



Getting and Advocating for Community-Based Housing

Introduction

One goal of disability rights advocacy is to make sure that all disabled people are able to live:

- in their own homes
- within the community.

But in today's world, a lot of housing for disabled people doesn't meet this goal. A lot of disabled people are forced to live in places where they don't have the freedom to live how they would like. They are also separated from non-disabled people. People with disabilities may struggle to find housing that they can afford. This is because many disabled people live in poverty. Also, a lot of homes are not accessible to people with disabilities.

What's in this guide

This guide will:

- Define important words and laws you need to know to talk about good housing for disabled people
- Explain the situation that disabled people face today when it comes to housing, including:
 - the types of housing for disabled people (both good and bad),
 - how disabled people are separated from non-disabled people through housing
- explore the best types of housing for disabled people, using examples of housing policies
- look at steps disabled people and their families can take to get better housing

Important words to know

Olmstead

Olmstead was a U.S. court case. The case focused on two women. These women felt that they were unfairly kept in an institution. They believed they could have gotten better help in their community.

The *Olmstead* case had a positive result. It decided that disabled people have the right to get services in their communities. If someone living in an institution wants to live in the community, their state has new obligations. Their state has to give them the same kinds of services in their community that they got in the institution.

Community

“**Community**” has a specific definition when talking about housing. It means disabled people are able to live in the same place and do the same things as non-disabled people.

For example, disabled people living in their community would go to the same:

- supermarket
- doctors, and
- sporting events as their non-disabled neighbors.

They would interact with non-disabled people other than their carers in their communities.

Housing that doesn't meet these standards are not part of a “community.” This includes:

- institutions
- group homes that disabled people are not allowed to leave, or
- places that are not in an area where other people live

HCBS

HCBS stands for ‘**Home and Community Based Services**’. These services are programs that are run through Medicaid.

HCBS lets disabled people get support services in their own homes within their communities. This way, disabled people don't have to go to institutions to get support services. They can stay in their communities.

States can choose what kinds of services they will provide through HCBS. Some services that HCBS can provide:

- help with chores and making meals
- making changes to homes to make them more accessible
- transportation services, and
- supported employment services.

Not everyone on Medicaid can get HCBS. There is often a long waiting list.

Congregate housing

Congregate housing is housing for disabled people that keeps them separate from non-disabled people. This includes:

- institutions
- group homes, and
- gated communities for disabled people.

Disabled people living in these environments are often separated from non-disabled people. They often don't have the chance to interact with non-disabled people other than doctors or institution staff.

They also may not have the freedom to choose what they want to do each day. They might not be allowed to choose what supports they want for their disability. Instead, the non-disabled people who are in charge of the congregate housing may make those decisions.

People in congregate housing have to share their space with other people with disabilities. They might have to share their bedroom with a roommate.

Integrated housing

Integrated housing for disabled people is housing that is within their community. This means people without disabilities are also living in the same building or neighborhood.

Integrated housing usually lets disabled people decide what they want to do in their house. For example:

- when they want to leave or come back, or
- when to have guests.

Integrated housing usually also lets disabled people decide what supports that they want. They get to decide who will provide those supports.

Scattered-site

Scattered-site housing is a type of integrated housing. This is housing that is made for people who can't afford to live in a certain area. For example, disabled people or people with low income.

Housing is built in a bunch of different places scattered throughout a neighborhood. This makes it so that all the disabled or low-income people are not grouped together in one place. When everyone is grouped in one place, these groups usually become separated from the rest of the neighborhood.

Accessible housing

Accessible housing is housing that disabled people can use in the same way as non-disabled people. For example, an accessible house for a wheelchair user would need to have:

- a ramp to the entrance
- an elevator if the house or apartment had many floors, and
- fixtures like sinks and toilets that are at a height that they can be used by someone in a wheelchair.

A lot of places to live are not accessible housing. It can be hard for a disabled person to find a house that works for them while also staying in their community.

Good Housing Policy

Location

Where housing for disabled people is located is just as important as the house itself. Good housing should be based in the community, alongside housing for non-disabled people. This could be in a city, suburb, or rural area. This makes it so that there is less of a chance of disabled people being separated from the rest of society. Disabled people will be more likely to have access to the same opportunities as everyone else. Scattered-site housing is one example of good housing policy when it comes to deciding where to put a house for disabled people.

Integration

Just having housing in a good location isn't enough. Disabled people must be able to integrate into their community. This means that disabled people must have the chance to do the same things in their community as non-disabled people do. For example, go the store or go to social events.

When disabled people do these things, they should be doing them at the same time as non-disabled people. For example, let's say a group of people with disabilities want to go to a museum. They should be able to go during the same hours that the museum is open for non-disabled people. They shouldn't just be allowed to go during a time when only disabled people are allowed to go. This is so disabled and non-disabled community members can meet each other.

