ASAN
AUTISTIC SELF ADVOCACY NETWORK

Community Living Policy Center

Plain Language Version

Institutions:

The Old, The New, And What We Should Do

To Start

This toolkit is about institutions and living in the community. It talks about why institutions are bad, and why people with disabilities should live in the community.

The toolkit will answer questions like:

- What is an institution? What is living in the community?
- When did institutions get made, and what were they like?
- Why did people start closing institutions?
- What rules and laws help us live in the community?
- What happened when people moved from institutions into the community?
- Why is living in the community better than living in institutions?
- What kinds of institutions are there today?
- What are new institutions like, and how are they different from the old institutions?

We talk a lot about institutions in this toolkit. We talk about people getting hurt in institutions, so it may hurt to read about it. It's okay to take a break from reading if you need to, or to not read this toolkit if it will hurt you.

Institutions and Living in the Community

Some people with disabilities need **long-term services and supports (LTSS)**. LTSS are services that help people with disabilities live our everyday lives.Some kinds of LTSS are job coaches, transportation, or an in-home helper.

Some people with disabilities live in **institutions**. Institutions are places where a lot of disabled people live. People living in institutions were usually put there by someone else, and did not decide to live there. Institutions are run by the people who work there, not by the people living there. People living in institutions usually can't leave when they want to, or spend their free time how they want to.

Other people with disabilities get LTSS in their own homes in the community. Getting LTSS in the community is also called **home and community-based services**, or "**HCBS**" for short. People with disabilities have the right to live in the community. We want to live in the community, and not in institutions.

ASAN is a group of autistic people that does disability rights work. We believe people with disabilities have the same rights as everyone else. One important right ASAN fights for is the right to live in the community. So ASAN talked with some people with disabilities about what living in the community means to us. We decided that living in the community means things like:

- Making your own choices.
- Going out when you want to, and going where you want to.
- Living in the same places as everyone else.
- Getting the help you need to meet your goals.
- Getting to choose who helps you, and what help you get.

- Meeting new people, and being with family and friends.
- Getting treated like an adult.

You can learn more by reading What Does “Living in the Community” Mean?

Today, less people with disabilities live in institutions than before. Lots of institutions closed in the last 50 years, and more people with disabilities moved into the community.

This is a great step forward, but we think *everyone* should live in the community. Some people still live in institutions, and new kinds of institutions are still getting made. So we still have work to do.

We need to show others why the community is good, and why institutions are bad. To do so, it’s important to learn about institutions. This toolkit will talk about the history of institutions, and show why living in the community is better than living in institutions.

The History of Institutions

How did institutions get started?

Institutions first got made in the 1840s. Before that, some people with disabilities got put in prisons, and they got hurt a lot there. They got hit or yelled at by the prison workers. They didn't get food, water, or help going to the bathroom. They got kept in cold rooms, and left alone for a long time. They didn't get the health care they needed.

A woman named Dorothea Dix saw people with disabilities getting hurt in prisons. So she helped make different places to put people with disabilities. These places were called state hospitals. **State hospitals** were the first kind of institutions.

A few years later, another kind of institution got made. These places were called state schools. **State schools** were the first institutions just for people with intellectual disabilities.

What were state schools like?

State schools got made to try and help people with disabilities, because people thought we wouldn't get hurt in a place "just for us". They thought state schools would be better than prisons, but they still were like prisons in a lot of ways. People with disabilities couldn't leave the state schools. They didn't get to choose how they spent their time, or get to be with non-disabled people.

Soon, people with disabilities started getting hurt in state schools. They got hit or yelled at by the school staff. They didn't get food, water, or help going to the bathroom. They got kept in cold rooms, and left alone for a long time. They didn't get the health care they needed. The state schools became just like prisons.

State schools kept people with disabilities separate from everyone else, so other people didn't notice that state schools hurt people with disabilities. People living in institutions kept getting hurt.

A couple of times, someone noticed how bad state schools were, and let the newspaper or the government know. Then, the state school would stop hurting people for a little bit.

