: an illustration by Simone V. A person is cooking for themselves with ingredients labeled "support," "decision making," and "self-determination.]

OUTLINE

- Overview
- Key terms
- Rights
- What is independence?
- What are Activities of Daily Living?
- What kind of supports might I use?
- Conclusion/summary

Overview

Being able to make decisions about how we live is a very important right for everyone, including and especially people with disabilities. Home and Community-Based Services can help you protect your independence while supporting you in the accommodations you need to be successful.

"Rights" is the first section and it talks about our right to live in the community. The next section, "What is independence?" explains that independence can mean different things for different people. "What are Activities of Daily Living?" talks about what activities of daily living are and the different kinds. The next section talks about what kinds of supports you might use to help with daily activities you need help with, including Personal Care Assistants, Centers for Independent Living, and community supports. HCBS waivers are a way the government funds community living supports, and people who don't have waiver funding can use natural supports.

Key terms

- **Activities of Daily Living (ADLs):** Daily self-care activities.
- **Center for Independent Living (CIL):** Non-profit run with people with disabilities in charge that provides independent living support.
- **HCBS waiver:** Allows people with disabilities to receive care in a home or community-based setting instead of an institution.
- **Personal Care Assistant (PCA):** A hired support person who helps people with disabilities with daily tasks.

Rights

- People with disabilities have the right to live in the community
- This right is protected by the **Olmstead** decision

What is independence?

The dictionary definition of independence is "freedom from outside control or support." Different people with disabilities may need their own definition of independence. For many of us, independence means freedom of choice. A person may not be able to live without help, but we may choose where to live and what supports we need.

Supports are an important part of independent living. With supports, a person can live on our own, work at our preferred job, participate in our community, and choose how to live our lives. In this chapter, we will discuss what supports are available to enable people with disabilities to live on our own.

What are Activities of Daily Living?

Activities of daily living (ADLs) means daily self-care activities. ADLs may be difficult for people with disabilities.

Basic activities of daily living are everyday needs. Examples are eating, moving from one place to another, bathing, and dressing. Instrumental activities of daily living are long-term needs. Examples are shopping, managing finances, managing personal health (including procuring and taking medication as needed), and preparing meals.

A person's ability to perform some ADLs is not always proof of their ability to perform others. A person with a physical impairment such as paralysis, for example, might be able to manage their own finances but physically unable to bathe or dress without assistance.

What kind of supports might I use?

Supports exist to help people who have trouble with ADLs. For example:

- ➔ If a person cannot bathe or dress, they might be able to hire a personal care assistant to help them perform these tasks.
- ➔ A person unable to shop may be able to purchase the things they need online and have them delivered
- ➔ A person who cannot manage finances can hire an accountant or financial manager.
- ➔ A person who cannot prepare meals can have someone prepare meals for them, or can purchase ready-made meals that require little or no preparation.

Below, we will explain three sources of support in more detail: Personal Care Assistance, Centers for Independent Living, and community supports.

Personal Care Assistance

A **Personal Care Assistant (PCA)** or a Direct Support Person (DSP) helps people with disabilities follow their daily routine.

A PCA/DSP can help people with important daily tasks and chores. A PCA/DSP can help a person with a disability with day-to-day tasks such bathing and dressing, preparing a meal, or managing household chores. They can also support you in accessing the community or anything else that is a part of your day-to-day life.

PCAs and DSPs services are trained staff, usually hired through Medicaid. The laws stating who is acceptable may vary by state. More detailed information about Medicaid can be found in Chapter 12.

***Chapter 12** has more information about PCAs.*

Centers for Independent Living

A **Center for Independent Living (CIL)** is a non-profit organization. They are designed by people with disabilities. CILs are run with people with disabilities in charge - at least 51% of the staff are people with disabilities and at least 51% of the Board of Directors are too. That means that CILs can focus on the needs of the people they help. They use insights from people with similar disabilities to better help people.

Centers for Independent Living Provide:

- ➔ Peer Support
- ➔ Information and Referral
- ➔ Individual and Systems Advocacy
- ➔ Independent Living Skills Training

America is home to:

- ➔ 403 Centers for Independent Living (CILs)
- ➔ 330 branch offices

➔ 56 Statewide Independent Living Councils (SILCs)[7]

CILs also provide **peer mentors**. Peer mentors are people with disabilities who serve as role models. Peer mentors help people with disabilities adapt to daily challenges.

Community supports

Every community has organizations where people with and without disabilities can seek information and support. These organizations might be skill shares, volunteer networks, community groups organized around specific needs like Meals On Wheels or transportation cooperatives, United Way, community centers, or faith-based organizations. 211 is a good starting point designed to help you locate existing community supports.

***Chapter 14** has lists of resources in Appendix B and Appendix C.*

Government funded options: HCBS waivers

Home-and-Community-Based Services are a way for long term care to be done outside of an institution. HCBS, as the name states, can be done in a person's home and in the community in which they live. For many people with disabilities, HCBS care is preferred because they can stay in their homes and stay near their families and friends.

HCBS waivers can make HCBS care possible. A HCBS waiver allows for people who would otherwise be in institutions to receive care in the community.

***Chapter 9** has more information about HCBS waivers.*

Natural supports

People without waiver funding can use naturally occurring supports, community supports, and centers for independent living to help us live in our community. You can find more

[7] http://www.ncil.org/about/aboutil/

information on community supports and centers for independent living earlier in this chapter. Naturally occurring supports are supports that are embedded in our everyday lives and relationships, like:

- ➔ a friend giving you a ride
- ➔ a partner reminding you to brush your teeth
- ➔ ordering groceries online instead of struggling in the grocery store
- ➔ going to a community supper instead of making dinner, or
- ➔ living with a roommate.

Conclusion/summary

This chapter explored what "independent living is" and how supports factor into leading an independent life. Key terms this chapter were "activities of daily living," "Centers for Independent Living," "HCBS waivers," and "Personal Care Assistants." The next chapter will provide information about our right as people with disabilities to participate in our communities, and the supports available to help us accomplish that.

Accessing the community

CHAPTER 7

[Above: An illustration by Corbin K. Four smiling people standing and waving. There is a sign reading "Bus #1" next to them.]

OUTLINE

- Overview
- Key terms
- Rights
- Transportation
- Community participation
- Building relationships
- Government funded options
- Natural supports
- Conclusion/summary

Overview

Everyone has a right be able to be involved their community. Being a part of your community could include going to a church, meeting new people, visiting friends, going shopping, or many other things. It can be harder for people with disabilities to join our communities for many reasons, but that doesn't make it any less important. Fortunately, there are many supports for people with disabilities to help us to do all of the things we might want to do in our communities. Being involved in your community can also help you access more supports.

The first section explains that we all have the right to move and participate in our communities the way we want to, and those rights are protected by the law. "Transportation" talks about different ways to get around our communities for people who don't drive. The next section talks about everyone's right to "community participation" and what that means. "Building relationships" talks about the importance of friendships and some ideas for finding friends. The next sections talk about services for accessing the community that are funded by the government, and about natural supports.

Key terms

- **HCBS waiver:** Allows people with disabilities to receive care in a home or community-based setting instead of an institution.
- **Paratransit:** An alternative mode of flexible transportation that does not follow fixed routes or schedules.
- **Personal Care Assistant (PCA):** A hired support person who helps people with disabilities with daily tasks.

Rights

People with disabilities have the right to:

- Use public transportation
- Leave the places we live if we want to
- Shop at stores
- Participate in church or other community services

For people with disabilities, having accessible transportation is key in getting to work and going into the community.

***Public buildings that are not accessible need to be reported**. This is because they violate Title II of The Americans with Disabilities Act.*

They can be reported to the Justice Department Civil Rights Division: http://www.justice.gov/crt/complaint/#two.

Transportation

There are many transportation options available to who don't drive. Some people may rely on family or friends. In some areas, taxis are an option. Another option might be ride shares or transportation cooperatives, where volunteers coordinate rides for people who don't drive. Many areas also have **paratransit** available. These are programs which require you to sign up and demonstrate eligibility, and will then provide pre-scheduled vans.

*For more information about public transportation, see Appendix B: Resources by Chapter **page 119.***

Availability of public transportation will vary, depending on where you live, but in many areas this is an option. Public transportation could include busses, street cars, and trains, and most public transportation companies have websites that have information about routes, costs, and stops. Travel training is available in all areas to teach people with disabilities how to use public transit; to learn more, go to the website for your local public transit authority or ask a local chapter of the ARC or a local Easter Seals.

Community participation

Community participation is a measure of how easy it is for someone to go into the community. Community participation may include visiting friends, going to the store, or attending community events like concerts or town halls. If you go to the movies, attend a community potluck dinner, go to church, volunteer in a community garden, or window shop at the mall on the weekends, you are participating in the community.

As a person with a disability, you have a right to participate fully in all parts of the community. Barriers to community participation can include transportation, which we discuss in the previous section, and inaccessibility, which we discuss in the Rights section. Some people with developmental disabilities need direct support in order to participate in the community.

*For more information about direct support, see the section on personal care attendants in **Chapter 12.***

Building relationships

Friendships are a basic human need. Everyone wants to be accepted and loved for who they are. The more friends you have, and the closer they are, the stronger your support network will be. Some suggested places to meet and make new friends include faith communities, if you follow a particular religion, local organizations, groups associated with your special interests, and social media. There are also volunteering organizations such as United Way (www.unitedway.org) you can join. Your local library might have a book club or other organized events you can join in on.

*For more resources, see Appendix B: Resources by Chapter **page 120**.*

To find groups, near you, you can use an online directory. For example, www.whitepages.com or www.yellowpages.com are online directories, similar to a phonebook. Meetup.com is a website specifically designed for advertising groups. Many cities have similar websites to advertise community groups and events.

Also online are social media websites such as Facebook or Foursquare. These sites can be used to keep in touch with friends or with other people who share your special interest. Many groups, both local and national, have Facebook pages you can “like” and join.

Government funded options

HCBS waivers can fund a Direct Support Professional (DSP) or Personal Care Attendant (PCA) to accompany you in the community and provide support. Some HCBS waivers also include funding for transportation, such as paratransit.

***Chapter 9** has more information about HCBS waivers.*

Natural Supports

Natural supports for accessing the community might include public transportation, community networks such as rideshares, and doing thing with friends and families. For more options, see the sections above.

Conclusion/summary

All human beings have the right to build relationships with people and join groups in their communities that interest them. Being able to join your community is important so that you can have a support network and make new friends. There are many kinds of supports to help you access your community, from different transportation options to the supports you can find from friends and family.

This chapter was about the rights we have to participate in our own communities and what supports are available to help us to fully participate. Key terms in this chapter were "HCBS waiver," "paratransit," and "Personal Care Assistant." The next chapter is about different options for employment and supports available for people with disabilities in the workforce.

Employment

CHAPTER 8

[Above: an illustration by Jo M. Two people are shaking hands over a desk.]

OUTLINE

- Overview
- Key terms
- Rights
- Real jobs for real pay
- Employment First
- Integrated & competitive employment
- Customized employment & self-employment
- Accommodations
- Government funded options
- Natural supports
- Conclusion/summary

Overview

Having a job is a big part of life for most adults. A job gives you a source of money so that you can afford to pay bills and buy things for yourself. It can give you the chance to work on the skills you have and to learn new ones. A job can also be a place to meet new people and gain self-esteem. For people with disabilities, there are sometimes things that get in the way of being able to work in your community for fair pay and with the supports you need.

The first section talks about the work-related rights people with disabilities have according to the law. It is really important that people with disabilities can get jobs that are not segregated and that pay the same as jobs for people without disabilities. The next section explains the “Employment First” program. After that, this chapter will explain the meaning and importance of “Integrated and competitive employment”. Next, you will learn about different kinds of employment that exist to help people with disabilities join the workforce. After that, you will learn what a workplace accommodation is, how it can help you, and how it is

protected. The next section is "Government funded options", which explains vocational rehabilitation and supported employment. Finally there are suggestions for natural supports in employment.

Key terms

- **Americans with Disabilities Act (ADA):** Civil rights law protecting people from being discriminated against on the basis of having a disability.
- **Competitive employment**: In an integrated employment setting, people with disabilities get paid at least the minimum wage for their work.
- **Customized employment:** An employment setting where an employee with a disability may have the job duties tailored to fit their strengths/weaknesses.
- **Employment First**: An approach to employing people with disabilities in which community-based, integrated employment is the first option.
- **Essential job functions:** Basic functions of a job that an employee must be able to do with or without reasonable accommodations.
- **Integrated employment:** An employment setting where people with disabilities work alongside non-disabled people and are paid at least the minimum wage.
- **Reasonable accommodations:** Adjustments made in a system to accommodate or make fair the same system for a person with a disability.
- **Self-employment:** A form of customized employment where a person receives support to own and operate their own business.
- **Sheltered workshop:** An employment setting where people with disabilities are segregated from non-disabled people and their employers are allowed to pay them less than the minimum wage.
- **Supported employment:** Government-funded individualized supports for people with disabilities in the workplace.
- **The Fair Labor Standards Act of 1938 (FLSA):** Legislation that establishes many of the federal rules about employment. A loophole in this law allows some employers to pay people with disabilities less than the minimum wage.

- **Vocational rehabilitation:** A program that helps people with disabilities find and prepare for employment.

Rights

- The right to receive **reasonable accommodations** in the workplace
- A person with a disability must be given the same opportunities that non-disabled people are given.
- Workplaces must be accessible to people with disabilities.

Real jobs for real pay

Many people with disabilities are still paid less than minimum wage. This practice is legal because of a loophole in the **Fair Labor Standards Act of 1938 (FLSA)**[8]. This loophole is Section 14(c) of the FLSA. Section 14(c) allows the Secretary of Labor to give employers Special Wage Certificates that let them pay workers with disabilities wages that are less than the federal minimum wage, primarily in **sheltered workshops**.[9]

In sheltered workshops, people with disabilities have to work separately from people without disabilities and are paid much less. These sheltered workshops do not have to follow the rest of the FLSA, which is a big problem for people with disabilities who work there.

There are hundreds of thousands of people with disabilities who are paid less than the minimum wage for their work. This is very harmful to these workers. Since they are paid such a small amount, many workers with disabilities have to rely on many government social programs to have enough money to survive. These programs can be difficult to sign up for, and often have their own limits on how much money can be given. This makes life more difficult for many people with disabilities. If people with disabilities get the supports we need at work, we can participate in jobs just like people without disabilities. Because of this, disability advocates argue that people with disabilities should be able to get the same wages as people without disabilities.

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[8] http://www.dol.gov/compliance/laws/comp-flsa.htm
[9] https://nfb.org/fair-wages

According to the **Equal Employment Opportunity Commission (EEOC)**, the **Americans with Disabilities Act (ADA)** should protect people with disabilities from being paid less than workers without disabilities. The ADA makes sure that paying less to people with disabilities than people without disabilities is illegal. There are many different kinds of work environments besides sheltered workshops where people with disabilities are treated more fairly. You will learn more about other kinds of workplaces in the next sections of this tool.