Location of housing in the community is not enough. The disabled people in the community must be able to join in and actively take part in their communities.

Freedom to make choices

Integration gives disabled people the chance to take part in their community. But, it also has to be their choice how they choose to take part in their community. Disabled people should be allowed to decide where they will go and what they will do, just like non-disabled people do. Housing is an important part of this. A good housing policy will let disabled people decide:

- who can come over to their house
- when they want to leave their house, and
- when they want to do things in their house like eat, sleep, or watch tv.

Ownership

People with disabilities may get help from the government to pay for a house or apartment. The person who owns or rents a house or apartment should be the person with a disability. It should not be a caregiver or medical provider.

This is so the disabled person is able to make their own decisions about what to do with their house or apartment. It is also so the disabled person is protected under the same laws that protect all people that own homes or rent apartments. Having ownership of a house or apartment lets disabled people do things like

- get their own keys
- decide their own decorations, and
- choose their own roommates.

Supports

Many people with disabilities will need support to live successfully in the community. Good housing policies let disabled people choose who gives them the support they need for their disability. Some common support options include:

- Living alone, but having a personal care assistant (PCA) that comes to help the disabled person with things like
 - cooking
 - cleaning, or
 - getting around the neighborhood.
- Living with a “shared living provider”, who lives with the disabled person full-time to help meet their needs. In exchange, the provider gets to
 - live in the house for free, or
 - get paid by the government.
- Living with friends or family who can provide everyday supports.

A disabled person should also get to choose what supports they get. For example, if they decide they do not want to do a certain treatment for their disability, they should be able to say no and have their choice respected. If a disabled person wants to change who supports them or what supports they get, they should be able to do this without needing to move from their house.

Accessibility

Disabled people have the right to live in housing that is accessible to them. When we talk about accessibility, we are usually talking about **physical accessibility**. For example, living in a place without stairs or with a lift for someone who uses a wheelchair. But, it can also mean **environmental accessibility**. For example, having quiet, scent-free homes for people who are sensitive to certain sounds and smells.

There are other ways to make housing accessible. One way is fitting the housing with **assistive technology**. For example, a device that automatically turns off a stove for people who have disabilities that may make them forget to do so.

The law says that people with disabilities who are being supported by the government have a right to get housing that is accessible to them. Also, 5% of housing paid for by the government is required to be physically accessible. But, there is still a lot of housing that is inaccessible. Homeowners may deny housing to disabled people who want housing even though it is against the law.

Coordination

Disabled people usually don't receive support for their disability from just one person. They usually have a team of

- doctors
- caseworkers, and
- other people who work to help that disabled person.

But, these people may not communicate with each other about the disabled person. So, the team members aren't working together to make sure the needs of this person are being met in the best way.

For example, a doctor may make an appointment for a disabled person to come in. To get to the appointment, the person needs transportation. The doctor and the transportation team need to coordinate. If they don't, the disabled person may miss the appointment because they have no way to get there.

This is important when it comes to housing. A disabled person needs all kinds of supports for them to be successful in community-based housing. Because of this, a disabled person being able to choose who supports them and in what way is just the first step. All these supports must also work together to make sure each person gets all the support they need.

Availability

A lot of housing is not accessible and there may not be supports in the community set up right away. Because of this, a lot of disabled people are told that their needs cannot be met in the community. Instead, they have to live in congregate housing like institutions or group homes.

Disabled people can often be put on waiting lists for housing that may take years for them to be able to get. For example, in Florida, there are over 20,000 people on the waiting-list for community-based housing programs. Disability rights advocates believe that all disabled people are able to integrate into their community with the right types of housing and the right support. Integrated housing should be readily available to any disabled person who wants to live in these settings.

Bad housing policy

Institutions

Institutions are a type of congregate housing. Disabled people live in large groups in housing. A medical provider controls the housing. Disabled people in these settings usually live in a room instead of a house. They don't control when they get to leave the institution, and often do not get to go out into their community at all. They also don't control things like

- when they get to eat
- what supports they receive for their disability, and
- what they get to do in their spare time.

All these decisions are made for them by the people who run the institution.

Group homes

Group homes are like institutions, but they are usually smaller. Residents of group homes may be able to make some more choices that people in institutions can't. For example, when to eat or what furniture to put in their room. But big choices are still usually made by the medical provider in charge of the group home. For example, when to go out and what disability supports to get. It's now against the law for group homes to take away some of these kinds of choices. Group homes have until 2019 to start following the law. After that, if they are not letting people make choices like when to go out, the government might stop paying them.

"Planned" or "intentional" communities

Another type of congregate housing is '**planned communities**' or '**intentional communities**'. But these are not the kinds of communities disability rights advocates support. Many of these communities aren't the same as the ones people with disabilities in integrated housing live in.