But people didn't check the state schools that much, so the state schools would start hurting people again after a while.

This kept happening for a long time. New institutions kept getting made, that said they wanted to help people with disabilities. But they still took away our rights and hurt us. These institutions were never good places to live.

When did people start trying to help us live in the community?

In the early 1900s, a lot more people with disabilities got put in institutions, and some institutions had thousands of people in them. But institutions didn't get more money to hire more staff or build more rooms, so institutions became even worse to live in.

In the mid-1900s, some parents of people with disabilities got together. They saw how bad institutions were, and didn't want their kids to live in institutions. They thought their kids should get to live in the community, so they didn't put their kids in institutions. They fought for the rights of their kids with disabilities.

John F. Kennedy was the President from 1961-1963. He had a sister named Rosemary, who had an intellectual disability. He talked with the parents of kids with disabilities, and they worked together to help people with disabilities. They made the government set aside money to help people with disabilities. Some of this money went to institutions, but some of it also went to helping people live in the community. This was the first step to moving people out of institutions.

In 1972, a TV reporter visited an institution called Willowbrook. The reporter saw how bad Willowbrook was. People with disabilities were crowded in small rooms. They didn't get to eat, and got sick a lot. The reporter took a video of Willowbrook, and put it on TV.

That is how lots of people learned how bad institutions were, and it made more people want to close institutions.

Lots of changes happened after people learned about Willowbrook. States started working to move people out of institutions. They wanted more people with disabilities to live in the community, so they started paying for LTSS in the community. Lots of rules and laws also got made about people with disabilities. These rules try to make sure we don't get hurt in institutions, and help us live in the community.

Living in the Community: Important Rules and Laws

DD Act

The **DD Act** is a law that was made in 1975, 3 years after people learned about Willowbrook. It helps protect the rights of people with developmental disabilities by trying to make sure institutions can't hurt people like Willowbrook did.

Part of the DD Act is the **Developmental Disability Bill of Rights**, which lists what rights we have when we get LTSS. It says that we should have the freedom and support to live the way we want. It also made rules that institutions have to follow, and says that institutions can't get money from the government if they hurt us.

Medicaid and the HCBS Settings Rule

Medicaid is a government-run health care program in the United States. Medicaid helps people with disabilities get health care, and most people who get LTSS get them paid for by Medicaid.

At first, Medicaid didn't help us live in the community. Medicaid only paid for people to get LTSS in institutions, and wouldn't pay for us to get LTSS in the community. But in the 1970s, more people started trying to live in the community. They needed LTSS in the community, so they asked Medicaid to help pay.

In 1982, Medicaid started trying to help people live in the community. Medicaid set aside some money to give people LTSS in the community. More people got LTSS in the community, so more people got to live in the community, and institutions started getting smaller.

But there wasn't enough money for everyone to get LTSS in the community. Many people with disabilities got put on waiting lists, and had to wait years to get LTSS in their communities. Lots of people are still on waiting lists.

Another problem was that institutions took some of the money Medicaid set aside for LTSS in the community. These institutions said they helped people live in the community, but they were lying. Institutions used up some of the money Medicaid set aside, so there was less money to actually help us live in the community.

The government wanted to make sure that stopped happening, so they made a rule called the **HCBS Settings Rule.** This rule makes sure that Medicaid money only goes to LTSS in the community, so institutions can't take money meant for living in the community. The rule only starts in 2022, so it hasn't started working yet. You can learn more by reading the "This Rule Rules!" Toolkit.

The ADA and Olmstead

The Americans with Disabilities Act, or "the **ADA**" for short, is a law that came out in 1990. The ADA gave people with disabilities rights, and says we have the same rights as non-disabled people. It says we have the right to go to, live, and work in the same places as non-disabled people.

In 1999, two women named Lois Curtis and Elaine Wilson were living in an institution.

They wanted to live in the community instead, and said the ADA gave them the right to live in the community. They fought for their rights from the ADA, and went to the Supreme Court to fight for their rights. The **Supreme Court** is the biggest court in the United States, and has the final say on how laws work. The Supreme Court said that Lois and Elaine were right.