Employment First

Employment First is a government program that helps people with disabilities find and keep **integrated employment**. Integrated employment means jobs held by people with disabilities that pay at least minimum wage, paid directly by the employer, and are alongside people without disabilities.

*To learn more about Employment First, see Appendix B: Resources by Chapter **page 120**.*

As of June 2014, there are four states fully participating in Employment First. Washington is the leader. Iowa, Oregon, and Tennessee follow Washington's example. All four states share their best practices with each other and other states. Their goal is providing unlimited employment opportunities for people with disabilities.

Integrated & competitive employment

Integrated employment means that people with disabilities are not separated from people without disabilities in their place of work, like they are in sheltered workshops. People with disabilities and people without disabilities do their jobs in the same buildings and work environments in integrated employment settings.

*To learn more about these types of employment, see Appendix B: Resources by Chapter **page 121**.*

Competitive employment means that in an integrated employment setting, people with disabilities will get paid at least minimum wage for their work. You will be paid at a rate that is comparable to people without disabilities who work in the same place as them.

Integrated and competitive employment is very important for workers with disabilities. It helps them to be able to make enough money to live more independently. Working alongside people without disabilities and getting paid the same way also promotes self-confidence and a sense of acceptance in the workplace.

Customized employment & self-employment

In **customized employment**, an employee is hired based on their strengths and weaknesses. The company that hires them will often take duties from another employee to give to the new employee, based on what they can handle. Consideration is given to supports and services.

Self-employment is another form of customized employment. Self-employment means creating and owning a small business. It would be a match between your strengths, your weaknesses, and the needs of the local market. It would also include support strategies in order to help your business be successful.

Accommodations

Under the ADA, employees are protected from disability discrimination in the workplace as long as the employee can perform the **essential functions** of the job with or without reasonable accommodations.

What are reasonable accommodations?

Reasonable accommodations are any changes or adjustments to a job or work environment that allow a qualified applicant or employee with a disability to:

- ➔ participate in the job application process
- ➔ perform the essential functions of a job
- ➔ enjoy benefits and privileges of employment equal to those enjoyed by employees without disabilities

For example, reasonable accommodation may include:

- acquiring or modifying equipment or devices,
- job restructuring,
- part-time or modified work schedules,
- reassignment to a vacant position,
- adjusting or modifying examinations, training materials or policies,
- providing readers and interpreters, and
- making the workplace readily accessible to and usable by people with disabilities.

Reasonable accommodation also must be made to enable an individual with a disability to participate in the application process, and to enjoy benefits and privileges of employment equal to those available to other employees.

It is a violation of the ADA to fail to provide reasonable accommodation to the known physical or mental limitations of a qualified individual with a disability, unless to do so would impose an **undue hardship** on the operation of the business.[10]

An employee who is otherwise qualified (for example, because the employee has the degrees, license, and experience required for the position) is protected from disability discrimination if they can perform the essential job functions. It doesn't matter if the employee requires an accommodation from the employer to do so: As long as the employee can perform the essential functions of the job, with or without a reasonable accommodation, the employee is protected from discrimination by the ADA.

Which job functions are essential?

A job duty is an essential function if any of the following is true:

- The reason the job exists is to perform that function.
- Only a few employees can perform the function.
- The function is so highly specialized that the employer hires people into the position specifically because of their expertise in performing that function.[11]

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[10] http://www.eeoc.gov/facts/ada17.html

If a function is truly essential, and an applicant or employee cannot perform it even with a reasonable accommodation, then that person is not legally qualified for the job. This means that the person cannot bring a disability discrimination lawsuit against the employer.

Here are some examples of cases where a disability discrimination lawsuit would not apply if the job functions are essential:

- ➔ If a job requires you to be able to stand and lift 50+ pounds and you cannot
- ➔ If a job requires answering and speaking on telephones and you have difficulties with verbal communication
- ➔ If a job requires driving around in a car making deliveries and you are unable to drive due to a disability

Government funded options

Vocational rehabilitation

Vocational rehabilitation (or voc rehab) is a program that helps people with disabilities find and prepare for employment. It can serve people with a wide range of disabilities such as:

- ➔ Hearing impairment
- ➔ Intellectual disabilities
- ➔ Developmental disabilities
- ➔ Physical impairments or injuries
- ➔ Learning disabilities

*To learn more about voc rehab, see Appendix B: Resources by Chapter **page 122**.*

Supported employment

Supported employment is meant to help people with disabilities find and keep jobs that pay competitively alongside workers without disabilities. Supported employment provides individualized supports, often in the form of **job coaching**, which helps a person find and succeed in the type of job they want.

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[11] http://www.nolo.com/legal-encyclopedia/essential-job-functions-under-the-ada.html

A person who uses supported employment may be a person who requires high levels of support, and has not been able to work in a competitive setting or has had interruptions in work.

A state agency (usually some sort of vocational rehabilitation agency) pays for the Supported Employment. A community agency provides the service in a way the person with a disability prefers.

Natural Supports

Natural supports for employment could include:

- ➔ Customized & self-employment
- ➔ Your network of friends or family giving you job leads
- ➔ Getting informal help with writing resumes from friends or other sources, such as:
    - http://www.gcflearnfree.org/resumewriting
    - owl.english.purdue.edu/owl/resource/719/1/
- ➔ Family and friends helping you to practice for interviews
- ➔ The Job Accommodation Network (JAN) - https://askjan.org/

Conclusion/summary

Everybody should be able to work and make enough money to live a comfortable life. There are many different kinds of employment that are available for people with disabilities. Some of these can be helpful and supportive for people with disabilities. Some involve bad conditions that pay people less than they deserve. There are laws to try to shut down places like this. People with disabilities can be a very good part of the workforce with the right kinds of supports.

This chapter focused on different styles of employment available to us, and explained what workplace accommodations are and how they can support us. There were many key terms in this chapter: the "Americans with Disabilities Act," "competitive employment," "customized employment," "Employment First," "essential job functions," "integrated employment,"

"reasonable accommodations," "self-employment," "sheltered workshops," "supported employment," the "Fair Labor Standards Act," and "vocational rehabilitation." The next chapter will introduce you to what HCBS waivers are and how they can help you to receive needed services in a home or community setting.

HCBS waivers

CHAPTER 9

[Above: An illustration by Ianthe MBD. Two signs pointing in opposite directions. One is green and labeled "home + community," the other is red and labeled "institutions."

OUTLINE

- Overview
- Key terms
- What is an HCBS waiver?
- Why a waiver?
- How do I apply for a waiver?
- Waiting lists
- Conclusion/summary

Overview

In 1981, Medicaid first put out the Home and Community-Based Services (HCBS) Waiver. The Americans with Disabilities Act says that people have a right to help and support in their everyday lives. But before the HCBS Waiver, those who needed support in their everyday lives would usually be sent to institutions. In fact, anyone who needs this support has the right to live in an institution. But some disabled people find that institutions are not the best fit for them.

The HCBS Waiver is what it sounds like. When you sign it, you "waive," or let go of, your right to live in an institution. Instead of being committed to an institution, you can get services that will help and support you in your own neighborhood. This means you can stay in your home. The HCBS Waiver will get you started on getting these services.

This section will explain more about what an HCBS Waiver is and why you might want to have one. It will also tell you how to apply for one of these waivers. Finally, it will explain some of the waiting lists you might be put on after you apply.

Key terms

- **HCBS waiver:** Allows people with disabilities to receive care in a home or community-based setting instead of an institution.
- **Medicaid:** Federal- and state-funded program of medical assistance to low-income individuals of all ages.

What is an HCBS waiver?

A Home and Community-Based Services (HCBS) Waiver is for people with disabilities who want to live in the community but have historically received services in institutions. This waiver lets you ask for services at your home or in your community. HCBS services are paid for by the state and federal government - individuals with a waiver are not responsible for these expenses.

Why a waiver?

Under the current laws, people with disabilities have a right to be served in an institutional setting. When you receive waiver services, you are "waiving" your right to be served in an institution and choosing instead to be served in the community. Waiver programs are currently considered alternatives to institutionalization, rather than entitlements--for this reason, many waivers have waitlists and special application processes.

How do I apply for a waiver?

In order to be able to apply for an HCBS waiver, you must first apply for and receive **Medicaid** benefits.

Waiting lists

Because many people in each state apply for HCBS waivers, there are often waiting lists formed. These wait lists are for people who fill an HCBS waiver form but are not able to get a waiver immediately. Instead, these people are put on a list in case more waivers become available.

There are many different kinds of waiting lists, including ones for children, people with physical disabilities, people with intellectual or developmental disabilities, and others. Each state has different rules for these waiting lists. For example, some states may not have waiting lists for children, while others do.

Arizona, Rhode Island, and Vermont are the only states that do not have waiting lists for people with intellectual or developmental disabilities. Every other state, as well as the District of Columbia, offers a waiting list for waiver applicants with intellectual or developmental disabilities. Several of these states have waiting lists with zero applicants on them; some states have very long waiting lists.

Conclusion/summary

If you can get Medicaid, you may want to apply for an HCBS waiver so that you can get services in your own home or community instead of having to go to an institution. HCBS can give you help that is a better fit for your disability needs, instead of the general kinds of help that an institution might give you.

This chapter was about HCBS waivers, what they are, and why you might want to apply for one. Key terms in this chapter were "HCBS waiver" and "Medicaid." The next chapter will explain how Medicaid and Supplemental Security Income (SSI) are gateways to receiving HCBS benefits.

Gateways: Medicaid & SSI

CHAPTER 10

[Above: An illustration by Jo M. A person standing behind a white gateway about to open it.]

OUTLINE

- Overview
- Key terms
- Point of entry: SSI
- Point of entry: Medicaid
- Eligibility
- Conclusion/summary

Overview

In order to be eligible for HCBS, a person must receive Medicaid. Eligibility often includes limits on your income and assets, so people who are eligible for HCBS are also often eligible for Supplemental Security Income. This chapter will explain what these services are, how to know if you are eligible for them, and how to apply.

The first section explains what Supplemental Security Income (SSI) is, how to apply for it, and a few of the programs they have. The second section is a summary of Medicaid. In the fourth section will tell you if you are eligible for SSI, Medicaid, and a Medicaid HCBS waiver. This will include income limits, what qualifies as a disability, and other requirements.

Key terms

- **Level of care (LOC) requirement:** Amount of assistance required by a person with a disability which may determine their eligibility for programs and services.

- **Medicaid:** Federal- and state-funded program of medical assistance to low-income individuals of all ages.
- **Medical Assistance for the Working Disabled (MAWD):** A public health insurance program available to people with disabilities who work and receive compensation for their work but whose income ad resources do not exceed the established limits.
- **Social Security Disability Insurance (SSDI):** Federal insurance program designed to provide additional income to people who are restricted in their ability to work due to a disability.
- **Supplemental Security Income (SSI):** A program of support for low-income aged, blind and disabled people.

Point of entry: SSI

What is it?

There are many ways to get **Medicaid** benefits. The easiest way is to qualify for the **Supplemental Security Income (SSI)** program.

You can start the application for SSI by:

- visiting its website at www.socialsecurity.gov/applyfordisability/,
- calling the SSI's toll-free number at 1-800-772-1213,
- or visiting a Social Security office near you. You can find the nearest office by using the Social Security office locator here: www.ssa.gov/locator/

They will help you get the information you need to apply and help you with the application process. If you need help with the online application, you can ask someone to do it for you.

At the very least, you need to be able to fill out the checklist at http://www.socialsecurity.gov/hlp/radr/10/ovw001-checklist.pdf.

You may be asked to provide other forms (such as your birth certificate or **W-2 forms**), but if you cannot find any of these forms or do not have access to them, someone will help get them for you - do not put off applying for benefits because you don't have all the documents.

Cash benefits

The maximum payment for SSI is $721 a month ($1082 for couples who both qualify for SSI). How much you get depends on a few factors. For example, certain forms of income from sources other than SSI itself can be deducted from the payment. These include money earned from working and pensions, among others. If you earn money from these sources while on SSI, Social Security will disregard the first $20 of any earnings and the first $65 of money earned from work. Then, it would also disregard half of the rest of the earnings.

*To demonstrate how this works, suppose you make **$375** a month. Since the **first $20** of any earnings and the **first $65** of money earned from work are **not** counted in the calculation, this would make your countable income **$290**. Since half of this number is subtracted from your total benefits, your monthly SSI payment would be **$576** ($721 base payment minus $145).*

Some states allow for an additional supplementary payment onto the federal benefits, which can range from $10 to $200 depending on the state in question. However, some supplements are dependent on specific conditions (e.g. Georgia pays an extra $20 in benefits to individuals living in nursing homes, but not to people living independently). As these supplements may not be included in the SSI check, it may be necessary to apply for the supplemental payment directly from a state agency (ask a SSA official for help with this).

What is the difference between SSI and SSDI?

SSDI (short for **Social Security Disability Insurance**) is a benefit that is meant for people whose physical and/or mental disabilities prevent them from working. Unlike SSI, you must have previously worked in a job covered by Social Security, paid Social Security taxes, and earned enough money to qualify for a quarter of coverage.

*SSI is a gateway to getting HCBS services - SSDI is **not.** It is important to not get these two confused when trying to apply for HCBS services!*

Now what?

You need to apply in order to be granted health insurance through Medicaid. In order to apply, you must go online to medicaid.gov or to healthcare.gov to see if you are eligible. Your

eligibility, or ability to get health insurance through Medicaid, depends partly on what state you live in.

Some states are expanding Medicaid through the **Affordable Care Act**, and some states are not expanding Medicaid. Through medicaid.gov and healthcare.gov, you can check whether your state is expanding Medicaid access.

Do I need to be on SSI in order to get HCBS?

A person must receive Medicaid to be eligible for Home and Community-Based Services (HCBS). There are income and asset limits to receive Medicaid. A person can receive Medicaid and HCBS if they have a low income even if they are not getting Social Security payments.

Point of entry: Medicaid

What is it?

Medicaid is health insurance the government gives to people with low incomes and limited assets at no or reduced cost. The income and asset limits vary from state to state. Generally, one home, one car, and household items do not count toward the asset limit.

What is the difference between Medicaid and a Medicaid HCBS waiver?

Medicaid and the Medicaid HCBS waiver are **two different benefits**. Medicaid is health insurance for poor people, including acute care, dental, and other types of medical care.

Medicaid comes with an entitlement to services in an institution. An HCBS waiver allows you to receive long-term services in the community, rather than an institution. For people who want to live independently, HCBS services are very important.

*After you get Medicaid, you **must** apply for HCBS because you don't automatically get HCBS benefits after receiving Medicaid.*

Eligibility

This section is about the eligibility requirements for three things: Supplemental Security Income (SSI) benefits, Medicaid, and HCBS waivers. Requirements may be different depending on what state you're in, and this section will also explain how to find out your state's requirements.