Planned communities are usually a bunch of people with the same disability living together. They live on a farm or in a gated community and non-disabled people watch over them. People living here may get more of a choice about what they do every day. This is because their homes are built away from the rest of society on purpose. But, they don't get to interact with non-disabled people.

Some people say that because disabled people 'choose' to live in planned communities, that they aren't a bad thing. But a lot of times, disabled people are told by their families or service providers that they can't live in an integrated community. So, they feel like they have to live in a planned community instead. Once they move, these people don't get to meet non-disabled people and find out this isn't true. This is the same situation that takes place in institutions and group homes. Also, many intentional communities won't let people with certain disabilities live in them. Or, they will be too expensive for many disabled people to live in.

There are two other things places like institutions and planned communities do that can be harmful. One is not giving disabled people the supports they need. For example, a house may be physically accessible, but not give someone the support they need to be able to cook for themselves.

Another one is when the people that own a house also give the disability support services for the house. This is what usually happens in institutions. When this happens, disabled people don't get a choice about who gives them their support.

Some people try and say these bad housing policies are okay. They say that some people have disabilities that are too ‘severe’ to be able to live in their community. But, this is not true. Research has shown that even people with disabilities that are ‘severe’ can do well in integrated housing. All they need is the right supports.

But because a lot of people say it isn’t possible, less money is given by the government to let disabled people try living in their communities. So, people don’t get the chance to get out of institutions, group homes, and planned communities.

Good Housing Practices in Practice

Here are some examples of programs, ideas, and laws that help disabled people access community-based housing:

Housing First

Housing First is an idea that was first thought of to help people who are homeless. It says that instead of making homeless people go through a bunch of different “steps” to get a house, they should just be given a house right away. Then, they can work on any other problems they have. This is because having a house is so important to being able to get other supports, like

- a job
- transportation, and
- good food.

The Housing First idea can also be used for people with disabilities. 43% of people in homeless shelters said they have a disability. This may be because a lack of support for disabled people leads many to end up homeless. By moving a disabled person from being homeless or in an institution to a house in their community, they can get support in their new community without worrying about how they will take care of their housing.

Section 8/Housing Choice Voucher Program

The U.S. government runs a program called Section 8. It is also called the **Housing Choice Voucher Program (HCVP)**. This program helps people who make less than a certain amount of money by giving them housing “vouchers”. These vouchers can help people pay their rent or buy a house in their community. The government works with groups that provide housing, like apartment landlords. They make sure that there is housing that people who have housing vouchers can use.

The government makes sure that this housing

- is safe
- that people can afford it, and
- that it is not separate from the rest of the community.

Many people with disabilities live in poverty. This program can help a lot of disabled people, while also making sure that disabled people can stay in their communities. The government also has some housing vouchers that are set aside especially for disabled people to use. People who provide housing under the Section 8 program have to make their housing accessible to disabled people.

Supportive Housing

Supportive Housing services were first created for people with mental health conditions. This system places people in housing within their community given to them by the government. They usually live in the same building as non-disabled people. They are allowed to stay in these houses as long as they want.

The amount of support a person gets while living in supportive housing is based on the wants and needs of each person. They can get resources like

- care for their mental health conditions
- help finding a job,
- help learning life-skills like cooking and cleaning,
- and more.

A study was done on supportive housing. The study compared supportive housing with other housing paid for by the government. The study showed that people living in supportive housing were less likely to become homeless. They were also happier with their homes. Supportive housing also costs much less than living in homeless shelters, institutions, or prisons.

Centers for Independent Living

Centers for Independent Living (CILs) are centers that give support to a state or a local community. The government funds CILs. CILs are not housing for disabled people. But they are run by and for disabled people who need help getting into community-based housing.

The 5 services that CILs provide are:

1. Advocating for disabled people and teaching them how to self-advocate
2. Giving peer counseling to disabled people
3. Teaching Independent living skills to disabled people (like cooking)
4. Giving out information about community-based housing
5. Helping people living in institutions move to community-based housing.

Independent living services are there for anyone with a significant disability. There are 403 Centers for Independent Living across the United States.

New CMS Rule

In January 2014, the **Center for Medicare & Medicaid Services (CMS)** announced a new rule. This rule may help more people get community-based housing. The rule changed the way that home and community-based services (HCBS) are defined. It says that in order for something to be considered HCBS and get money from Medicaid, it must be based in the community and not in an institution. Before this rule, these places were considered “homes” because they housed people with disabilities.

The new rule says that any HCBS must:

- Be integrated into the community and help people access their community.
- Give disabled people the tools to be independent and make their own choices.
- Be chosen by the disabled person from a list of options, including
 - 24-hour supports
 - daytime supports, and
 - supports in places not specifically for disabled people.
- Make sure that disabled people are given
 - privacy
 - respect, and
 - freedom from being pressured into make a choice by someone else.
- Let disabled people choose their disability support services and who provides them.