Lois and Elaine's court case was called *Olmstead*. ***Olmstead*** means that you have a right to live in the community, and that you don't have to live in an institution. You have the right to get LTSS in the community.

Institutions Today

These rules and laws helped us get LTSS in the community, and move out of institutions. More and more people with disabilities got to live in the community, so less people live in institutions now.

Some states started closing institutions in the 70s and 80s, and in the 90s, some states closed all of their big institutions. Today, 17 states have no big institutions, but most states still have at least one.

Today, most people with disabilities live in the community, but some people still live in institutions. Some still live in bigger institutions, like state schools. These are sometimes called ICFs or developmental centers. Others live in smaller institutions, like group homes. We want to make sure everyone can live in the community.

Why is Community Living Better?

There are lots of people that study institutions.They talk to people with disabilities in institutions to see what life is like in institutions. They also study living in the community.

They talk to people with disabilities who live in the community to see what life is like for people with disabilities in the community. They also talk to people who moved out of institutions, and ask about how living in the community is different from institutions.

Lots of studies came out about institutions and the community. You can see a list of some of these studies at the end of this toolkit. The studies can be hard to read, so this part of the toolkit explains what the studies found out.

The studies show that living in the community is better than living in institutions for a lot of reasons. Here are some things the studies show:

Freedom and Happiness

People with disabilities get more freedom when we live in the community. Studies show that people who live in the community get to make more choices. We get to choose what we do during the day, and when and where we go out. We get to choose who lives with us, and who helps us. We also get to see friends and family more.

We get less choices when we live in institutions. We might not get to choose who lives with us, where we go, or what we do.

Getting to make our own choices helps in other ways, too. It feels good to have control over our lives, so it helps us feel better about ourselves. It lets us make sure things work well for us.

For example:

> Sunil is autistic, and he lives in an institution. He doesn't get to choose his roommate, and his roommate is very loud. Loud noises hurt Sunil, so he needs his room to be quiet. But the institution doesn't let Sunil get a different roommate. Sunil is unhappy at the institution.
>
> Then, Sunil moves into the community. He gets to choose his own roommate, so he chooses a roommate who is also quiet. Sunil is happier living in the community, since he gets to have his own quiet space. He feels better because he gets what he needs.

One study talked to people with disabilities who moved out of institutions. They said they liked living in the community more, and that they never wanted to move back to an institution.

Learning New Things

People with disabilities learn more when we live in the community. Living in the community helps us learn new things. We learn important skills that help us live on our own, like how to take care of ourselves and make a schedule. We learn how to cook, how to clean our house, and how to shop for our own food and clothes. We don't get to learn these things as much in institutions.

We also learn more about getting along with other people. We get to meet more non-disabled people when we live in the community, so we get more chances to talk to others. We learn to communicate in ways that work for us.

We get treated better in the community, so we feel safer and feel better about ourselves.

That makes it easier for us to learn. We can learn new ways to say what we need, and new ways to get along with people.

Less people try to communicate with us in institutions, so we get less chances to learn about communicating. We might not get treated well in institutions, which makes it harder to get along with other people.

Learning new things helps us in other ways, too. For example, when we learn to shop, we also learn about money, and learning about money helps us get better at math.

Learning to make a schedule can help us read better, and talking with more people can help us write better.

Living in the community helps us get better at all these things. Not everyone learns all these things, but we usually learn more when we live in the community. We don't learn as much when we live in institutions.

Being Part of the Community

Living in the community lets us be around more non-disabled people.

We can work in the community and make money, join groups in the community, make new friends, and get new hobbies. We can feel like a part of the community, and feel like we belong there.

Institutions keep us separate from non-disabled people. We might not get to make friends outside the institution, or get to go into the community at all. We might not feel like we belong in the community.