SSI

Asset caps and income limitations

To get SSI, you must:

- be 65 or older, blind, or disabled (have substantial limited activity for 12 months)
- be a U.S. citizen or legal alien
- live in the country for more than 11 months a year
- apply to all other eligible benefits
- give Social Security and Assistance Offices permission to contact any financial institution to request records
- file an application
- have a limited income (up to about $2,000 a month for a single person or $3,000 a month for a couple).

Disability determinations

- "Disability" is defined as a medically determined physical or mental impairment.
- Will result in death or will limit a person's ability to work or go about their life.
- Will last or has lasted for more than 12 months.
- Has substantially limited activity for 12 months

How will this affect my employment?

You can earn up to $2,000 a month and still be eligible for SSI. After the first $85 of each month, divide your income in half. That's how much will be subtracted from your SSI benefits. If your income changes, let Social Security and the Assistance Office know. Any change will show up in the following months.

Medicaid

Medicaid is a program run by the states, so eligibility requirements vary from state to state. To learn more about your state's eligibility requirements, visit the website for your state's department of health & human services.

In general, if you qualify for Social Security, you will also qualify for Medicaid. For this reason, many people recommend applying for Social Security first.

Medicaid buy-in: a potential exception

If you are on Medicaid, you can receive benefits even if your income is over the limit as long as you are still disabled. The program that allows these continuing benefits is called **Medical Assistance for the Working Disabled (MAWD).** You will have to fill out a MAWD application and pay MAWD monthly **premiums** that are equal to 5% of your monthly income. If when you add your SSI payments plus what you earn for a month the total is $1000, your MAWD premium will be $50.

Medicaid HCBS Waiver

Disability determination

- ➔ "Disability" is defined as a medically determined physical or mental impairment.
- ➔ Will result in death or will limit a person's ability to work or go about their life.
- ➔ Will last or has lasted for more than 12 months.

Level of care

Under most waivers, people need to have an "institutional level of care" to be able to receive services. HCBS is designed for people who would otherwise be receiving services in

an institution. The **level of care (LOC)** requirement is another eligibility requirement to be able to get HCBS services.

Some newer waivers will not have the LOC requirement for a person seeking HCBS services. You will have to check with your state's specific HCBS waiver requirements to find out:

- ➔ If there is a level of care requirement
- ➔ If you qualify for it

You may have support needs but not meet the institutional LOC, and therefore not be eligible in some states.

***Chapter 13** has more information on system alternatives for people who do not qualify for their state's HCBS programs.*

Conclusion/summary

This chapter was about how applying and qualifying for Supplemental Security Income and/or Medicaid is the first step to getting HCBS benefits, and what the eligibility requirements are for each. Because there are so many eligibility requirements, you may not qualify. That is why this tool also provides many options for alternatives to HCBS-funded support. Key terms in this chapter were "level of care requirement," "Medicaid," "Medical Assistance for the Working Disabled," "Social Security Disability Insurance," and "Supplemental Security Income." The next chapter is about the process of applying for benefits and what you can expect.

Applying for benefits

CHAPTER 11

[Above: an illustration by Jo M. There are different colored pieces of paper spread out with a pen laying on top of them.]

OUTLINE

- Overview
- Key terms
- What to expect
- Roadblocks
- Conclusion/summary

Overview

Applying for benefits is a complicated process but we hope this tool will make it simpler for you. This chapter also explains and shows you how to find other resources as we talk about them.

"What to expect" talks about difficult parts of the process and ways to make it easier. The next section explains how to deal with specific "roadblocks" in the process and has lots of resources.

Key terms

- **Appeal:** Process for requesting a formal change to an official decision.
- **Case manager/coordinator:** Person who helps someone with a disability to coordinate their Medicaid support services.

- **External review:** Part of the appeal and review process in which a third-party reviews your insurance claim.
- **Protection & Advocacy (P&A) agencies:** P&A investigates reports of abuse and neglect and advocates for disability rights in areas such as health care, education, employment and housing.

What to expect

Applying for benefits takes patience and determination. Below is a list of some things to expect to run into while applying.

- It may take many months from the time you first apply until the time you get benefits.
- You will need to fill out forms and answer questions in writing. There is a lot of paperwork.
- If your medical or school records aren't sent promptly, you will have to call the sources and remind them to send the records. You may have to make other phone calls.
- To start your application, you will need to go to your local Social Security office. If you decide to use a lawyer, you will have to go to their office.
- Social Security may want you to see one of their doctors for an evaluation. Social Security will pay for this exam.
- You will absolutely have to have a doctor of your own because Social Security will want your doctor's records.
- Your application may be rejected a few times.
- If you get a rejection, you will need to appeal within the time Social Security allows.

Suggestions for applicants

- You will need some support throughout the process whether it be a family member or a professional **case coordinator**.
- You might want to get a case coordinator, especially if you are applying for more than one benefit. Medicaid case coordinators

*To learn more about case coordinators, see Appendix B: Resources by Chapter **page 126**.*

start working for you the minute you apply in most states to help with the process.

- ➔ If you are applying for SSI, the easiest way to apply is usually online. That can be done here: https://secure.ssa.gov/iClaim/dib.

Roadblocks

Paperwork & phone calls

There is a lot of paperwork involved in applying for benefits, and often times you will have to make phone calls to get some of the information that you need or to follow up with somebody who is supposed to send you certain information.

The complete checklist for applying for disability benefits can be found here: http://www.socialsecurity.gov/hlp/radr/10/ovw001-checklist.pdf

In this section, we will discuss some of the checklist items that may be more confusing or time-consuming.

List of medical conditions

You will be asked to list all of your medical conditions. The Social Security Administration has a long list of medical conditions that are taken into consideration when making a decision about whether or not you are considered disabled under their legal definition.

You can find the list here:

http://www.ssa.gov/disability/professionals/bluebook/listing-impairments.htm

There are links to "Part A" of the list, for Adult conditions, and "Part B" for Childhood conditions.

The Adult listings page can be found here:

http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm. It is divided into several categories. See below for what this page looks like.

Disability Evaluation Under Social Security

Listing Of Impairments - Adult Listings (Part A)

The following sections are applicable to individuals age 18 and over and to children under age 18 where criteria are appropriate.

1.00 Musculoskeletal System	2.00 Special Senses and Speech	3.00 Respiratory System
4.00 Cardiovascular System	5.00 Digestive System	6.00 Genitourinary Impairments
7.00 Hematological Disorders	8.00 Skin Disorders	9.00 Endocrine Disorders
10.00 Congenital Disorders that Affect Multiple Body Systems	11.00 Neurological	12.00 Mental Disorders
13.00 Malignant Neoplastic Diseases	14.00 Immune System Disorders	

You may be required to provide medical records as proof of your impairments.

Medical records

If you are filing for benefits on your own, you have to make sure that all of your requests for medical records are signed properly. These records often consist of:

- ➔ check-ups,
- ➔ medications, and
- ➔ diagnoses.

Because they contain sensitive personal information, medical records are often confidential, and your doctors must receive your permission before they can release them.

Requesting medical records

To request your medical records, you must often contact your doctors by phone. This can be time consuming due to the legal issues surrounding medical records.

When you call your doctors, they will probably ask you:

- ➔ why you are asking for your records
- ➔ who you will be providing the records to
- ➔ for your verbal or written permission to release the records

After this, your doctors will release the records to you.

- ➔ You will have to keep track of the records once you get them
- ➔ If your doctors don't send your records within a few weeks, you will have to call to remind them
- ➔ If you have trouble using a phone in any way, personal helpers and disability accessible facilities are some examples of assistance.

Employment and bank records

Part of the process is verifying your income. You will need to provide records of employment as well as bank records.

Employment details

You will need to provide:

- ➔ Employer Details for Current Year and Prior 2 Years
- ➔ Employer name
- ➔ Employment start and end dates
- ➔ Total earnings (wages, tips, etc.)

Finding some of this information might require calling old employers for information.

Bank records

It is **very important** that you keep this information safe. You do not want your personal banking information to be revealed to somebody who cannot be trusted.

There are two important pieces of information about your bank account that you might need help finding. These are:

- ➔ Account type and number
- ➔ Bank routing number

"Account type" would be something like checking or savings account.

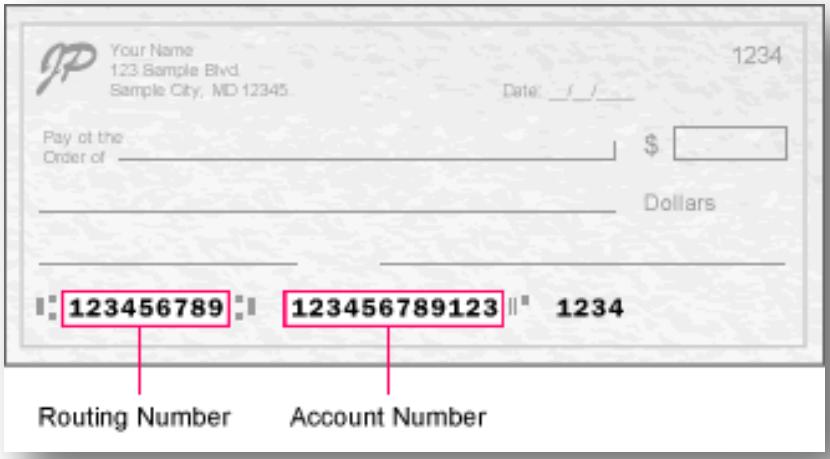
You can find out your bank account and routing number in different ways. There is a guide to finding these numbers here: http://www.socialsecurity.gov/hlp/global/hlp-rtn.htm

If your account is in the United States, you can locate your bank or financial institution's Routing Transit Number (RTN) and your account number on one of your blank checks.

At the bottom of your check are three sets of numbers.

The Routing Transit Number is usually the first nine numbers in the bottom left-hand corner.

The account number is usually the second set of numbers.



Your Routing Transit Number may also appear on your checking or savings account statements.[12]

You can also call your bank or go into your bank's branch. Be prepared to answer security questions before they will give you bank record information. This is to make sure that your information stays safe.

Ignorance of programs & resources

Hopefully everything goes smoothly with your application, but it's always best to plan for the worst. If you feel the person handling your application doesn't know a program exists or messes up your application, there are a few things you can do. This section will give you some general tips as well as specific information about Medicaid Coordinators and Protection & Advocacy agencies.

General tips

- ➔ Be proactive and plan ahead.
- ➔ Write things down as they happen or soon after. Having a written record is helpful if you need to tell a lawyer or somebody else specific information about something that happened in the past.
- ➔ Clarify your requests if you need to.
- ➔ Be persistent as you seek services - they are there to help you, but may be difficult to get

Medicaid Service Coordination

Medicaid Service Coordination is provided by a person (known as a Medicaid Service Coordinator, or case coordinator) who knows the services available through Medicaid. Medicaid Service Coordinators (MSCs) can:

- ➔ advise you and your family about what services are available

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[12] http://www.socialsecurity.gov/hlp/global/hlp-rtn.htm

- ➔ help you access these services
- ➔ work with you to develop, implement and maintain your life plan
- ➔ help to protect and uphold your personal rights
- ➔ work to ensure that your living environment is safe[13]

MSCs can also help you find and access:

- ➔ medical care
- ➔ vocational training
- ➔ career opportunities
- ➔ educational services
- ➔ housing
- ➔ recreational resources[14]

There is no national website for finding an MSC. The best way to find a Medicaid Service Coordinator is to search online for "Medicaid coordinators" and the name of your state.

Protection & Advocacy

Protection & Advocacy (P&A) agencies represent people with disabilities free of charge any time we feel that our civil rights have been violated.

The National Disability Rights Network (NDRN) represents P&A agencies across the country. There is a P&A agency in every state and U.S. territory, as well as one serving the Native American population in the four corners region.[15] The NDRN website has a printable list of the contact information for P&A agencies in every state.

NDRN website
http://www.ndrn.org/en/ndrn-member-agencies.html

[13] http://www.wwaarc.org/coordination.php
[14] http://www.alleganyarc.org/Services/MSCServices/
[15] http://www.ndrn.org/en/ndrn-member-agencies.html

Eligibility

People with disabilities sometimes need financial help in order to live independently. We may need in obtaining healthcare. Sometimes there are barriers to this help. These barriers can be based on eligibility. Assistance can take a while because of appeals or wait lists.

Eligibility is how they decide if someone who applies for benefits actually needs those benefits. Sometimes this means people must earn less than a given amount of money. Supplemental Security Income (SSI) benefits are for people earning less than $1,070. If two people on SSI get married their benefits are reduced. They will receive 25% less in benefits than they did before.

Rejection & Appeals

People who do not receive disability benefits can ask for a review of their case. This is called an **appeal**. When benefits are denied, the applicant can also appeal. Sometimes the applicant can't appeal. For example, a person with cerebral palsy might be recommended a therapy by his doctor. But if the insurance company refuses to pay for the therapy, there are few options left for him to get that care. Under the Affordable Care Act, an applicant who is turned down for treatment has greater power to appeal.

One type of appeal is known as "**external review**." This allows someone who is a third party to come in and help mediate the dispute. The third party is an unbiased person. An insurance company employee would not be considered a third party.

Wait lists

Wait lists often limit the number of people who receive health treatment at a time. There are currently over 300,000 people with disabilities on waiting lists for home and community-based long term services. Their wait can be as long as 8-10 years. These wait lists can seriously delay access to many services. This is especially true if budget cuts limit how much aid is available.

Conclusion/summary

The focus of this chapter was the process of applying for benefits and what you can expect during that process. There are many roadblocks that may come up, and this chapter provided some insight into what may slow down your application process and how to deal with potential

problems. Key terms in this chapter were "appeal," "case manager/coordinator," "external review," and "Protection & Advocacy agencies."

Applying for HCBS benefits can sometimes be tricky. There is a lot of paperwork to go through, and not all of it is written in a way that is easy to understand. However, we hope that this chapter was able to help explain the application process a bit more clearly.

Also, because each state has a different program, applying for HCBS benefits may be a different process depending on where you live. While the state programs are all very similar to each other, there are some small differences too. Also, even though each state should have very similar paperwork, there may be some differences from one state to another.

The next chapter focuses on the concept of self-directed services and how they help people with disabilities to have control over our own lives.

Self-directed services

CHAPTER 12

[Above: an illustration by Simone V. A person in a t-shirt with ASAN's logo is acting as an orchestra conductor. They are seemingly conducting the words "services," "assistive tech," "schooling," and "buddy programs."]

OUTLINE

- Overview
- Key terms
- Self-direction
- Person-centered plans
- Service plan
- Employer authority & managing staff
- Personal Care Assistants
- Budget authority & managing money
- Case management
- Conclusion/summary

Overview

One of the really important parts of being independent is having a say in your own services. It is especially important to have a say in the way your services are being planned as a person with a disability.

