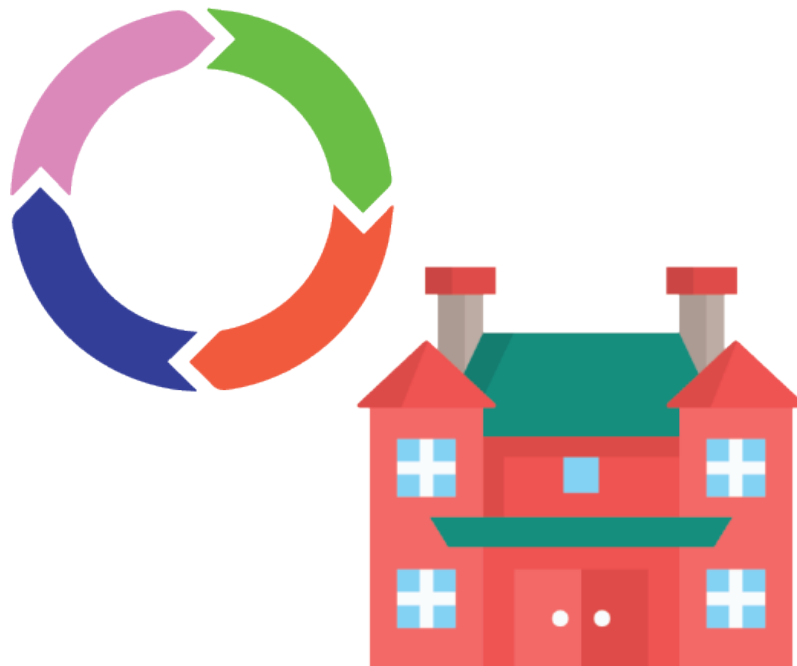




*Easy Read Edition*

# The Cycle of Institutions





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# The Cycle of Institutions

Part 1: To Start

# Words to Know in Part 1



## 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.

## To Start

---



Some people with disabilities live in **institutions**.



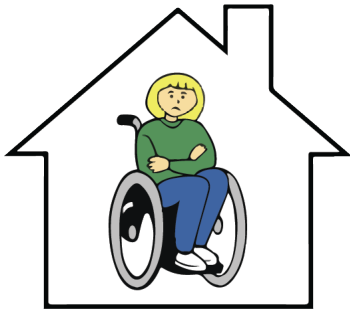
Institutions are places where a lot of disabled people live.



People living in institutions did not decide to live there.



They were usually put there by someone else.



Institutions are not run by the people living there.



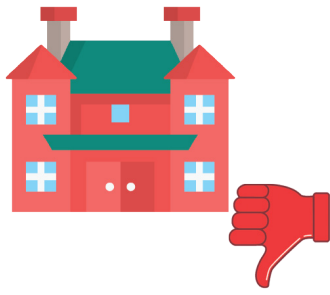
Institutions are run by the people who work there.



People living in institutions usually can't leave when they want to.



They usually can't spend their free time how they want to.



Institutions are bad places to live.



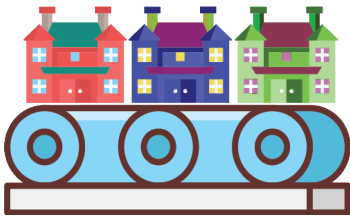
We know institutions hurt people with disabilities.



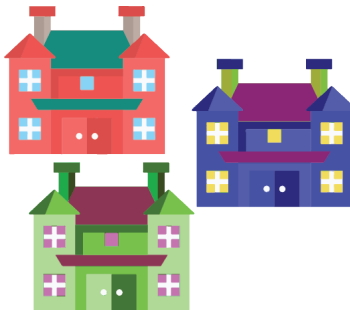
People with disabilities should get to live in the community.



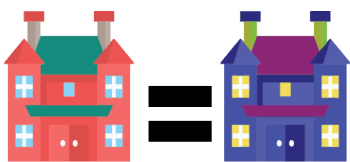
Sometimes, some institutions will close down.



But new institutions keep getting made.

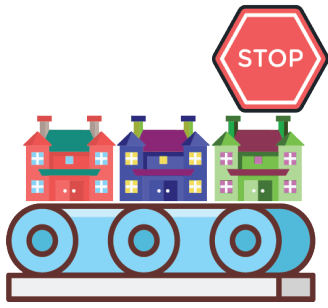


The new institutions might look different from the old ones.