The rule also says that disabled people living in any housing that is owned by a service provider—like a group home—must also be able to:

- have privacy
- choose what they do each day
- choose when they eat, and
- choose when they have visitors

Disabled people must have these rights in order for the housing to be called HCBS. Lastly, the rule says that institutions and hospitals do *not* count as HCBS for any reason.

Where can I go to advocate for community-based housing for myself?

NASDDDS

The [National Association of State Directors of Developmental Disability Services](#) (NASDDDS) has a list of contacts for state agencies that help people with intellectual and developmental disabilities. These agencies support people who have developmental disabilities and their families in

- living
- learning, and
- working in their communities.

These agencies can help you get a job and find supported living services.

UCEDDs

[University Centers for Excellence in Developmental Disabilities](#) (UCEDDs) are organizations based in a college or university. There is at least one in each state. They work with

- people with disabilities
- members of their families
- state and local government agencies, and
- community providers.



UCEDDs make projects that provide help to people with disabilities, including

- trainings
- disability services, and
- research

Here is the [directory for all the state UCEDDs](#).

The Arc

[The Arc](#) is a national disability rights advocacy organization. They help people with intellectual and developmental disabilities. They do this by advocating for policies that help disabled people. They connect disabled people with opportunities like supported housing and job programs. Here is the page where you can find [your local chapter of The Arc](#).

Protection & Advocacy

Each state is required to have a **Protection and Advocacy (P&A)** group for people with disabilities. Anyone from the state with a disability-related problem is can get help from this group. They can help give you information about community-based housing. You can find [your state's P&A agency here](#).

Public Housing Agencies (PHAs)

Public Housing Agencies (PHAs) are group that run the Section 8 programs. These groups can work with you to help you get a housing voucher. There are many different PHAs, and each controls the Section 8 program in one city or county. You can find a list of the PHAs in the United States and search for the one in your area [here](#).

Where can I go to advocate for more community-based housing in my area?

SILCs

Try reaching out to your state's **Statewide Independent Living Council (SILC)**! This group works alongside the CILs in each state to draft a **State Plan for Independent Living (SPIL)**. The SPIL is a document written every 3 years. It says how each state is going to improve independent living services for people with disabilities over the next three years.



To find out where your closest SILC is, visit <http://www.ilru.org/projects/silc-net/silc-directory>. Members of your state's SILC would be good people to talk to about how to make your state's community-based housing situation better.

Online

<https://hcbsadvocacy.org/> is a website that let you choose your state and see what they are doing to follow the new CMS rule about HCBS. You can find a guide here on how to write letters to your state government to give them ideas on how to improve the HCBS in your state.

You can also contact the Centers for Medicare & Medicaid Services (CMS) directly. You can ask them about what is being done nationally to improve access to community-based housing. You can write comments to them at Hcbs@cms.hhs.gov.

DD Councils

[Developmental Disabilities Councils \(DD Councils\)](#) are groups that advocate for the rights of people with developmental disabilities. This includes the right to live in the community. They believe that disabled people should be the main people to have a say in laws that affect their lives. Many of the people on the DD Council are disabled themselves.

It may be a good idea to reach out to this group if you are interested in helping others access community-based housing. DD Council meetings are open to the public, so you can go watch a meeting if you are interested. They also have leadership trainings to teach people about self-advocacy skills. You can find [your state's DD Council on this page](#).

Glossary

Accessible housing

Accessible housing is housing that disabled people can use in the same way as non-disabled people.

Assistive technology

Any products or devices that help people with disabilities to function in everyday life.

Center for Medicare & Medicaid Services (CMS)

The government agency in charge of Medicaid and Medicare. Medicaid pays for a lot of services people with disabilities use to live in the community.

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Environmental accessibility

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Group homes

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Olmstead

A U.S. court case. It decided that disabled people have the right to get services in their communities.

Physical accessibility

Physical accessibility means that there are no physical barriers to accessing housing. For example, buildings with an elevator or without stairs for wheelchair users.

Planned communities/intentional communities

Planned communities are usually a bunch of people with the same disability living together. They live on a farm or in a gated community and non-disabled people watch over them. People living here may get more of a choice about what they do every day. This is because their homes are built away from the rest of society on purpose. But, they don't get to interact with non-disabled people.

Protection & Advocacy agencies

State-level organizations that protect the rights of people with disabilities.

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State Plan for Independent Living

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Statewide Independent Living Council (SILC)

SILCs work alongside the Centers for Independent Living in each state. They work to figure out how to improve independent living services for people with disabilities. They draft a State Plan for Independent Living (SPIL).

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