The first section explains how self-directed services let us to make decisions about every part of the support and services that we get. The next section explains what person-centered planning is based on, why it is important, and what it looks like.

A "service plan" is a complete plan for your HCBS services that has goals and risks included, as well as making sure your services are meeting all of the requirements. Part of the self-directed services is managing your employees, which gives your control and means you have certain responsibilities. The next section talks about what "Personal Care Assistants" do, how to start and keep working with one. "Budget authority and managing money" explains

how you can manage money when you are using self-directed services. The last section explains "case management" and gives you tools to look into it more.

Key terms

- **Activities of Daily Living (ADLs):** Daily self-care activities.
- **Budget authority:** The decision-making authority over how your Medicaid funds are spent.
- **Case management:** Services that provide a case coordinator to help people with disabilities to secure needed services.
- **Employer authority:** The decision-making authority to recruit, hire, train, and supervise your own support staff.
- **Financial Management Services (FMS):** A service that helps a self-directing person with a disability to manage and distribute funds in their individualized budget.
- **Instrumental Activities of Daily Living (IADLs):** The complex skills needed to successfully live independently.
- **Personal Care Assistant (PCA):** A hired support person who helps people with disabilities with daily tasks.
- **Person-centered planning:** Focuses on people with disabilities and our needs by putting us in charge of defining the direction for our lives, not on the systems that may or may not be available to serve us.
- **Self-determination:** Self-determination is a combination of attitudes and abilities that lead people to set goals for ourselves, and to take the initiative to reach these goals.
- **Service plan:** Written document which outlines the types and frequency of the long-term care services that a person with a disability receives.
- **Support brokerage:** Another term for service/case managers/coordinators - a person who helps someone with a disability to coordinate their Medicaid support services.
- **Vocational rehabilitation:** A process which enables people with disabilities to overcome barriers to accessing employment.

Self-direction

What are self-directed services?

Self-directed Medicaid services are all about **self-determination** and letting people with disabilities choose and control the supports we need in order to live the lives we want to in our communities. Self-direction of services allows us to have the responsibility for managing every aspect of service delivery in a **person-centered planning** process.

Employer authority

Participants are given the decision-making authority to recruit, hire, train and supervise the individuals who provide their services. This is called "**employer authority**."

Budget authority

Participants may also have decision-making authority over how the Medicaid funds in a budget are spent. This is called "**budget authority**."

We will discuss both employer authority and budget authority in more detail later in the chapter.

Self-direction guidelines

Each **Medicaid funding authority** has different guidelines, but all authorities share some common characteristics:

Person-Centered Planning Process

The Centers for Medicare & Medicaid Services (CMS) require that a person-centered planning process and assessment be used to develop a person-centered plan.

Service plan

A **service plan** is the written document that:

- ➔ outlines the services and supports that are to be given to meet your preferences, choices, abilities and needs
- ➔ helps you to direct those services and supports
- ➔ helps you remain in the community.

Individualized Budget

An individualized budget is the amount of funds that is under your control and direction. The budget plan is developed using a person-centered planning process and is individually tailored in accordance with the individual's needs and preferences as established in the service plan. States must:

- ➔ describe the method for calculating the dollar values of individual budgets
- ➔ define a process for making adjustments to the budget when changes in participants' person-centered service plans occur and define a procedure to evaluate participants' expenditures.

Information and Help in Support of Self-Direction

States are required to provide to you or arrange for you to get a system of supports that is tailored to your needs and desires for assistance. The amount and frequency with which you use available supports is likely to vary from person to person and change in response to situations that arise.

Among the types of assistance to be made available on an as-needed basis are:

- ➔ help in developing a person-centered service plan and individualized budget
- ➔ managing personal support workers and services
- ➔ performing other employer-related and budget management tasks.

The state also is responsible for ensuring that participants are informed about such matters as:

- ➔ the operation of self-directed services
- ➔ individual rights and responsibilities
- ➔ available resources
- ➔ counseling
- ➔ personal support worker supervision and training
- ➔ the use of **Financial Management Services (FMS)**
- ➔ access to an independent advocacy system

Some states have created a separate Medicaid-reimbursable service—referred to as **support brokerage**, individual counseling, or personal guide—to perform these functions and act as a **liaison** between the individual and program administrators. In these situations, the support broker, consultant, counselor, or guide usually acts as an agent of the program participant and takes direction from the participant.[16]

Person-centered plans

What is person-centered planning?

Person-centered planning helps people with disabilities to make plans for their lives.[17] The person sets goals and makes plans to reach those goals. These goals usually promote self-determination and independence, which will ultimately help us to pursue those goals[18]. People with disabilities can use person-centered planning to gain our own independence.

People with disabilities are the best experts when it comes to our own interests and talents. It can also help us apply our skills to a job. Family, friends, or a counselor can help people with disabilities to decide how to pursue a chosen career; however, in the end the choice is up to the individual.[19]

*To learn more about person-centered planning, see Appendix B: Resources by Chapter **page 124.***

Person-centered planning is more than how to do it. It is also a way to look at things. It was developed from the social model of disability.[20] The social model says that disability is about how your needs interact with your environment. Your environment includes both physical things and how people interact with each other. When it takes adaptations for your needs to be met in your environment, you are considered disabled. Adding adaptations can enable your access, but won't change who you are[21].

Person-centered planning is a **mandatory** part of any HCBS waiver, and it determines what services will be used and how they will be set up.

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[16] http://www.ncd.gov/publications/2013/05222013A/05222013ACh4/
[17] http://www.ncdhhs.gov/MHDDSAS/providers/personcenteredthinking/index.htm
[18] http://www.opwdd.ny.gov/opwdd_services_supports/person_centered_planning
[19] http://www.pacer.org/tatra/resources/personal.asp
[20] http://www.lookbackplanforward.com/links/
[21] http://www.copower.org/models-of-disability/182-social-model-of-disability.html

Service Plan

What items must be included in the service plan?

- **Setting:** The plan must indicate that you chose the setting in which you live. The State must make sure that the setting supports full integration of Medicaid-eligible people into the greater community.
- **Goals and strengths:** The plan must reflect your strengths and preferences, and identify individual goals and desired outcomes.
- **Services and supports:** The plan must indicate the services and supports (paid and unpaid) that will assist you in achieving identified goals, along with the providers of those services and supports.
- **Risks:** The plan must include risk factors along with measures in place to minimize risk, such as individualized backup plans and strategies.
- **Monitoring:** The plan must identify the person and/or entity responsible for monitoring the plan.[22]

Protecting your right to choose

Your service plan must reflect your choices about how HCBS services will be given. There are some protections in place to make sure that your decisions are reflected in your service plan:

- **Understandable Style and Format:** The plan must be understandable to you and the people supporting you. At a minimum, the plan must be written in plain language and in a manner accessible to people with disabilities. "Accessibility" includes other aids and services at no cost for people with disabilities.
- **Consent:** You must show **informed consent** to the plan in writing, and anyone responsible for carrying out the plan must sign it.
- **Appeal Rights:** All Medicaid service plans must give you an opportunity for a fair hearing if your plan is not carried out properly.[23]

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[22] http://www.nsclc.org/wp-content/uploads/2014/04/Advocates-Guide-HCBS-Just-Like-Home-05.06.14-2.pdf
[23] http://www.nsclc.org/wp-content/uploads/2014/04/Advocates-Guide-HCBS-Just-Like-Home-05.06.14-2.pdf

Employer authority & managing staff

What is employer authority?

Employer authority means that you have as much control as you want of the whole process of hiring, firing, and managing your personal support workers. It is part of the self-directed services model.

This means you can have control over:

- ➔ recruiting job candidates
- ➔ interviewing applicants and checking their references (unless you know the applicant very well)
- ➔ deciding who to hire
- ➔ setting and negotiating work schedules and determining training needs
- ➔ assigning tasks to workers
- ➔ supervising and evaluating the workers' job performance
- ➔ deciding when to fire a worker whose performance has been unsatisfactory

People who self-direct their services also play a role in paying workers. At a minimum, people self-directing HCBS services should approve workers' timesheets. In some programs, however, you also are responsible for co-signing the workers' paychecks.[24]

Managing staff

Managing staff is all about managing relationships. Managing staff is also about having good communication skills when there is a problem.

It also means finding personal care assistants who fit the personality of the person they are taking care of. If this is not happening, then you need to hire another aid or tell the agency you're working with to send another person. If the agency cannot meet your needs, then you might want to find a new agency.

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[24] http://www.ncd.gov/publications/2013/05222013A/05222013ACh1

Rights & responsibilities

As the employer of personal care assistants, you have certain rights and responsibilities to yourself and to your personal care assistants (PCAs).

As a person who is self-directing you have the right to:

- ➔ Decide who your PCA will be
- ➔ Direct your personal care
- ➔ Decide when your PCA will work for you
- ➔ Make choices about how much help you want from your provider agency, if you use one
- ➔ Be treated with dignity and respect, which includes respect of your privacy and confidentiality
- ➔ Replace PCAs who don't respect your rights

Experienced employers offer this advice: being a responsible employer makes it easier to keep good PCAs. As you understand your responsibilities as an employer, you'll be better able to decide when you are willing or not willing to compromise on your PCA services.

People self-directing have the following responsibilities:

- ➔ Be honest and detailed when explaining your needs
- ➔ Provide adequate training
- ➔ Do not ask your PCAs to do tasks that were not agreed upon
- ➔ Give positive and constructive feedback
- ➔ Be respectful when talking to your PAs
- ➔ Make sure your PAs get paid on time
- ➔ Develop a workable emergency/back-up plan[25]

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[25] http://www.sncddo.org/cddo/KPASS/K-PASS_Toolkit.pdf

Personal Care Assistants

What do personal care assistants do?

Personal care assistants (PCAs) can help you with **Activities of Daily Living (ADLs)** and **Instrumental Activities of Daily Living (IADLs)**.

Activities of Daily Living include:

- bathing
- toileting
- grooming
- dressing
- extension of therapies
- exercise
- routine care of adaptive equipment primarily involving cleaning as needed
- meal preparation
- assistance with eating
- incidental household cleaning and laundry

For more information and resources related to PCAs, see Appendix B: Resources by Chapter ***page 125.***

PCAs can also help with Instrumental Activities of Daily Living, including:

- shopping
- banking
- budgeting
- using public transportation
- social interaction
- recreation
- leisure activities

- accompaniment, coaching and minor problem solving necessary to achieve the objectives of increased independence
- productivity and inclusion in the community.[26]

PCAs might also support you at an integrated workplace or transport you places in their own vehicle.

Finding a Personal Care Assistant

Before the search

Before beginning the search for a personal care assistant, there are several things to consider, such as:

- your preference for a male or female caregiver
- whether you would like the caregiver to live-in or just come in for several hours at a time to provide assistance
- the level of care that you require
- space limitations in your home and your need/desire for privacy.

If space and your personal lifestyle permits, you may consider offering a personal care assistant room and board in exchange for personal assistant services.

It may be helpful to make a list of characteristics you would like in a caregiver. Give careful consideration to factors such as:

- honesty
- reliability
- consideration
- promptness
- ability to listen
- willingness to learn new or different tasks

[26] http://www.mh.alabama.gov/Downloads/IDCP/Self-DirectedServiceOption.pdf

➔ how important each of these characteristics are to you in your PCA.

What are the most important, and least important, and what are you willing to compromise on? Think about whether or not you want an attendant with shared interests, and how important issues such as having reliable transportation, smoking, drug and alcohol use, and previous driving record are to you.[27]

Developing a job description

There are five steps to creating a job description for your PCA.

Step 1. Identify the tasks that must happen.

Step 2. Identify tasks that you need to have happen but are flexible about when they happen.

Step 3. Match what you want done to what you can pay for through your plan of care (person-centered plan).

Step 4. Identify the skills and qualities for employees carrying out these tasks.

Step 5. Write your job description with the information you have collected.[28]

Next steps

After this, you will need to advertise that you are seeking a PCA in places like local bulletin boards, newspaper classified sections, and the internet. Then you will conduct interviews with potential PCAs and make a decision about who to hire.

The Kansas Personal Assistance Supports and Services (K-PASS) Self-Direction Toolkit, available at http://www.sncddo.org/k-pass.htm, provides much more in-depth information and checklists for every part of the process of finding and training Personal Care Assistants.

[27] http://www.tbi-sci.org/pdf/pas.pdf
[28] http://www.sncddo.org/cddo/KPASS/K-PASS_Toolkit.pdf

Your relationship with your PCA

Personal Assistants are expected to:

- ➔ Provide the services and supports outlined in the person-centered plan
- ➔ Arrive at the scheduled time and be ready to work.
- ➔ Finish assigned tasks at the time given.
- ➔ Use a time sheet to record the exact amount of time worked.
- ➔ Tell a boss when you will be more than 15 minutes late.
- ➔ Show you respect of your personal property.

Personal Assistants expect their employers to:

- ➔ Offer a list of job duties. Make it as specific as possible, so that there is little opportunity for confusion.
- ➔ Finish the PA contract with each staff member as needed.

Interdependent relationships work best when you and your PCA establish:

- ➔ Mutual trust and respect
- ➔ Open communication
- ➔ Shared goals[29]

Budget authority & managing money

What is budget authority?

Having budget authority means that you are allowed to use your HCBS funding to not only hire personal support workers, but also to purchase other goods and services designed to meet disability-related needs and recovery-related supports.

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[29] http://www.nasuad.org/sites/nasuad/files/hcbs/files/95/4725/PCA_Handbook.pdf

Some of these goods and services may replace human assistance or otherwise enhance your independence, for example:

- ➔ assistive technology
- ➔ home modifications
- ➔ transportation services
- ➔ laundry services
- ➔ meal services
- ➔ personal care supplies
- ➔ non-covered prescription and nonprescription medications

Participant-directed goods and services usually include items that would not be covered under traditional HCBS programs, and these goods and services may be purchased from nontraditional sources. Each self-direction program establishes its own ground rules about what kinds of things you can purchase.

Everyone is different in terms of how much you want or need assistance in carrying out your responsibilities under HCBS programs. You might rely on considerable support from friends and family members to manage your services, or you might self-direct with minimal assistance.

You might also depend on a paid support broker, a navigator, or a recovery coach to establish goals, develop budgets, and navigate your way through the service system.[30]

Financial Management Services

Financial Management Services (FMS) must be available to help individuals to exercise budget authority. Individuals can perform some or all of the FMS functions themselves. Typically, however, individuals prefer that FMS performs these functions for them.

FMS helps individuals:

- ➔ Understand billing and documentation responsibilities;
- ➔ Perform payroll and employer-related duties, such as:

[30] http://www.ncd.gov/publications/2013/05222013A/05222013ACh1

- withholding and filing federal, state, local and unemployment taxes
- purchasing workers' compensation or other forms of insurance
- collecting and processing worker timesheets
- calculating and processing employee benefits
- issuing payroll checks

➔ Purchase approved goods and services;

➔ Track and monitor individual budget expenditures; and

➔ Identify expenditures that are over or under the budget.[31]

Money management is an important skill to have. You need to know how much money you are earning, saving, and spending. You need to know when bills are due and make sure you have enough money to make those payments.