But they are just like the old institutions.





We need to make sure no more new institutions get made.



We should work to close all institutions for good.



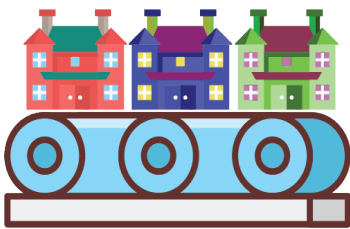
To close institutions, we need to learn why they keep opening.



This toolkit will teach you about the history of institutions.



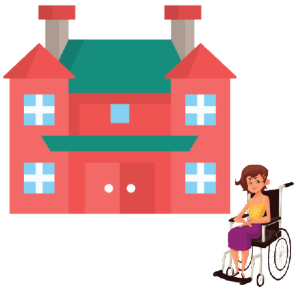
It will tell you about why some institutions got closed.



It will also tell you why new institutions still get made.



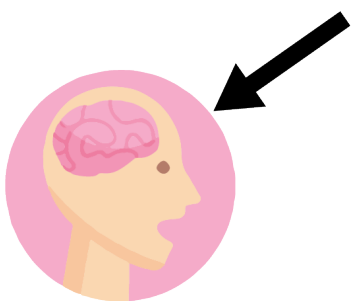
This toolkit talks about institutions just for people with intellectual disabilities.



There are other kinds of institutions, too.



But not as many people talk about people with intellectual disabilities.



We wanted to focus on people with intellectual disabilities.



We talk a lot about institutions in this toolkit.



We talk about people getting hurt in institutions.



It may hurt to read about it.



It's okay to take a break from reading if you need to.



It's okay to not read this toolkit if it will hurt you.

*Support for this toolkit was provided by The Community Living Policy Center at Brandeis University. Funding for this center is provided by the National Institute on Disability, Independent Living, and Rehabilitation Research (grant number 90RTCP0004). However, the contents of this brief do not necessarily represent the policy of the federal government.*



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# The Cycle of Institutions

## Part 2: The Cycle of Institutions

# Words to Know in Part 2

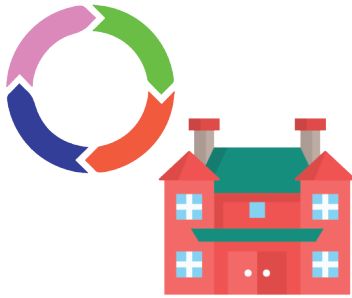


## Cycle

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



# The Cycle of Institution



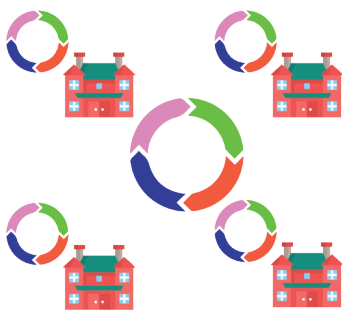
In this toolkit, we talk about the cycle of institutions.



A **cycle** is when something happens over and over again.



The cycle of institutions is when institutions keep closing and opening again.



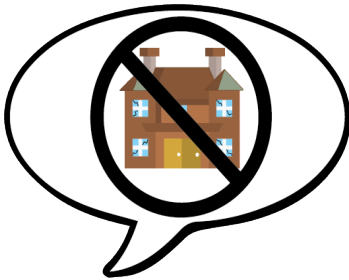
The cycle of institutions has happened many times in the U.S.

Here is what the cycle of institutions looks like:



## Step 1:

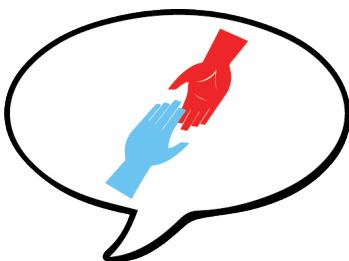
New institutions get made.



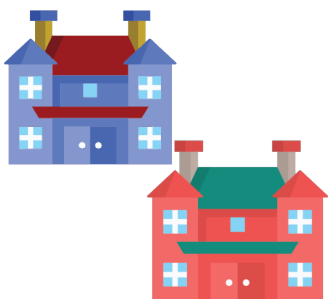
People say they aren't like the old institutions.