Staying Safe

People with disabilities are safer in the community. We get hurt less when we live in the community. We get hit less and get yelled at less. We don't get left alone when we need help. We get food when we need it, and we get help going to the bathroom when we need to.

People with disabilities get hurt a lot more in institutions. We still get hit and yelled at, or we still might not get food or water. We might get left alone when we need help.

The government made rules to try and keep us safe in institutions, but we still get hurt in institutions today. The same things that happened in state schools still happen today.

Questions about Institutions

Is Community Living Better for Everyone?

Some people say that certain people with disabilities can't live in the community. They say that some people with disabilities have to live in institutions. They think some people can only get the help they need in an institution.

Some people with disabilities need a lot of help to live in the community. People with intellectual disabilities might need more help, or non-speaking people might have a hard time showing others what they need. But that doesn't mean people with these disabilities need to live in institutions. Everyone should get to live in the community.

The studies show that everyone should live in the community, too. The studies found out that living in the community is better for everyone. It helps everyone make more choices, learn new things, and be more safe. It doesn't matter what kind of disability someone has. People with intellectual disabilities, non-speaking people, and other people who need a lot of help all do better in the community. Nobody needs to be in an institution.

Does the community have no problems at all?

The studies found that the community is better than institutions, but we are still learning how to help people live in the community. There are still things that can be better, and problems can still happen in the community. People can still get hurt in the community.

We don't always have enough choices, and sometimes we get treated unfairly.

The studies show that these problems happen less in the community, but they do still happen. We need to work hard to help fix these problems. Everyone deserves a good life in the community.

What Counts as an Institution?

Different studies have different ideas about what counts as an institution. Some studies say an institution has to have more than 16 people, while others say an institution has to have more than 4 people. The studies also found out that institutions with less people are usually less bad.

For example:

> Richelle lives in an ICF with 30 other people with disabilities. She doesn’t get to choose what she eats, and she never gets to leave the institution.
>
> Maya lives in a group home with 5 other people with disabilities.
>
> Maya gets to choose what they eat for breakfast, and they take a field trip to the movies once a week. But Maya can only go to the movies, and can’t go anywhere else.
>
> Maya gets to make more choices and go out more than Richelle, but they still both live in institutions.

Smaller institutions might be less bad than bigger institutions, but they all take away the rights of people with disabilities. They don’t let us make all the choices about our lives, and they keep us separate from other people.

ASAN thinks about institutions in a different way. We think big buildings and group homes are institutions, but the most important thing is how people get treated. Smaller places can still be institutions. Someone who lives with their family can be in an institution, and even someone who lives in their own apartment can be in an institution.

If they get kept separate from other people and don’t get to make choices, then they are living in an institution.

New Institutions

We know that living in the community is better than institutions, but people keep building new institutions anyway. These institutions might be called group homes or “intentional communities” instead of institutions. People try and say these new places aren’t like the old institutions, but they are still institutions.

The new institutions might look like living in the community. They might be in a regular house, or look like every other neighborhood. But only disabled people live there. They don’t get to be around non-disabled people, or go outside their neighborhood. They don’t get to decide what to do each day.

Some institutions say that people with disabilities choose to live there. But usually, the people with disabilities didn’t get good choices. They didn’t get to learn about living in the community, or they got told they couldn’t live in the community. They didn’t really get a choice, just like when they got sent to the old institutions.

People keep making these new institutions because they think we need institutions.

They think people with disabilities need to live in places that are “just for us”, but that is the same reason the old institutions got made. The old institutions kept us away from other people. They made it easier for us to get hurt, and took away our freedom. New institutions do the same thing.

We know the history of institutions. We know that institutions kept hurting us for many years, and keep hurting us today. We know that studies show we should live in the community.

We also know one very important thing: that people with disabilities don’t want to live in institutions. We know that we want to live in the community.

We need to make sure new institutions stop getting made. We need to make sure people know about new institutions, and that new institutions are just like the old ones.

Words to Know

The Americans with Disabilities Act (ADA)

A law that came out in 1990. The ADA gave people with disabilities rights.