If you have problems managing money, there are several resources to help you. There are more than 100 (mostly free) money management apps on smartphones and tablets. Another resource you could use is payee services.

Payee services are used when a Social Security or Supplemental Security Income (SSI) recipient cannot make their own decisions about how to spend their payments from Social Security or SSI. In that case, the Social Security Administration (SSA), the part of the government that operates Social Security, looks for a qualified person to make spending decisions for the recipient.

The SSA prefers to pay money directly to recipients, without payee services. If payee services are necessary, the SSA prefers close family members, such as parents, to serve as "representative payees" to spend payments on behalf of the recipient.[32]

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[31] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html

[32] http://www.ssa.gov/payee/http://www.fsisc.org/topic.asp?pid=12

Case management

Another resource available to people is **case management** services. **Case managers** (also known as case coordinators/service coordinators) can help you find other resources in your area that can provide the services that you need. Some organization's case management services are specialized. For example, some focus primarily on families, others on certain disabilities. The eligibility for services varies from location to location.

Case management is where a caseworker and client work together in order to meet the client's needs for health services. They develop a plan for the services and see that plan through from beginning to end.

*For more information and resources about case management, see Appendix B: Resources by Chapter **page 126**.*

Many states offer their own version of **vocational rehabilitation** case management services. The website for your state's department or division of social services, mental health, or health services would be a great place to find information. The doctor you see for your disability will probably know the process for applying for case management.

Conclusion/summary

This chapter was about self-directed services and how they are a required part of HCBS services. Self-direction includes having a service plan created with a person-centered approach so that our needs and wants are top priority. Key terms in this chapter were "activities of daily living," "instrumental activities of daily living," "budget authority," "case management," "employer authority," "Financial Management Services," "Personal Care Assistants," "person-centered planning," "self-determination," "service plans," "support brokerage," and "vocational rehabilitation."

The next chapter is about alternative sources of support outside of the HCBS system for those people who do not qualify for their state's HCBS program.

System alternatives

CHAPTER 13

[Above: an illustration by Jo M. A person with a question mark above their head stands looking at a machine with many different levers.]

OUTLINE

- Overview
- Housing
- Independent living
- Accessing the community
- Employment
- Conclusion/summary

Overview

Although the name of this tool is *Accessing Home and Community-Based Services,* not everybody who applies will be able to get HCBS services. Because of this, we also discuss what alternatives there are to receiving support outside of the HCBS system. This is usually in the form of natural or informal supports. These are options that are not funded by the government.

The first section of this chapter, “housing,” will give you resources for finding natural supports when seeking a place to live. “Independent living” will explain what supports are available to help us to live the kind of life we want to live. “Accessing the community” provides more information about support options for participating in the community, and “employment” discusses what non-government funded options you have as a worker with a disability.

Housing

Roommates

*For links to system alternative resources, see the Chapter 13 section of Appendix B beginning on **page 127**.*

Living with others is a great opportunity to get natural support. Roommates live with you, so they are around most of the time. You can share chores with roommates, and ask them to do the chores that you have difficulty doing yourself. It is also possible to ask roommates to remind you to do tasks, like pay the bills. If your roommate is trustworthy, you could ask them for advice or help with taxes, medical issues, or other concerns.

Paying out-of-pocket

If you have too many financial resources qualify for Medicaid and HCBS, you can use your money to pay for services that will let you stay in the community you choose. You can hire your own caregivers and therapists. You will not need to worry about using only providers covered by Medicaid, so you will have a lot of freedom. In choosing providers, it is helpful to ask friends and family about their experiences and for recommendations.

Independent Living

People without waiver funding can use naturally occurring supports, community supports, and centers for independent living to help us live in our community. Naturally occurring supports are supports that are embedded in our everyday lives and relationships, like:

- ➔ a partner reminding you to brush your teeth
- ➔ ordering groceries online instead of struggling in the grocery store
- ➔ going to a community supper instead of making dinner

Accessing the community

System alternatives for accessing the community might include public transportation, community networks such as rideshares, and doing thing with friends and families.

Employment

System alternatives for employment could include:

- ➔ Customized & self-employment
- ➔ Your network of friends or family giving you job leads
- ➔ Family and friends helping you to practice for interviews
- ➔ Getting informal help with writing resumes from friends or other sources, such as:
  - http://www.gcflearnfree.org/resumewriting
  - http://owl.english.purdue.edu/owl/resource/719/1/
- ➔ The Job Accommodation Network (JAN) - https://askjan.org/

Conclusion/summary

This chapter grouped information about available natural supports that appeared in other places in this tool. Appendix B and Appendix C in the next chapter will provide you with specific links to more information, tools, and resources to use while seeking HCBS or alternative support services.

Appendices

CHAPTER 14

- Appendix A: Glossary
- Appendix B: Resources by chapter
- Appendix C: National resources

Appendix A: Glossary

This section contains definitions of words/terms used in the text of this tool (bold green words), as well as words/terms you may encounter during the process of researching and applying for HCBS benefits.

A

ACA

Affordable Care Act. Also known as the Patient Protection and Affordable Care Act (PPACA) and ACA, PL 111-148. The Affordable Care Act was passed by Congress and signed into law by the President in March 2010.

Accessibility of Service

The relative opportunity for people in need to obtain relevant services.

ACL

Administration for Community Living. Developed in 2012, this federal agency brings together the Administration on Aging, the Office on Disability and the Administration on Developmental Disabilities into a single agency that supports both cross-cutting initiatives and efforts focused on the unique needs of individual groups.

Activities of Daily Living (ADLs)

Basic personal activities which include bathing, dressing, transferring from bed to chair, toilet assistance, mobility and eating. ADL's are used to measure how dependent a person may be on requiring assistance in performing any or all of these activities.

Americans With Disabilities Act (ADA)

The ADA prohibits discrimination on the basis of disability in employment, by state and local government entities and by places of public accommodation.

Adult Day Care

A daytime community-based program for functionally impaired adults that provides a variety of health, social, and related support services in a protective setting.

Agency with Choice (AwC)

A model of Financial Management Services wherein the Agency with Choice provides services under a co-employment arrangement with participants. In the Agency with Choice model the agency is the common law employer and the participant is a managing employer of workers who serve the participant.

AGI

Adjusted Gross Income. A measure of income used to determine how much of your income is taxable.

Aging and Disability Resource Center (ADRC)

The Aging and Disability Resource Center Grant Program, a cooperative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS), was developed to assist states in their efforts to create a single, coordinated system of information and access for all persons seeking long term support to minimize confusion, enhance individual choice, and support informed decision-making.

Affordable Care Act

See "Patient Protection and Affordable Care Act (PPACA)."

Appeal

In law, an appeal is a process for requesting a formal change to an official decision.

Assisted Living Facility (ALF)

See "Residential Care Facility (RCF)."

B

Board and Care Home

See "Residential Care Facility (RCF)."

C

Caregiver

A person who provides support and assistance with various activities to a family member, friend, or neighbor. May provide emotional or financial support, as well as hands-on help with different tasks. Caregiving may also be done from long distance.

Care plan

See "service plan."

Case management

Services that assist eligible enrollees to secure medical and other services necessary for appropriate health care treatment. Services include the assessment of an eligible individual to determine service needs, development of a specific care plan, referral and related activities to help an individual obtain needed services, and monitoring and follow-up activities.

Case Manager

Case Manager is the term for "service coordinator" used by the Medicaid Program and some state HCBS programs. *See "service coordinators" for more information.*

Cash & Counseling Demonstration and Evaluation

An implementation and study of consumer-directed PAS programs offering cash allowances and information services. Consumers use the allowances to purchase services, assistive devices, and home modifications. The goal is to enable Medicaid PAS consumers to exercise maximum consumer direction.

CD-PAS

Consumer Directed Personal Assistance Services

CDDO

Community Developmental Disabilities Organization

Center for Independent Living (CIL)

The term "center for independent living" means a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services.

Certificate of Need (CON)

A certificate issued by a government body to a health care provider who is proposing to construct, modify, or expand facilities, or to offer new or different types of health services. CON is intended to prevent duplication of services and overbedding. The certificate signifies that change has been approved.

CMHSP

Community Mental Health Service Program

Cost of Living Adjustment (COLA)

Legislation enacted in 1973 provides for cost-of-living adjustments, or COLAs. With COLAs, Social Security and Supplemental Security Income (SSI) benefits keep pace with inflation.

Community Health Center

A health care program usually serving an area that has scarce or nonexistent health services or a population with special health needs. These centers attempt to coordinate federal, state, and local resources in a single organization capable of delivering both health and related social services to a defined population. While such a center may not directly provide all types of health care, it usually takes responsibility to arrange all medical services needed by its patient population.

Community-Based Services

Services designed to help people remain independent and in their own homes; can include senior centers, transportation, delivered meals or congregate meals site, visiting nurses or home health aides, adult day care, and homemaker services.

Community First Choice (CFC)

The "Community First Choice Option" lets States provide HCBS attendant services to Medicaid enrollees with disabilities under their State Plan.

Community-Integrated Personal Assistance Services and Supports (CPASS)

The goal of this project is to develop an infrastructure and create products that will promote the effective recruitment and retention of personal assistants, and ensure that people with disabilities have the knowledge, access and resources available to maximize choice and control in the use of Personal Assistance Services.

Competitive employment

As it pertains to vocational rehabilitation, competitive employment is work performed by a person with a disability in an integrated setting at minimum wage or higher and at a rate comparable to non-disabled workers performing the same tasks.

Congregate Housing

Individual apartments where residents may receive some services, such as a daily meal with other tenants. Other services may be included as well. Buildings usually have some common areas such as a dining room and lounge as well as additional safety measures such as emergency call buttons. May be rent subsidized (known as section 8 housing).

Consumer choice

Provided when there is a range of service options to meet the diverse needs of consumers. The degree to which consumers have choice must go beyond the range of service choices and include opportunities for consumers to decide when and where services will be provided, and how and by whom tasks will be performed.

Custodial care

See "personal care."

Customized employment

Customized employment is a flexible process designed to personalize the employment relationship between a job candidate and an employer in a way that meets the needs of both. It is based on an individualized match between the strengths, conditions, and interests of a job candidate and the identified business needs of an employer.

D

DDP

Developmental Disabilities Profile- The DDP is a four page instrument designed to record important characteristics of individuals with developmental dis-abilities. The information collected via the DDP includes a broad range of adaptive functioning skills as well as behavioral challenges and health factors.

Deinstitutionalization

A policy that calls for the provision of supportive care and treatment for medically and socially dependent individuals in the community rather than an institutional setting.

Delegation

Transfer of authority from a licensed professional health care provider to an individual not licensed to perform delegated tasks.

Developmental Disability

A disability that originates before age 18, can be expected to continue indefinitely, and constitutes a substantial handicap to the person's ability to function normally.

Direct Support Person (DSP)

See "personal care assistant (PCA)."

Disability

"With respect to an individual (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such impairment; or (C) being regarded as having an impairment." (ADA, 42 USC 12102)

"The phrase physical impairment includes but is not limited to … orthopedic, visual, speech and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV disease (whether symptomatic or asymptomatic), tuberculosis, drug addiction, and alcoholism… The phrase major life act-ivities means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working." (ADA Handbook, pp.II-16 through II-19.)

Dual Eligibles

Individuals with certain combinations of needs who enroll in both the state-administered Medicaid program and the federally-administered Medicare pro-gram are referred to as dual eligibles. Currently, dual eligibles receive prescription drugs and most long-term care benefits from Medicaid, while they are covered by Medicare for acute benefits such as doctor's visits and inpatient hospital care. (also referred to as Dual-Elibible or Duals)

Durable medical equipment

See "Home Medical Equipment."

E

Employment First

Employment First is a concept to facilitate the full inclusion of people with the most significant disabilities in the workplace and community. Under the Employment First approach, community-based, integrated employment is the first option for employment services for youth and adults with significant disabilities.

Equal Employment Opportunity Commission (EEOC)

The U.S. Equal Employment Opportunity Commission (EEOC) is responsible for enforcing federal laws that make it illegal to discriminate against a job applicant or an employee because of the person's race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information. It is also illegal to discriminate against a person because the person complained about discrimination,

filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit.

Most employers with at least 15 employees are covered by EEOC laws (20 employees in age discrimination cases). Most labor unions and employment agencies are also covered.

The laws apply to all types of work situations, including hiring, firing, promotions, harassment, training, wages, and benefits.

Escort services

See "transportation services."

Essential job functions

Essential functions are the basic job duties that an employee must be able to perform, with or without reasonable accommodation.

External review

External review is part of the health insurance claims denial process. It typically occurs when an independent third party reviews your claim to determine whether the insurer is obligated to pay. External review is one of several steps that comprise the appeal and review process. It is performed after the appellant has exhausted the insurance company's internal review process without success.

Most, but not all, states sponsor an external review program.

F

Fair Labor Standards Act of 1938 (FLSA)

The FLSA establishes minimum wage, overtime pay, recordkeeping, and youth employment standards affecting employees in the private sector and in Federal, State, and local governments.

Financial Management Services (FMS)

A service/function that helps a participant directing family or participant to manage and distribute funds in the participant-directed budget. It's also key in facilitating the employment of staff along with fiscal accounting and expenditure reports for the participant, family and state authorities.

Fiscal intermediaries

Organizations that provide third party and fourth party financial services between the providers of a benefit and the person who is to receive it. May perform one or more of the following tasks to support consumers: Provide training on worker management issues. Assist consumers with managing their workers. Assist with paperwork required when consumers use vouchers or cash to pay their workers (such as filling out time sheets, completing tax forms, paying Social Security taxes).

Fiscal/Employer Agent Services (F/EA Services)

An Agent serves on behalf of participants enrolled in public programs under Section 3504 of the Internal Revenue Code. An F/EA Employer Agent may be a government entity, a private non-profit or for-profit entity that's been contracted to serve public program enrolled participants.

Federal Medical Assistance Percentage (FMAP)

FMAP are the percentage rates used to determine the matching funds rate allocated annually to certain medical and social service programs in the United States of America.

Formative evaluation

Formative evaluation is a method of judging the worth of a program while the program activities are forming or happening.

Full participation

This is a term used in the ADA with a specific legal meaning. In short, full participation means that just like a person with a disability can't be shut out of a business or public building altogether, it is also not okay for us to be shut out of specific parts of a building, event, or system.

G

Gated community

A gated community is a form of residential community or housing estate containing strictly controlled entrances for pedestrians, bicycles, and automobiles, and often characterized by a closed perimeter of walls and fences. Gated communities usually consist of small residential streets and include various shared amenities. For smaller communities this may be only a park or other common area. For larger communities, it may be possible for residents to stay within the community for most daily activities.