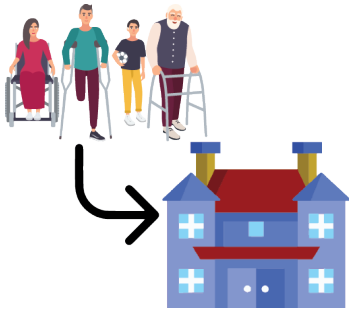
They say they aren't institutions.



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.



They don't actually get help.



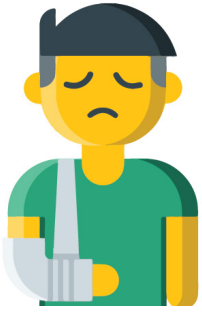
They don't get to go to school.



They don't learn how to do jobs.



They don't learn how to live on their own.



They start getting hurt in the new institutions.

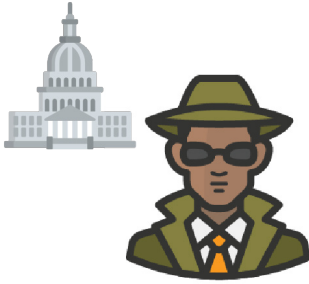


Just like the old ones!



### Step 3:

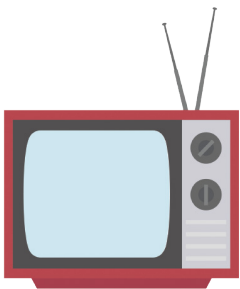
People start to notice how bad the new institutions are.



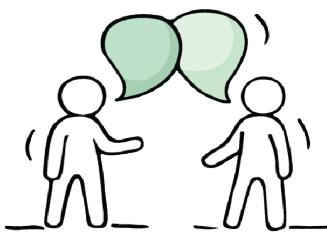
Maybe a government worker visits one



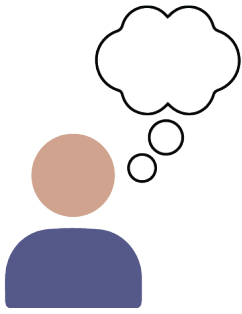
Or a newspaper writes an article.



Or a report shows up on TV.



People say “Something needs to be done about these institutions!”

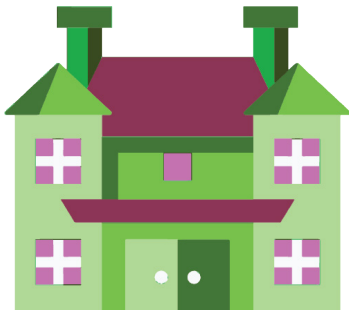


## Step 4:

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.

*Support for this toolkit was provided by The Community Living Policy Center at Brandeis University. Funding for this center is provided by the National Institute on Disability, Independent Living, and Rehabilitation Research (grant number 90RTCP0004). However, the contents of this brief do not necessarily represent the policy of the federal government.*



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# The Cycle of Institutions

## Part 3: The Start of the Cycle



# Words to Know in Part 3

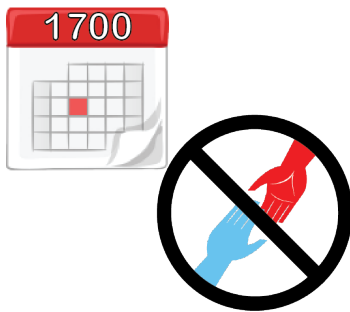


## State Schools

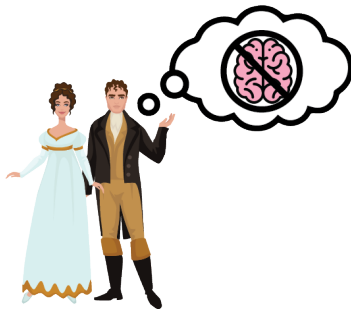
The first institutions just for people with intellectual disabilities.

# The Start of the Cycle

## How did institutions get started?



Before the 1800s, people with intellectual disabilities didn't get any kind of help.



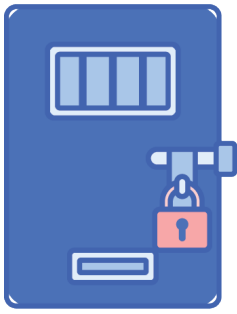
Other people didn't think we could think, or feel, or learn.



So they didn't know what to do with us.



We usually didn't get to go to school, or work.



