



ASAN
AUTISTIC SELF ADVOCACY NETWORK



Plain Language Version

The Cycle of Institutions



To Start

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.

Institutions are bad places to live. We know institutions hurt people with disabilities, and that people with disabilities should get to live in the community.

Sometimes, some institutions will close down, but new institutions keep getting made.

The new institutions might look different from the old ones, but they are just like the old institutions. We need to make sure no more new institutions get made. To close all institutions for good, we need to learn why they keep opening.

This toolkit will teach you about the history of institutions. It will tell you about why some institutions got closed, and why new institutions still get made.

This toolkit talks about institutions just for people with intellectual disabilities. There are other kinds of institutions, but not as many people talk about people with intellectual disabilities, so we wanted to focus on people with intellectual disabilities.

The Cycle of Institutions

In this toolkit, we talk about the cycle of institutions. A **cycle** is when something happens over and over again. The cycle of institutions is when institutions keep closing and opening again, and has happened many times in the U.S. Here is what the cycle of institutions looks like:

Step 1:

New institutions get made. People say they aren't like the old institutions, or that they aren't institutions at all. They say these new places will actually help people with disabilities, but they look and act a lot like the old institutions.

Step 2:

People with disabilities get sent to the new institutions, and they don't actually get help. They don't get to go to school, learn how to do jobs, or learn how to live on their own. They start getting hurt in the new institutions, just like the old ones!

Step 3:

People start to notice how bad the new institutions are. A government worker might visit one, or a report shows up in the newspaper or TV. People say "Something needs to be done about these institutions!"

Step 4:

People try to think of a new way to help people with disabilities. They can't think of a way to help us live in the community, so they come up with a new kind of institution.

Repeat Step 1.

The Start of the Cycle

How did institutions get started?

Before the 1800s, people with intellectual disabilities didn't get any kind of help. Other people didn't think we could think, or feel, or learn, so they didn't know what to do with us. We usually didn't get to go to school or work, and we got put in prison a lot.

Our families were ashamed of us. They didn't want other people knowing we existed, so we got kept secret by our families. We might not have been allowed to leave our houses. Sometimes, people decided our lives weren't living, so they killed us.

This started to change in the mid-1800s. People made institutions for other kinds of disabilities.

Sometimes, people with intellectual disabilities got put there, but there weren't any places just for people with intellectual disabilities.

Some people started studying intellectual disabilities because they wanted to make us as "normal" as possible. They wanted to see if we could think and learn, so they made institutions for us. These places were called state schools. **State schools** were the first institutions just for people with intellectual disabilities.

For example:

An institution called the Massachusetts School for Idiotic and Feeble-Minded Youth got made in 1848. It got made just for people with intellectual disabilities by a man named Dr. Samuel Gridley Howe. Dr. Howe helped open many other institutions like this one around the country.

What were state schools like?

People living in state schools got “training” to try and cure their disabilities. They learned things like how to do heavy labor and factory work. The goal of the institution was to teach people with disabilities how to work. That way, we could go back to living in the community, help our families, and make money.

Some institutions were big buildings with large groups of people. Others looked like farms, and people with disabilities learned how to do farm work there. Others looked like a big group of houses, where people with the same disabilities would live together. For example, people with epilepsy would all live in one house.

The people who studied disability worked with other groups, like families of people with disabilities and civil rights advocates. They talked with the government about institutions, and convinced the government to pay for state schools to get made. Parents got told that institutions were the only hope for their kids with disabilities, so more and more people with disabilities got sent to institutions.

How did institutions hurt people with disabilities?

Institutions got built to try and help us, but they started hurting people with disabilities pretty quickly. They got too crowded and dirty. The staff at institutions didn't take care of us, and made people with disabilities take care of each other. Some of them made people with disabilities do hard work for free.

But most people in institutions did nothing all day. They didn't get enough food, or get help to eat or go to the bathroom. Staff would yell at them or hit them.

Dr. Howe even realized the institutions were getting bad! He told people to stop building them, but it was too late. More institutions got built anyway, and people kept getting sent to institutions.

What happened when other people noticed how bad institutions were?

Sometimes, people would notice how bad institutions were. They would try and make other people notice so that the institutions would get pressured to do better.

Nellie Bly wrote news stories for magazines, and wrote a story about an institution in 1887.

She pretended to have a disability to get put in an institution called Blackwell's Island in New York. She saw how people with disabilities got hurt there, and wrote a story called 10 Days in a Mad-House about how bad Blackwell's Island was.

The government read Nellie's story, and decided to give Blackwell's island more money to try and help the institution get better. They also said the government would come check the institution more often to make sure it didn't get bad again. But then the money ran out, and the government stopped coming to check Blackwell's island, so things got bad again.

In 1948, Albert Deutsch wrote Shame of the States. He went to 12 institutions and took photos to show how the institutions hurt people with disabilities. He said institutions should be more like a good hospital that tries to make people with disabilities better so we can go back to the community.

A lot of people read Albert's book. Some new institutions got built in the 1950s that were supposed to be better. They were supposed to be like what Albert wanted, but then they got worse again!

President John F Kennedy had a brother named Robert Kennedy, who also worked for the government. In 1965, he took a tour of an institution called Willowbrook, and saw how bad Willowbrook treated people with disabilities. He talked to the government about Willowbrook.

He wanted to make sure people at Willowbrook got to go to school and got taken care of, but not much at Willowbrook changed for 7 more years.

Things started to change in 1972. A reporter named Geraldo Rivera took some videos of Willowbrook, and put the videos on the news. It showed people packed together in dirty rooms.