Group home

Residence which offers housing and personal care services to a small number of residents (usually 3 to 16). Services (such as meals, supervision, and transportation) are usually provided by the owner or manager. May be single family home.

H

HCFA

Health Care Financing Administration

HIPAA

Health Insurance Portability and Accountability Act of 1996. Title I protects health insurance coverage for workers and their families when they change or lose their jobs. The Administrative Simplification provisions (HIPAA, Title II) require the Department of Health and Human Services to establish national standards for electronic health care transactions and national identifiers for providers, health plans, and employers. It also addresses the security and privacy of health data.

HMO

Health Maintenance Organization

Home and Community-Based Services (HCBS)

Services or other supports to help people with disabilities of all ages to live in the community. Each state has a mix of programs and funding sources. The Medicaid program pays for many of these services in all states. There are also other federal, state and local dollars that fund home and community-based services, including the Social Services Block Grant (SSBG), Older Americans Act (OAA), Education and Rehabilitation funds and State General funds.

Home and Community-Based Waivers

Section 2176 of the Omnibus Reconciliation Act of 1987 permits states to offer, under a waiver, a wide array of home and community-based services that an individual may need to avoid institutionalization. Regulations to implement the act list the following services as community and home-based services which may be offered under the waiver

program: case management, home-maker, home health aide, personal care, adult day health care, habilitation, respite care and other services.

Home health agency

A public or private organization that provides home health services, supervised by a licensed health professional in the patient's home, either directly or through arrangements with other organizations.

Home health aide

A person who, under the supervision of a home health or social service agency, assists elderly, ill or disabled persons with household chores, bathing, personal care, and other daily living needs. Social service agency personnel are sometimes called personal care aides.

Home health care

Includes a wide range of health-related services such as assistance with medications, wound care, intravenous (IV) therapy, and help with basic needs such as bathing, dressing, mobility, etc., which are delivered at a person's home.

Home Medical Equipment

Equipment such as hospital beds, wheelchairs, and prosthetics used at home. May be covered by Medicaid and in part by Medicare or private insurance. (Also called “durable medical equipment.”)

Housing authority

A governmental body that governs some aspect of the territory's housing, often providing low rent or free apartments to qualified residents.

Housing vouchers

The housing choice voucher program is the federal government's major program for assisting very low-income families, the elderly, and the disabled to afford decent, safe, and sanitary housing in the private market. Since housing assistance is provided on behalf of the family or individual, participants are able to find their own housing, including single-family homes, townhouses and apartments.

The participant is free to choose any housing that meets the requirements of the program and is not limited to units located in subsidized housing projects.

Housing choice vouchers are administered locally by public housing agencies (PHAs). The PHAs receive federal funds from the U.S. Department of Housing and Urban Development (HUD) to administer the voucher program.

HUD

Housing and Urban Development

I

Individual budgets

These are the funds or resources available to participants to meet their needs. They may directly manage their services and expenditures or assign this task to a representative who can express the participants' preferences. An individual budget is the key program element that increases choice and control.

Informed consent

Informed consent is the process by which the treating health care provider discloses appropriate information to a competent patient so that the patient may make a voluntary choice to accept or refuse treatment.

It originates from the legal and ethical right the patient has to direct what happens to her body and from the ethical duty of the physician to involve the patient in her health care.

Institution

An institutional setting is a living arrangement in which a person applying for or receiving Medicaid lives in a Medicaid-certified long-term care facility. HCBS waivers are designed to divert people from institutional settings and instead receive care in a home or community setting.

Institutional level of care

See "level of care (LOC)."

Instrumental Activities of Daily Living (IADLs)

The complex skills needed to successfully live independently. Include housekeeping, cooking, shop-ping, laundry, medication management, money management, and communication.

Integrated employment

Integrated employment refers to jobs held by people with the most significant disabilities in typical workplace settings where the majority of persons employed are not persons with disabilities. In these jobs, the individuals with disabilities earn wages consistent with wages paid workers without disabilities in the community performing the same or similar work; the individuals earn at least minimum wage, and they are paid directly by the employer.[36]

Intermediary service organizations (ISOs)

See "fiscal intermediaries."

J

Job coaching

A job coach is a person, usually supplied by an outside agency, who provides specialized on-site training to employees with disabilities. Typically, a job coach will help an employee learn to perform his/her job accurately, efficiently and safely. In many cases, the job coach may also help the employee acclimate to his/her work environment

L

Level of Care (LOC)

Amount of assistance required by consumers which may determine their eligibility for programs and services. Levels include: protective, intermediate, and skilled.

Liaison

A person who helps relay information between two groups and helps them to efficiently communicate and cooperate.

Long-Term Care (LTC)

Range of medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short- or long-term and may be provided in a person's home, in the community, or in residential facilities (e.g., nursing homes or assisted living facilities).

Long-Term Care Insurance

Insurance policies which pay for long-term care services (such as nursing home and home care) that Medicare and Medigap policies do not cover. Policies vary in terms of what they will cover, and may be expensive. Coverage may be denied based on health status or age.

M

Medicaid (Title XIX)

Federal- and state-funded program of medical assistance to low-income individuals of all ages. There are income eligibility requirements for Medicaid.

Medicaid Infrastructure Grant (MIG)

This grant program supports people with disabilities in securing and sustaining competitive employment in an integrated setting. This is achieved by providing money to the states to develop and implement the core elements of the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999, so as to successfully modify their health care delivery systems to meet the needs of people with disabilities who want to work.

Medicaid managed long-term services and support (MLTSS) program

A plan in which a contractor is accountable for providing beneficiaries with a defined set of long-term care services and support in exchange for a prepaid capitation payment. MLTSS is present in a range of models. Some plans include just Medicaid benefits; others include Medicare and Medicaid benefits.

Medicaid Service Coordinator (MSC)

See "service coordinator."

Medical Assistance for the Working Disabled (MAWD)

A public health insurance program available to people with disabilities who work and receive compensation for their work but whose income ad resources do not exceed the established limits.

Medical home

Provides accessible, continuous, comprehensive, family-centered, co-ordinated, compassionate, and culturally effective medical care to patients, and are managed by a primary care physician in order to maximize patients' health outcomes.

Medicare (Title XVIII)

Federal health insurance program for persons age 65 and over (and certain disabled persons under age 65). Consists of 2 parts: Part A (hospital insurance) and Part B (optional medical insurance which covers physicians' services and outpatient care in part and which requires beneficiaries to pay a monthly premium).

Variety of services provided to people of all ages, including counseling, psychotherapy, psychiatric services, crisis intervention, and support groups. Issues addressed include depression, grief, anxiety, stress, as well as severe mental illnesses.

Money Follows the Person (MFP)

A federal initiative that allows people who are living in nursing homes or other institutions to have the money or funding go with them as they move out into the community onto community-based services.

N

Natural supports

As defined in the Lanterman Developmental Disabilities Services Act, Section 4512 of the Welfare and Institution Code, Part (e):

"Natural Supports" means personal associations and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to, family relationships; friendships reflecting the diversity of the neighborhood and the community; association with fellow students or employees in regular classrooms and work places; and associations developed though participation in clubs, organizations, and other civic activities.[42]

Nurse

An individual trained to care for the sick, aged, or injured. Can be defined as a professional qualified by education and authorized by law to practice nursing.

Nurse Practitioner (NP)

A registered nurse working in an expanded nursing role, usually with a focus on meeting primary health care needs. NPs conduct physical examinations, interpret laboratory results, select plans of treatment, identify medication requirements, and perform certain medical management activities for selected health conditions. Some NPs specialize in geriatric care.

O

Obamacare

See "Patient Protection and Affordable Care Act (PPACA)."

Office of Federal Contract Compliance Program (OFCCP)

OFCCP conducts compliance evaluations to determine whether a contractor is complying with its obligation to maintain nondiscriminatory employment practices. OFCCP also investigates complaints filed against a Federal contractor that suggest discrimination against a group of individuals or discrimination that is systemic in nature. If the complaint alleges that a Federal contractor discriminated against an individual, OFCCP will refer the complaint to the Equal Employment Opportunity Commission (EEOC) for processing.[43]

Olmstead v. LC

The case of Olmstead v. L.C. involved two Georgia women who had dual diagnoses (mental illness and intellectual disability) and who were residing in a state mental health facility. They were denied home care because of inadequate funding. In June of 1999, the Supreme Court found that unjustified isolation is properly regarded as discrimination under the Americans with Disabilities Act, and required that the women be served "in the most integrated setting appropriate to [their] needs." (Olmstead v. L.C., June 1999, p.6)

In the Olmstead decision, the Supreme Court established specific conditions when community-based services were required for persons with disabilities: the State's treatment professionals have determined that community placement is appropriate the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others.

P

Paratransit

Paratransit is an alternative mode of flexible passenger transportation that does not follow fixed routes or schedules, and can offer door-to door service that is particularly important for people with disabilities. These services often feature modified vans that are equipped with lifts to accommodate passengers who use wheelchairs. Paratransit passengers must be certified as eligible to use the services, which usually consists of filing an application that describes the passenger's disability, explains why he/she is unable to use regular transit, and requires the signature of a health care professional. Eligible passengers usually receive a special card that allows them to purchase paratransit fares and schedule rides on the system.

Paratransit services must be provided by a public entity that also operates a fixed route service. The law says all new vehicles purchased or leased by these public entities must be accessible (retrofitting of existing vehicles is not required), and good faith efforts must be demonstrated with regard to the purchase or lease of accessible used vehicles. Paratransit services are frequently limited by budget constraints in most areas.

Patient Protection and Affordable Care Act (PPACA)

This act was put in place with the goals of increasing the quality and affordability of health insurance and expanding coverage. It was the most significant change to the United States healthcare system since Medicare and Medicaid were added in 1965.

Payee service

Working through a payee service, your representative payee receives your disability benefit payments for you and must use the money to pay for your current needs. After your payee pays those expenses for you, your payee can use the rest of the money to pay any past-due bills you may have, provide entertainment for you, or save the money for your future use.

Peer mentor

Person with a disability who acts as a role model and helps you learn from their experience and find resources.

Person Centered Planning

Person-centered planning is a process-oriented approach to empowering people with disabilities. It focuses on the people and their needs by putting them in charge of defining the direction for their lives, not on the systems that may or may not be available to serve them. This ultimately

leads to greater inclusion as valued members of both community and society.

Personal Assistance Services (PAS)

Include many different kinds of assistance to people with disabilities who need help with Activities of Daily Living (ADL's) or Instrumental Activities of Daily Living (IADL's). The main payment methods are cash payments to consumers or their representatives, payments to vendors or vouchers.

Personal Care

Assistance with activities of daily living as well as with self-administration of medications and preparing special diets. (Also called "custodial care.")

PHP

Prepaid Health Plan

Premium

An amount of money paid for an insurance policy to guarantee coverage.

Professional Management Model (PMM)

A program where PAS workers are employees of organizations that are defined and regulated by licensing, other laws, and contractual arrangements with public financing programs.

Protection & Advocacy (P&A)

P&A investigates reports of abuse and neglect and advocates for disability rights in areas such as health care, education, employment and housing. P&A serves people of all ages and disabilities. P&A does not charge for its services.

Public Housing Agency (PHA)

These are organizations created by local governments in order to administer HUD programs.

Q

Quality

The degree to which services and supports for individuals and populations increase the likelihood for desired health and quality of life measurable outcomes and are consistent with current professional knowledge. The goal of quality services and supports is to maximize the quality of life, functional independence, health and well-being of the population.

R

Reasonable accommodation

An adjustments made in a system to accommodate or make fair the same system for a person with a disability.

Residential Care Facility (RCF)

RCFs provide room, board, house-keeping, supervision, and personal care assistance with basic activities like personal hygiene, dressing, eating, and walking. Facilities usually centrally store and distribute medications for residents to self-administer.

This level of care and supervision is for people who are unable to live by themselves but who do not need 24 hour nursing care. They are considered non-medical facilities and are not required to have nurses, certified nursing assistants or doctors on staff. (Also known as “assisted living facilities,” “board and care homes,” or “rest homes.”)

Real Choice Systems Change (RCSC)

Grants for Community Living that will help states and territories enable people with disabilities to reside in their homes and participate fully in community life. These grants are part of the New Freedom Initiative, a nationwide effort to remove barriers to community living for people of all ages with disabilities and long-term illnesses.

Registered Nurse (RN)

A nurse who has graduated from a formal program of nursing education and has been licensed by an appropriate state authority. RNs are the most highly educated of nurses with the widest scope of responsibility, including all aspects of nursing care. RNs can be graduated from one of three educational programs: two-year associate degree program, three-year hospital diploma program, or four-year baccalaureate program.

Rehabilitation Services

Services designed to improve/restore a person's functioning; includes physical therapy, occupational therapy, and/or speech therapy. May be provided at home or in long-term care facilities. May be covered in part by Medicare.

Reimbursement

The process by which health care providers receive payment for their services. Because of the nature of the health care environment, providers are often reimbursed by third parties that insure and represent patients.

Residential Care

The provision of room, board and personal care. Residential care falls between the nursing care delivered in skilled and intermediate care facilities and the assistance provided through social services. It can be broadly defined as the provision of 24-hour supervision of individuals who, because of old age or impairments, need assistance with the activities of daily living.

S

Section 8

See "housing voucher."

Self-determination

Self determination is believing you can control your own destiny. Self-determination is a combination of attitudes and abilities that lead people to set goals for themselves, and to take the initiative to reach these goals. It is about being in charge, but is not necessarily the same thing as self-sufficiency or independence. It means making your own choices, learning to effectively solve problems, and taking control and responsibility for one's life. Practicing self-determination also means one experiences the consequences of making choices.

Self-employment

A situation in which a person works for themselves instead of working for an employer that pays them. A self-employed person earns their income through conducting profitable operations from a trade or business that they operate directly.

Service coordinators

Assist consumers to assess their need for services, arrange and coordinate the services, and monitor the services. Different programs use different terms, including "case managers," "care managers" and "service brokers."

Case Manager is the term for "service coordinator" used by the Medicaid Program and some state HCBS programs. In addition to assessing the need for services, arranging and coordinating services, case managers may also approve or "authorize" payments for home and community-based services.

The service coordinator acts on behalf of the consumer to arrange services and supports. A key principle of self-determination is the shifting of control from the funding agency to the consumer.

Service plan

Written document which outlines the types and frequency of the long-term care services that a consumer receives. It may include treatment goals for him or her for a

specified time period. (Also called "care plan" or "treatment plan.")

Shared living provider

Person who lives with and supports a person with a disability in a shared living arrangement.

Shared living is an arrangement in which the shared living provider in the community shares life's experiences with the person with a disability.

Sheltered workshop

An organization or environment that employs people with disabilities separately from others. Sheltered workshops are authorized to pay workers with disabilities less than the federal minimum wage.

Social Security Disability Insurance (SSDI)

Federal insurance program managed by the SSA. It I designed to provide additional income to people who are restricted in their ability to work due to a disability.