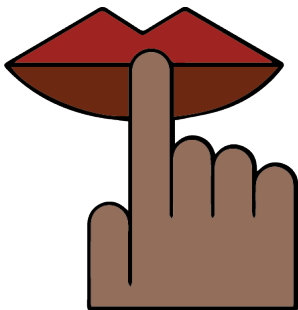
We got put in prison a lot.



Our families were ashamed of us.



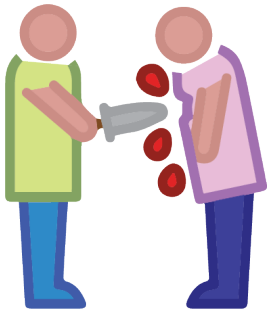
They didn't want other people knowing we existed.



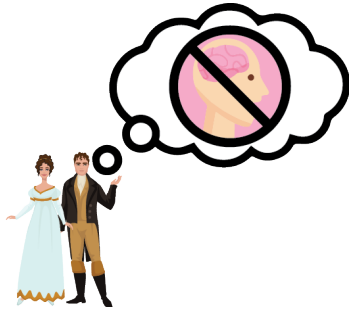
So we got kept secret by our families.



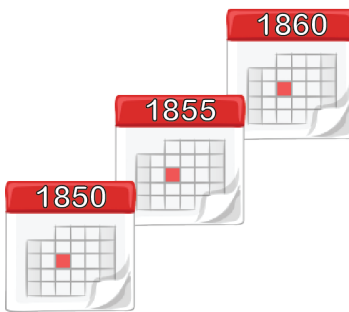
We might not have been allowed to leave our houses.



Sometimes, people killed us.



They decided our lives weren't worth living.



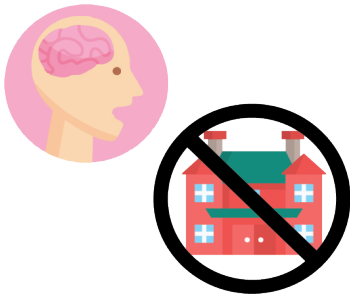
This started to change in the mid-1800s.



People made institutions for other kinds of disabilities.



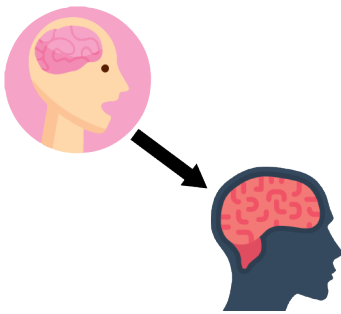
Sometimes, people with intellectual disabilities got put there, too.



But there weren't any places just for people with intellectual disabilities.



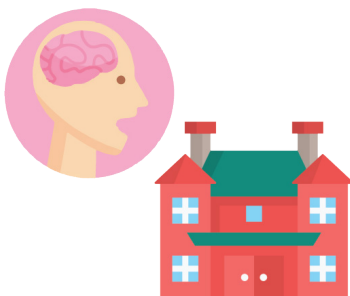
Some people started studying intellectual disabilities.



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.



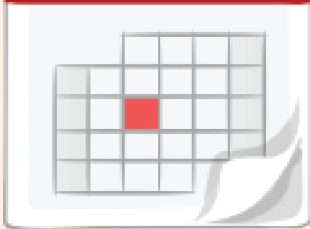
These places were called state schools.



**State schools** were the first institutions just for people with intellectual disabilities

For example:

1848



One institution got made in 1848.



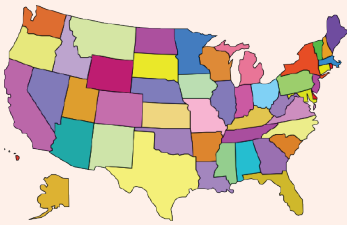
It was called the Massachusetts School for Idiotic and Feeble-Minded Youth.



It got made just for people with intellectual disabilities.



A man named Dr. Samuel Gridley Howe made this institution.



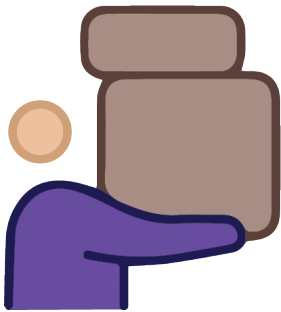
Dr. Howe helped open many other institutions around the country.



## 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 hard work, like lifting heavy stuff.



The goal of the institution was to teach people with disabilities how to work.



That way, we could help our families and make money.



We could go back to living in the community.