DD Act

A law that got made in 1975. It helps protect the rights of people with developmental disabilities.

Developmental Disability Bill of Rights

Part of the DD Act. It lists what rights we have when we get LTSS. It also made rules that institutions have to follow.

home and community-based services (HCBS)

Getting LTSS in the community.

HCBS settings Rule

A rule the government made. It makes sure that Medicaid money set aside for HCBS goes to the right places.

institutions

Places where a lot of disabled people live. People living in institutions did not decide to live there. They usually can't leave when they want to.

long-term services and supports (LTSS)

Services that help people with disabilities live our everyday lives. Some kinds of LTSS are job coaches and in-home helpers.

Medicaid

A health care program in the United States. Medicaid helps people with disabilities get health care.

Olmstead

A big court case in 1999. It says that you have a right to live in the community. It says that you don't have to live in an institution.

state hospitals

The first kind of institutions.

state schools

The first institutions just for people with intellectual disabilities.

Supreme Court

The biggest court in the United States. They have the final say on how laws work.

Studies on Institutions and Community Living

Behavioral Outcomes of Deinstitutionalization for People with I/DD: Third Decennial Review of U.S. Studies, 1977-2010. By K. Charlie Lakin, Sheryl A. Larson, and Shannon Kim.

> https://www.nasddds.org/resource-library/closing-institutions/reports-and-studies/behavioral-outcomes-of-deinstitutionalization-for-people-with-idd-review-of/

Correlates of Everyday Choice and Support-Related Choice for 8,892 Randomly Sampled Adults with Intellectual and Developmental Disabilities in 19 States. By Renata Ticha, K. Charlie Lakin, Sheryl A. Larson, Roger J. Stancliffe, Sarah Taub, Joshua Engler, Julie Bershadsky, and Charles Moseley.

> https://www.ncbi.nlm.nih.gov/pubmed/23256691

Costs and Outcomes of Community Services for Persons with I/DD. By Roger J. Stancliffe and K. Charlie Lakin.

> https://www.nasddds.org/resource-library/closing-institutions/reports-and-studies/costs-outcomes-of-community-services-for-persons-with-intellectual-developm/

Deinstitutionalization: Unfinished Business. From the National Council on Disability.

> https://ncd.gov/policy/deinstitutionalization-unfinished-business-companion-paper-policy-toolkit-0

Effect of Deinstitutionalization on Quality of Life for Adults with Intellectual Disabilities: a systematic review. By Mary McCarron, Richard Lombard-Vance, Esther Murphy, Peter May, Naoise Webb, Greg Sheaf, Philip McCallion, Roger Stancliffe, Charles Normand, Valerie Smith, and Mary-Ann O'Donovan.

> https://www.nasddds.org/resource-library/closing-institutions/reports-and-studies/effect-of-deinstituionalization-on-quality-of-life-for-adults-with-i-dd/

The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities. By Charlie Lakin, Sheryl Larson & Shannon Kim.

> https://www.nasddds.org/resource-library/closing-institutions/reports-and-studies

Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community. From the National Council on Disability.

> https://ncd.gov/publications/2015/02242015

Medicaid Home and Community-Based Services for Persons with I/DD. By K. Charlie Lakin, Robert Doljanac, Soo Yong Byun, Roger Stancliffe, Sarah Taub, and Giuseppina Chiri.

> https://www.nasddds.org/resource-library/closing-institutions/reports-and-studies/medicaid-home-and-community-based-services-for-persons-with-idd/

National Core Indicators.

https://www.nationalcoreindicators.org/

Satisfaction, Safety, and Supports: Comparing People with Disabilities' Insider Experiences about Participation in Institutional and Community Living. By Alisa Jordan Sheth, Katherine E. McDonald, Louis Fogg, Nicole E. Conroy, Edward H.J. Elms, Lewis E. Kraus, Lex Frieden, and Joy Hammel.

https://www.nasddds.org/resource-library/closing-institutions/reports-and-studies/insider-experiences-about-participation-in-instiituional-and-community-livi/