SSA

Social Security Administration

Supplemental Security Income (SSI)

A program of support for low-income aged, blind and disabled persons, established by Title XVI of the Social Security Act. SSI replaced state welfare programs for the aged, blind and disabled in 1972, with a federally administered program, paying a monthly basic benefit nationwide of $512 for an individual and $769 for a couple in January 2000. States may supplement this basic benefit amount.

Support Broker(age)/Service Broker(age)

See "service coordinators."

Support groups

Groups of people who share a common bond who come together on a regular basis to share problems and experiences. May be sponsored by social service agencies, senior centers, religious organizations, as well as organizations such as the Alzheimer's Association.

Supported employment

Supported employment refers to entitlements or service provisions wherein people with disabilities and mental illness are assisted into getting work.

T

Ticket to Work and Work Incentives Improvement Act (TWWIIA)

This legislation was enacted to allow individuals with disabilities to work. Title I of the act provides access to employment training and placement services and Title II of the act provides health care supports for working individuals with disabilities.

Transportation services

Provide transportation for people to services and appointments. May use bus, taxi, volunteer drivers, or van services that can accommodate wheelchairs and persons with other special needs. (Also known as "escort services.")

Treatment plan

See "care plan."

U

Undue hardship

In the context of providing workplace accommodations, this means that a workplace accommodation would require significant difficulty or expense.

V

Vocational rehabilitation

A process which enables persons with functional, psychological, develop- mental, cognitive and emotional impairments or health conditions to overcome barriers to accessing, maintaining or returning to employment or other useful occupation.

W

W-2 form

This is the Wage and Tax Statement form, which is used to report wages paid to employees and what taxes were withheld. All employers must fill out a W-2 form for each employee that they pay wages to.

Waiver

This is when the Federal Government allows or grants States permission to waive certain Federal requirements in order to operate a specific kind of program. They are often used to authorize managed care, or alternative delivery or reimbursement systems (Example: 1915c waiver).

Glossary references

http://en.wikipedia.org/wiki/Gated_community
http://en.wikipedia.org/wiki/Vocational_rehabilitation
http://healthinsurance.about.com/od/glossary/g/external.htm
http://pandasc.org/about/
http://www.americasheroesatwork.gov/forEmployers/factsheets/jobCoaching/
http://www.canhr.org/RCFE/rcfe_what.htm
http://www.dds.ca.gov/Publications/docs/Natural_Supports.pdf
http://www.dol.gov/odep/topics/EmploymentFirst.htm
http://www.dol.gov/odep/topics/IntegratedEmployment.htm
http://www.dol.gov/ofccp/TAguides/sbguide.htm#Q3
http://www.dol.gov/whd/flsa/
http://www.eeoc.gov/eeoc/
http://www.nasuad.org/hcbs/glossary
http://www.ssa.gov/oact/cola/latestCOLA.html
http://www.ssa.gov/payee/faqbene.htm#a0=4
http://www.thearc.org/what-we-do/public-policy/policy-issues/transportation
https://depts.washington.edu/bioethx/topics/consent.html

Appendix B: Resources by chapter

Chapter 2: I'm disabled, now what?

Developmental disabilities

Administration on Intellectual and Developmental Disabilities (AIDD)

➔ http://www.acl.gov/programs/aidd/index.aspx

American Association on Intellectual and Developmental Disabilities (AAIDD)

➔ http://aaidd.org/

The Arc

➔ http://www.thearc.org/

Developmental Disabilities topic page on CDC.gov

➔ http://www.cdc.gov/ncbddd/developmentaldisabilities/

Developmental Disabilities Resource Center (DDRC)

➔ http://www.ddrcco.com/

National Association of Councils on Developmental Disabilities

➔ http://www.nacdd.org/

Olmstead

ADA.gov – Olmstead: Community Integration for Everyone

➔ http://www.ada.gov/olmstead/

The Center for an Accessible Society – Supreme Court Upholds ADA 'Integration Mandate' in *Olmstead* decision

➔ http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm

NDRN – Olmstead v. L.C. Decision Q&A

- ➔ http://ndrn.org/issues/community-integration/311--olmstead-v-lc-decision-qa.html

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Self Determination

Checklist for Enhancing the Participation and Input of People with Disabilties

- ➔ http://www.nasuad.org/hcbs/article/checklist-enhancing-participation-and-input-people-disabilities

National Gateway to Self-Determination

- ➔ http://www.ngsd.org/

PACER Center – Self Determination

- ➔ http://www.pacer.org/tatra/resources/self.asp

Chapter 3: Services overview

Patient Protection and Affordable Care Act (PPACA)

AAPD – Health Reform and People with Disabilities

- ➔ http://www.aapd.com/resources/fact-sheets/health-reform-people-with-disabilities.html

APHA – Health Reform Resources

- ➔ http://www.apha.org/advocacy/Health+Reform/

Disability.gov – What the Affordable Care Act Means for You & Your Family

- ➔ https://www.disability.gov/resource/the-affordable-care-act-you-family/

Families USA – Our Work: The Affordable Care Act

- ➔ http://familiesusa.org/issues/affordable-care-act

HealthReformGPS – Summary of the Health Reform Legislation

- ➔ http://healthreformgps.org/summary-of-the-legislation/

HHS.gov/HealthCare – About the Law

- ➔ http://www.hhs.gov/healthcare/rights/

Kaiser Family Foundation – For Consumers: Understanding Health Reform

- ➔ http://kff.org/aca-consumer-resources/

Kaiser Family Foundation – The Affordable Care Act's Impact on Medicaid Eligibility, Enrollment, and Benefits for People with Disabilities

- ➔ http://kff.org/health-reform/issue-brief/the-affordable-care-acts-impact-on-medicaid-eligibility-enrollment-and-benefits-for-people-with-disabilities/

Medicaid.gov – Affordable Care Act

- ➔ http://www.medicaid.gov/AffordableCareAct/Affordable-Care-Act.html

MM+A – Patient Protection and Affordable Care Act (PPACA)

- ➔ http://www.ppaca.com/

The Arc – Provisions in the Health Care Reform Law that are Most Important for People with Intellectual and Developmental Disabilities

- ➔ http://www.thearc.org/page.aspx?pid=3044

The Patient Protection and Affordable Care Act Detailed Summary

- ➔ http://www.dpc.senate.gov/healthreformbill/healthbill52.pdf

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Community First Choice

Medicaid.gov – Community First Choice 1915 (k)

- ➔ http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Community-First-Choice-1915-k.html

NOLO – Understanding Medicaid's Community First Choice Program

➔ http://www.nolo.com/legal-encyclopedia/community-first-choice.html

The Arc – The Community First Choice (CFC) Option

➔ http://www.thearc.org/page.aspx?pid=3045

Chapter 5: Housing

Consent & Community Living Assessment Form

➔ http://www.nasuad.org/hcbs/article/consent-community-living-assessment-form

HUD Housing Vouchers

HUD.gov – Housing Choice Vouchers Fact Sheet

➔ http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet

HUD.gov – Mainstream Vouchers

➔ http://www.hud.gov/offices/pih/programs/hcv/pwd/mainstream.cfm

HUD.gov – Section 504

➔ http://portal.hud.gov/hudportal/HUD?src=/program_offices/fair_housing_equal_opp/disabilities/sect504

Chapter 6: Independent living

Independent Living Institute - Links to Disability and Independent Living Resources

➔ http://www.independentliving.org/links/

Independent Living Research Utilization

➔ http://www.ilru.org/

National Council on Independent Living

➔ http://www.ncil.org/

Activities of Daily Living

Assistive Technology for Activities for Daily Living

- ➔ http://www.wati.org/content/supports/free/pdf/Ch11-ActivitiesDailyLiving.pdf

Disability Secrets – What Are Activities of Daily Living for Social Security Disability?

- ➔ http://www.disabilitysecrets.com/resources/social-security-disability/social-security-basics/activities-daily-living.htm

PBS – Checklist of Activities of Daily Living

- ➔ http://www-tc.pbs.org/wgbh/caringforyourparents/handbook/pdf/cfyp_adl_checklist.pdf

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Centers for Independent Living

ILRU Directory of Centers for Independent Living (CILs) and Associations

- ➔ http://www.ilru.org/projects/cil-net/cil-center-and-association-directory

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Community supports

2-1-1

- ➔ http://www.211.org/
- ➔ http://211us.org/
- ➔ Dial 2-1-1

Administration for Community Living - People with Disabilities

- ➔ http://www.acl.gov/Get_Help/Help_Indiv_Disabilities/Index.aspx

American Network of Community Options and Resources

- ➔ http://www.ancor.org/

Meals on Wheels

➔ www.mowaa.org/

TaskRabbit

➔ https://www.taskrabbit.com/

Chapter 7: Accessing the community

Community For All Tool Kit: Resources For Supporting Community Living

➔ http://thechp.syr.edu/toolkit/

Model Communities Forum: A Sharing of Ideas on Community Inclusion for People with Disabilities

➔ http://www.nasuad.org/node/50359#sthash.EFLM2svm.dpuf

Tips for Working with Refugees with Disabilities & Connecting Them to Community Resources

➔ http://www.nasuad.org/node/52154#sthash.RtFD9ZNa.dpuf

Transportation

Disability.gov – Transportation Resources

➔ https://www.disability.gov/?s=&fq=topics_taxonomy:%22Transportation%5E%5E%22

National Organization on Disability – Transportation Resources

➔ http://nod.org/disability_resources/transportation_resources

The Arc – Transportation Issues for People with Disabilities

➔ http://www.thearc.org/what-we-do/public-policy/policy-issues/transportation

Building relationships

Disabled Friends Network

- ➔ http://www.disabledfriends.net/

Disabled United

- ➔ http://www.disabledunited.com/friends/Login.aspx

Friends: Connecting people with disabilities and community members

- ➔ http://rtc.umn.edu/docs/Friends_Connecting_people_with_disabilities_and_community_members.pdf

Self-Advocacy Online: Can DSPs help you make friends in the community with the right training?

- ➔ http://www.selfadvocacyonline.org/research/friends/

Chapter 8: Employment

Cornell University Employment and Disability Institute

- ➔ http://www.edi.cornell.edu/

Job Accommodation Network

- ➔ http://askjan.org/

Return-to-Work Toolkit for Employees & Employers

- ➔ http://www.dol.gov/odep/return-to-work/

Employment First

Association of People Supporting Employment First - Employment First Map

- ➔ http://www.apse.org/employment-first/map/

US Department of Labor Office of Disability Employment Policy – Employment First

- ➔ http://www.dol.gov/odep/topics/EmploymentFirst.htm

Integrated & competitive employment

Institute for Community Inclusion - Access to Integrated Employment (AIE) Project

- ➔ http://www.communityinclusion.org/aie

Integrated Employment Services

- ➔ http://www.integratedemploymentservices.com/

US Department of Labor Office of Disability Employment Policy – Integrated Employment Toolkit

- ➔ http://www.dol.gov/odep/ietoolkit/

Customized employment

US Department of Labor Office of Disability Employment Policy – What Is Customized Employment?
http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/what/

Self-employment

Disability Secrets - Disability Benefits for the Self-Employed

- ➔ http://www.disabilitysecrets.com/resources/disability/disability-benefits-self-employed.htm

Disability.gov's Guide to Self-Employment & Starting a Small Business

- ➔ https://www.disability.gov/resource/disability-govs-guide-self-employment-starting-small-business/

Diversity World - Self Employment

- ➔ http://www.diversityworld.com/Disability/selfempl.htm

Home and Community-Based Waivers and Self Employment – fact sheet

- ➔ http://www.nasuad.org/node/51732#sthash.Ov4BlZST.dpuf

National Disability Institute - Self-Employment

- ➔ http://www.realeconomicimpact.org/Asset-Building-Opportunities/Self002DEmployment.aspx

START-UP / USA Self-Employment Technical Assistance, Resources and Training

- ➔ http://www.nasuad.org/node/51906#sthash.xG2mreFX.dpuf

United States Department of Labor Office of Disability Employment Policy - Self-Employment & Entrepreneurship

- ➔ http://www.dol.gov/odep/topics/SelfEmploymentEntrepreneurship.htm

United States Department of Labor Office of Disability Employment Policy - Small Business & Self-Employment

- ➔ http://www.dol.gov/dol/topic/disability/selfemployment.htm

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Vocational rehabilitation

Council of State Administrators of Vocational Rehabilitation

- ➔ http://www.rehabnetwork.org/

JAN - Vocational Rehabilitation Agencies

- ➔ https://askjan.org/cgi-win/TypeQuery.exe?90

Chapter 10: Gateways: Medicaid and SSI

SSI

Disability Secrets - Filing Social Security Disability Forms

- ➔ http://www.disabilitysecrets.com/resources/social-security-disability/filing-for-social-security/forms.htm

How Resources Affect SSI Eligibility

- ➔ http://www.worksupport.com/documents/howResourcesAffectSSIEligibilityFeb08.pdf

NOLO - Income and Asset Limits for SSI Disability Eligibility

- ➔ http://www.nolo.com/legal-encyclopedia/income-asset-limits-ssi-disability-eligibility.html

Social Security Disability: Application for Benefits

- ➔ http://www.disabilitysecrets.com/application.html

Supplemental Security Income (SSI) Benefits

- ➔ http://www.ssa.gov/disabilityssi/ssi.html

Understanding Supplemental Security Income SSI Resources

- ➔ http://www.ssa.gov/ssi/text-resources-ussi.htm

Medicaid

CMS.gov - Common Medicaid Rip-Offs and Tips to Prevent Fraud

- ➔ http://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/FraudAbuseforConsumers/Ripoffs_and_Tips.html

Find a Medicare And Medicaid Lawyer or Law Firm by State

- ➔ http://www.lawyers.com/medicare-and-medicaid/find-law-firms-by-location/

HealthCare.gov - Qualifying for Medicaid coverage

- ➔ https://www.healthcare.gov/do-i-qualify-for-medicaid/

LongTermCare.gov - Applying for Medicaid

- ➔ http://longtermcare.gov/medicare-medicaid-more/medicaid/applying-for-medicaid/

NOLO - Legal encyclopedia Medicaid law page

- ➔ http://www.nolo.com/legal-encyclopedia/medicaid-law

Chapter 12: Self-directed services

Self-direction

PASS User's Guide: A Comprehensive Guide to Assist Individuals in Self-Direction

- ➔ http://www.nasuad.org/hcbs/article/pass-users-guide-comprehensive-guide-assist-individuals-self-direction

What is Self Direction? Webinar by Caregivers of NJ

- ➔ http://youtu.be/euTpZ_Fdel8

Person-centered planning

Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning – A Manual for Person-Centered Planning Facilitators

- ➔ http://rtc.umn.edu/docs/pcpmanual1.pdf

Look Back, Plan Forward – What is Person Centered Planning?