Some institutions were big buildings with large groups of people.



Others looked like farms. People with disabilities learned how to do farm work there.



Others looked like a big group of houses.



People with the same disabilities would live together.



For example, people with epilepsy would all live in one house.



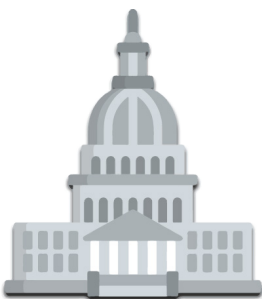
The people who studied disability worked with other groups.



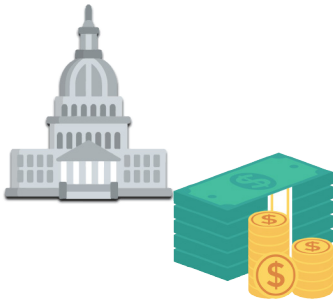
They worked with families of people with disabilities.



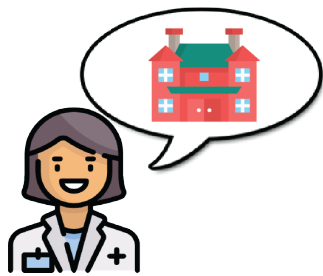
They worked with civil rights advocates.



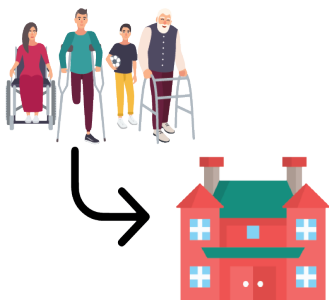
They talked with the government about institutions.



So the government started to pay for state schools to get made.



Parents got told that institutions were the only hope for their kids with disabilities.

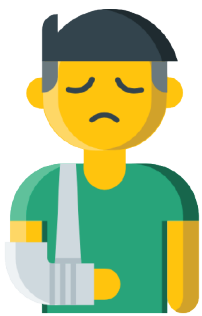


More and more people with disabilities got sent to institutions.

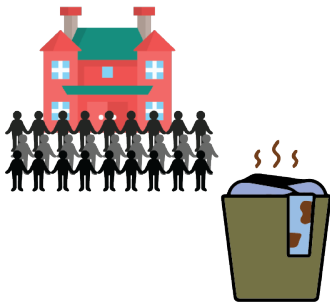
## How did institutions hurt people with disabilities?



Institutions got built to try and help us.



But they started hurting people with disabilities pretty quickly.



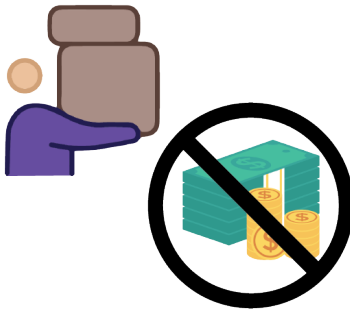
They got too crowded. They got dirty.



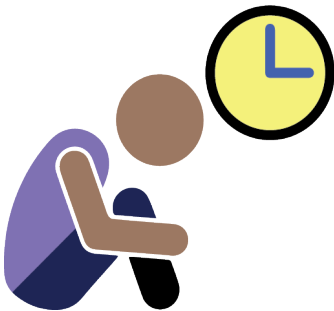
The staff at institutions didn't take care of us.



They made people with disabilities take care of each other.



Some of them made people with disabilities do hard work for free.



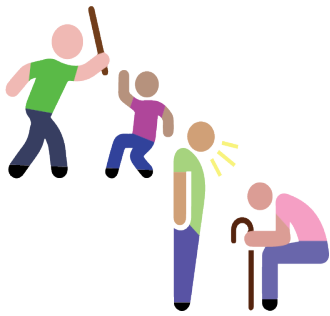
But most people in institutions did nothing all day.



They didn't get enough food.



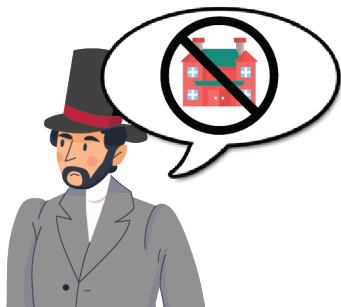
They didn't get help to eat or go to the bathroom.



Staff would yell at them or hit them.