People were starving and very skinny, and nobody was around to help them. That is when everyone realized how bad institutions were, and the government decided institutions needed to be changed.

The Second Cycle: ICFs and Group homes

What rules got made to help institutions get better?

The government made rules that institutions needed to follow. The biggest one was a law called the **Developmental Disabilities Act**, which is called DD Act for short. The DD Act got made in 1975, and said that institutions had to try and help people with disabilities. They have to help us go to school, and they aren't allowed to hurt us. The government also said they would check institutions more often.

Many old institutions couldn't follow these rules, so they got closed down. But there weren't a lot of places to help people with disabilities, so it was still hard to find help in the community. So new places, called ICFs and group homes, got made to replace institutions. They looked a little different, but they were still institutions.

What are ICFs?

Intermediate care facilities, or **ICFs** for short, were one new kind of institution. ICFs got made to take care of people with disabilities who need more help with everyday life. ICFs look a lot like hospitals, and they were supposed to take better care of us. They were supposed to help us move back into the community, but they ended up almost exactly like state schools. Sometimes, a state school would close its building, then they would open up an ICF in the same building.

That made it really easy to just go back to how things were before.

What are Group Homes?

Group homes are houses where only disabled people live, just like the houses state schools used to have. In state schools, people with the same kind of disability lived together in one house. Group homes do the exact same thing.

Sometimes, group homes are in the same houses that state schools used. They are in the same places as the old institutions, and are run by the same people as the old institutions. The group homes say they follow the new rules, but they don't always follow the rules. They act just like old institutions.

Sometimes, group homes are in houses in the community. But people with disabilities might not be allowed to go out, or go to school or work. They might get hurt, and nobody would know.

It doesn't matter that the house is in the community. These group homes aren't any better than group homes in other places.

What are ICFs and Group Homes like Today?

ICFs and group homes are still around today. There are a lot less ICFs than there used to be, but a lot of ICFs became group homes. Both ICFs and group homes still keep people with disabilities separate from everyone else. They still don't try to help us live better lives, and they still hurt people with disabilities. They are still just institutions.

People still sometimes notice how bad ICFs and group homes are. They tell other people about it, but not much has changed to make these institutions better. For example:

California has some ICFs called developmental centers. People got killed at the developmental centers. They didn't get help when they got sick, they got hurt by staff, and they got left alone for too long and died. The California government didn't do anything about it for a long time, until the news talked about it in 2012. So the government checked the institutions, and said they would close all the developmental centers. But some of these ICFs are still open today.

In 2019, a disabled woman living in an ICF in Arizona had a baby, but none of the institution staff even noticed she was pregnant. Some of the people living there were covered in bugs, but nobody helped clean them. They got left alone for days at a time.

In 2016, a newspaper called the *Chicago Tribune* wrote about group homes. They looked at group homes in Illinois for 5 years, and found out that people living in group homes got hurt 1,311 times. A lot of those times, the group homes didn't tell the government. That is against the law, but it happened anyway, and the group homes never got in trouble.

The U.S. government also looked at group homes across the country in 2018. They found out that group homes were hurting people, and that most group homes didn't tell anyone when people got hurt. That is against the law, but it still happens today.

The Third Cycle: Intentional Communities

What are Intentional Communities?

In the past 10 years, a new kind of institution showed up, made mostly by parents of disabled kids. They saw how bad ICFs and group homes are, and want their kids to live in a nicer place. They want their kids to feel like they have a community, but these parents still think their kids can't live in the community. They want their kids to live somewhere just for people with disabilities, so they built something called "intentional communities".

Intentional communities are a new kind of institution, that try to hide that they are institutions.

Some of them try to look like actual communities. Intentional communities make people with disabilities live together, and keep us away from non-disabled people.

How do we know intentional communities are institutions?

An intentional community might make people live in a bunch of houses, just like group homes. Or it could be on a farm, just like state schools. Or it could be in a big building, just like ICFs.

Intentional communities say they will teach us things. They will teach us how to work, just like state schools. Or they will teach us how to get ready for the community, just like ICFs.

Intentional communities are very new, so we don't know too much about them yet. But we know that they look a lot like group homes and state schools. Intentional communities are not real communities. They are institutions.

State schools, ICFs, and group homes didn't help people with disabilities. They kept us separate from everyone else, because they thought we needed to be kept separate. They thought that was what's best for us. But they didn't help us, and they even started hurting us. Intentional communities will do the same thing.

Words to know

cycle

When something happens over and over again. The cycle of institutions is when institutions keep closing and opening again.

DD Act

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

group homes

Houses where only disabled people live. They are another kind of institution.

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.

intentional communities

A new kind of institution. They got made to look like actual communities.

Intermediate Care Facility (ICF)

One kind of institution. ICFs got made to take care of people with disabilities. They were for people who need more help with everyday life.

state schools

The first institutions just for people with intellectual disabilities.

To Learn More

Disability History Exhibit. By the State of Alaska Governor's Council on Disability and Special Education.

http://dhss.alaska.gov/gcdse/Pages/history/html_content_main.aspx

Farms for Disabled People Aren't A New Idea. By Kit Mead.

<http://nosmag.org/farms-for-disabled-people-arent-an-innovative-new-idea-asylums/>

Forging a Federal-State Partnership: A History of Federal Developmental Disabilities Policy. By Robert M. Gettings.

<https://www.aaid.org/publications/bookstore-home/product-listing/forging-a-federal-state-partnership-a-history-of-state-and-federal-developmental-disabilities-policy>

Parallels in Time: A History of Developmental Disabilities. By the Minnesota Council on Developmental Disabilities.

<http://mn.gov/mnddc/parallels/>

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