- ➔ http://www.lookbackplanforward.com/what-is-person-centered-planning/

Navigating Choice and Change in Later Life: Frameworks for Facilitating Person-Centered Planning

- ➔ http://nasuad.org/hcbs/article/navigating-choice-and-change-later-life-frameworks-facilitating-person-centered

New Jersey Division of Developmental Disabilities - Person-Centered Planning Tool

- ➔ http://nj.gov/humanservices/ddd/documents/Documents%20for%20Web/PCPT.pdf

NYS Office for People With Developmental Disabilities – Person Centered Planning

- ➔ http://www.opwdd.ny.gov/opwdd_services_supports/person_centered_planning

Oregon Department of Human Services – The Employer's Guide

- ➔ http://nasuad.org/hcbs/article/employers-guide

PACER Center – Person Centered Planning

➔ http://www.pacer.org/tatra/resources/personal.asp

Think About Your Life: Person Centered Thinking Tools

➔ http://www.nasuad.org/node/52778

Individualized budget/budget planning

Rutgers Center for State Health Policy – Participant-Centered Planning and Individual Budgeting

➔ http://www.cshp.rutgers.edu/Downloads/6810.pdf

Service plan

New Jersey Division of Developmental Disabilities – Individualized Service Plan

➔ http://www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/NJISP%20form.pdf

Personal Support and Safety Plan Worksheet

➔ http://www.nasuad.org/node/50389

Personal Care Assistants/Direct Support

Find, Choose, and Keep Great Direct Support Professionals Toolkit

➔ http://www.nasuad.org/node/51595

Making the Move to Managing Your Own Personal Assistance Services (PAS): A Toolkit for Youth with Disabilities Transitioning to Adulthood

➔ http://www.nasuad.org/node/52666

PAS Center for Personal Assistance Services

➔ http://www.pascenter.org/home/index.php

PASS User's Guide: A Comprehensive Guide to Assist Individuals in Self-Direction

- ➔ http://www.nasuad.org/node/51011

Personal Assistance Services (PAS) Facts: Volume 1

- ➔ http://www.nasuad.org/node/51424

Personal Care Assistance (PCA) Program: Consumer Guide Book

- ➔ http://www.nasuad.org/node/50569

Personal Care Assistance 40 Hour Training Curriculum

- ➔ http://nasuad.org/hcbs/article/personal-care-assistance-40-hour-training-curriculum

PersonalChoice Functional Assessment

- ➔ http://www.nasuad.org/hcbs/article/personalchoice-functional-assessment-rhode-island

The Arc of Michigan – Hiring and Managing Personal Assistants

- ➔ http://www.nasuad.org/hcbs/article/hiring-and-managing-personal-assistants

The Arc of Tennessee – Personal Assistance Supports & Services: Self Assessment-Tool and User's Guide

- ➔ http://www.nasuad.org/node/50362

You Are the Employer: A Guide to Hiring and Managing Direct Support Staff

- ➔ http://www.nasuad.org/node/51208

Case management/support coordinators

Care Management Industry Directory

- ➔ http://caremanagementindustrydirectory.com/

Help Starts Here: Find a Social Worker

- ➔ http://www.helpstartshere.org/find-a-social-worker

The Boggs Center on Developmental Disabilities – Selecting a Support Coordination Agency

- ➔ http://rwjms.rutgers.edu/boggscenter/projects/documents/ChoosingaSupportCoordinationAgencyFamiliesfinal.pdf

Chapter 13: System alternatives

Housing

Apartment Hunting With a Disability

- ➔ http://apartments.about.com/od/disability/tp/apartmenthuntingdisability.htm

Disability.gov - Housing Resources

- ➔ https://www.disability.gov/?s=&fq=topics_taxonomy:%22Housing%5E%5E%22

Finding Apartment for Disabled Apartment Hunters

- ➔ http://www.apartmentguide.com/blog/finding-apartments-for-disabled-apartment-hunters/

FindMyRoommate (IN, MN, CT)

- ➔ http://www.findmyroommate.org/

PACER Center - National Housing Resources

- ➔ http://www.pacer.org/housing/resourcesnational.asp

Roommate survivalguide: 15 strategies to make it work

- ➔ http://realestate.msn.com/article.aspx?cp-documentid=19853321

Roommates.com

- ➔ http://www.roommates.com/

Roomster

- ➔ https://www.roomster.com/

The Directory of Accessible Housing

➔ http://www.accessiblehousing.org/

Independent living

*See list of resources beginning on **page 115.***

Accessing the community

American Public Transportation Association - Gateway to Public Transportation Links

➔ http://www.apta.com/resources/links/Pages/default.aspx

Disability.gov - Transportation Resources

➔ https://www.disability.gov/?s=&fq=topics_taxonomy:%22Transportation%5E%5E%22

The Arc Master Trust - Building Community Connections and Natural Supports

➔ http://www.thearctrust.org/future-planning/building-community-connections-and-natural-supports/

Using My Natural Supports Worksheets

➔ https://www.communityhousingnetwork.org/activek_apps/chn/assets/gmoa/31%20Ch%206%20Using%20My%20Natural%20Supports%20Worksheets.pdf

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Employment

ABILITYJobs

➔ http://www.abilityjobs.com/

CareerBuilder - Job seeking when you have a disability

➔ http://www.careerbuilder.com/Article/CB-2453-Job-Search-Strategies-Job-seeking-when-you-have-a-disability/

GettingHired

➔ http://www.gettinghired.com/

How to Prepare for a Job Interview

➔ http://jobsearch.about.com/od/interviewsnetworking/ss/job-interview.htm

Job Accommodation Network - Finding a Job that is Right for You: A Practical Approach to Looking for a Job as a Person with a Disability

➔ http://askjan.org/Job/

PACER Center - Disclosing a Disability in a Job Interview

➔ http://www.pacer.org/tatra/resources/POD/disclosedisability.asp

Resume-Help.org

➔ http://www.resume-help.org/

United States Department of Labor - Disability Resources - Job Search

➔ http://www.dol.gov/dol/topic/disability/jobsearch.htm

*See also the list of employment resources beginning on **page 118.***

Appendix C: National resources

2-1-1

2-1-1 provides free and confidential information and referral. Call 2-1-1 for help with food, housing, employment, health care, counseling and more.

➔ http://www.211.org/

➔ http://211us.org/

➔ Dial 2-1-1

ADA.gov

ADA.gov provides resources and information to protect against discrimination against disabled people.

➔ http://www.ada.gov/

Administration for Community Living

ACL brings together the efforts and achievements of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan.

➔ http://www.acl.gov/Index.aspx

American Disabled for Attendant Programs Today (ADAPT)

ADAPT are fighting so people with disabilities can live in the community with real supports instead of being locked away in nursing homes and other institutions.

➔ http://www.adapt.org/

American Public Transportation Association (APTA)

This organization represents large and small public transportation authorities and providers throughout the nation. Find a public transportation provider in your state.

➔ http://www.apta.com/Pages/default.aspx

AssistantPages

Free directory for home caregiving that offers detailed information about caregivers and jobs for both private individuals and agencies.

➔ http://www.assistantpages.com/

Association of University Centers on Disabilities

The Association of University Centers on Disabilities is a 501(c) non-profit organization that promotes and supports the national network of university centers on disabilities.

➔ http://www.aucd.org/

Centers for Independent Living

The Centers for Independent Living provide counseling, classes, and programs to help people with disabilities build relationships, learn to self-advocate, and more.

➔ http://www.virtualcil.net/cils/

Council on Quality and Leadership

The Council on Quality and Leadership is an international non-profit organization dedicated to advancing the quality of service.

➔ http://www.thecouncil.org/

Disability.gov

Disability.gov includes links to thousands of resources for disability-related programs, laws, services, and policies.

➔ https://www.disability.gov/

Disability Secrets

Disability Secrets provides information about the U.S. federal disability system, including an overview of how the process works and answers to specific questions that are often asked by applicants and appellants.

➔ http://www.disabilitysecrets.com

Disabled Businesspersons Association

Assist enterprising individuals with disabilities maximize their potential in the business world, and work with vocational rehabilitation, government and business to encourage the participation and enhance the performance of the disabled in the work force.

➔ http://www.disabledbusiness.org/

disABLEDperson.com

disABLEDperson Inc. is a 501(c)(3) 509(a)(1) non-profit public charity whose mission is to help reduce the near 70% unemployment rate amongst disabled Americans.

➔ http://www.disabledperson.com/

Diversity World: Disability and Employment Resources

Disability and employment information from Diversity World. A source of articles, websites, books, videos and other resources on the topic of disability and employment.

➔ http://www.diversityworld.com/

Easter Seals

Easter Seals provides exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities.

➔ http://www.easterseals.com/

GLADNET - Global Applied Disability Research and Information Network on Employment and Training

To promote the mainstream employment of persons with disabilities through knowledge generation, collection and dissemination on an international level.

➔ http://www.gladnet.org

HealthWrights

HealthWrights is a non-profit organization committed to advancing the health, basic rights, social equality, and self-determination of disadvantaged persons and groups.

➔ https://www.healthwrights.org

Home Of Hope

Home of Hope gives to the developmentally disabled an opportunity to regain and maintain dignity, and a sense of self-worth.

➔ http://www.homeofhope.org/

HousingPolicy.org

HousingPolicy.org is an online guide to state and local housing policy. The site includes easily accessible information on a broad range of state and local policy tools, as well as guidance on how to put them together to form a comprehensive and effective housing strategy.

➔ http://http://housingpolicy.org/

Independent Living Institute

The Independent Living Institute creates training materials and solutions for people with disabilities. They have an online library of information on independent living and other topics.

➔ http://www.independentliving.org/

JobAccess

The goal of JobAccess is to enable people with disabilities to enhance their professional lives by providing a dedicated system for finding employment.

➔ http://www.jobaccess.org/

Meals on Wheels

Meals on Wheels provides home-delivered meals to seniors, the disabled, and people who are homebound and are unable to shop and cook for themselves.

➔ http://www.mowaa.org/

National Council on Independent Living

The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities.

➔ http://www.ncil.org/

National Disability Rights Network

NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States.

➔ http://www.ndrn.org/index.php

SABE - Self Advocates Becoming Empowered

SABE protects the rights and equal treatment of people with disabilities.

➔ http://www.sabeusa.org/

Self-Advocacy Online

Self-advocacy online provides information to people with disabilities on topics such as relationships and being healthy. It also provides access to research and local self-advocacy groups.

- http://www.selfadvocacyonline.org/

Social Security's Representative Payment Program

Provides payee services for Social Security and SSI payments.

- http://www.ssa.gov/payee/
- 1-800-772-1213 (TTY 1-800-325-0778)

Society for Disability Studies

The Society for Disability Studies (SDS) is an organization devoted to a multidisciplinary analysis of disability. It is a multidisciplinary and international organization composed of social scientists, scholars in the humanities, disability rights advocates, providers, and agency personnel concerned with people with disabilities.

- http://www.uic.edu/orgs/sds/

Speaking For Ourselves

They teach the public about the needs and wishes and potential of people with disabilities. They also speak out on important issues and support each other through sharing, leadership development, and helping and encouraging each other.

- http://www.speaking.org/

The Arc

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

- http://www.thearc.org/page.aspx?pid=2530

The National Council on Disability

NCD is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities

➔ http://www.ncd.gov/

The National Organization on Disabilities

The National Organization on Disability (NOD) is a private, non-profit organization that promotes the full participation and contributions of America's 56 million people with disabilities in all aspects of life.

➔ http://nod.org/

US Department of Education

The US Department of Education has several jobs. It researches issues in education and provides information on findings. It also creates and distributes funds for education. Finally, it makes sure everyone has equal access to education.

➔ http://www.ed.gov/

US Department of Housing & Urban Development (HUD)

The US Department of Housing and Urban Development provides resources for people with lower-income to find housing. It also provides resources to protect against housing discrimination.

➔ http://portal.hud.gov/hudportal/HUD

US Equal Employment Opportunity Commission

The US Equal Employment Opportunity Commission enforces laws against workplace discrimination.

➔ http://www.eeoc.gov/

WorkSupport.Com

Information on disability, rehabilitation and employment.

➔ http://www.worksupport.com/

World Association of Persons with Disabilities (WAPD)

Advances the interests of persons with disabilities at national, state, local and home levels. They believe that all are entitled to high quality of life.

➔ http://www.wapd.org/

World Congress & Exposition on Disabilities - WCD

Their mission is to provide support to children and adults with disabilities and their families.

➔ http://www.wcdexpo.com/

Contributors

This tool was made possible by ASAN communications team members:

Catherine M. is a married ex-doctor and social worker with a cat. She figured out she had autism while she was reading about her nephew's diagnosis. Autism made sense of past relationship struggles and the loss of her profession due to not being able to deal with workplace politics.

Justin McLaughlin graduated from the University of Wisconsin-Oshkosh three years ago and is currently trying to get a job in journalism. He enjoys hanging out with friends, writing, reading and playing with cats.

Bennett Gaddes was diagnosed with autism when he was seven. He lives in Georgia.

Kitt is a 20 year old Autistic writer, self-advocate and Autism activist. She is the author of the blog Autisticchick. Kitt serves on the Central Oregon Disability Support Network board of directors and runs a peer group in her community. She enjoys writing, singing and drawing.

Allison Kimball is very artistic and crafty, and loves writing stories that have realistic fiction, dancing, making jewelry with glass beads, reading, and computers. She and her older brother are both adopted and love being a part of their forever family.

Theodore Van Dyke has recently graduated from high school. Diagnosed with autism in early childhood, his interests include writing, hiking, self-advocacy, and carpentry. Next year he will attend Quest University Canada to study English.

Marty Allen was finally diagnosed with Asperger's Syndrome in graduate school, after self-diagnosing herself at age ten. She uses her mad Aspie skills every day in her day job as a librarian and after-hours job as Supernatural and Guardians of Childhood geek.

Barbara Mader retired from teaching special needs populations in three states after many years. She writes for Examiner.com, blogs, is writing a novel, and makes Love the Skin coconut oil based skin care products. She is an avid gardener and enjoys teaching her grandchildren about green living.

Brandy Nightingale was diagnosed with autism in 2010 at the age of thirty-five. An entrepreneur, visual effects coordinator on feature films, retired stand-up comedian, and writer, she recently penned a book, *Everything's Hunky Dory: A Memoir*, and resides

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Michael Lopez was diagnosed with Aspergers as an adult, and holds A.S. and B.A. degrees. He currently work at SeaWorld San Antonio, but would love a career in autism awareness.

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Samantha Lee was diagnosed with PDD-NOS when she was three years old. She currently attends Auburn University pursuing a degree in Biomedical Sciences with minors in Spanish and Psychology. In the future, Samantha hopes to become a pediatric occupational therapist who specializes in working with children with developmental disabilities.

Simone is an autistic girl living in Europe with her parents, sister and cat. Currently in high school, she is studying for a future career in either one of the STEM fields or in art.

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