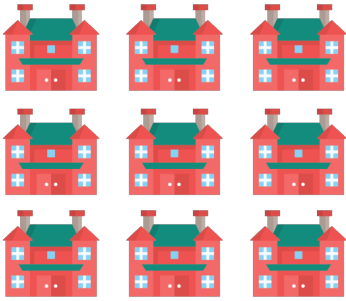
Dr. Howe even realized the institutions were getting bad!



He told people to stop building them.



But it was too late.



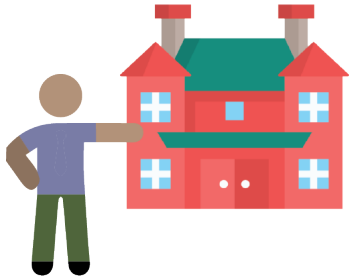
More institutions got built anyway.



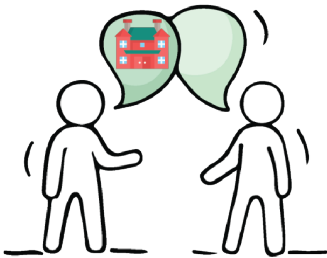
People kept getting sent to institutions.



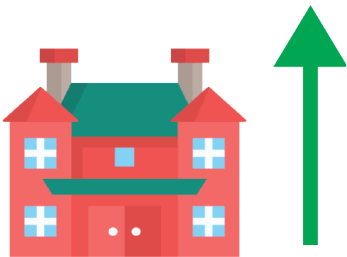
## What happened when other people noticed how bad institutions were?



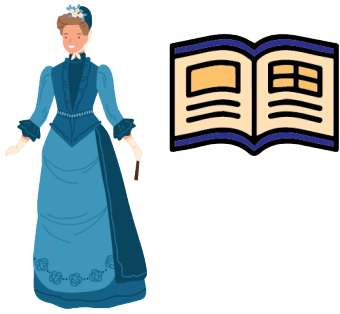
Sometimes, people would notice how bad institutions were.



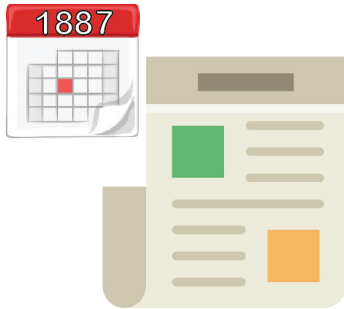
They would try and make other people notice, too.



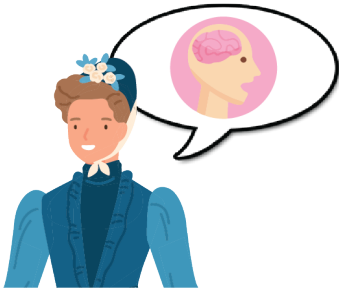
They wanted to make the institutions better.



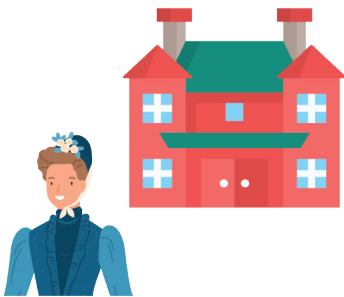
Nellie Bly wrote news stories for magazines.



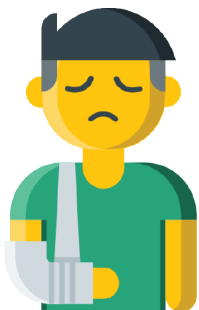
She wrote a story about an institution in 1887.



She pretended to have a disability to write the story.



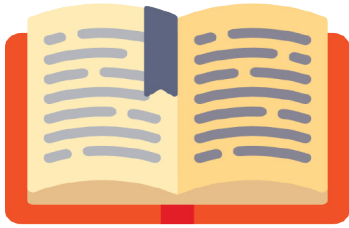
She got put in an institution called Blackwell's Island in New York.



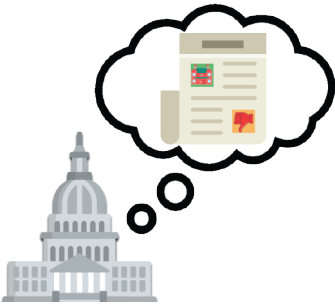
She saw how people with disabilities got hurt there.



Her story talked about how bad Blackwell's Island was.



It was called 10 Days in a Mad-House.



The government read Nellie's story.



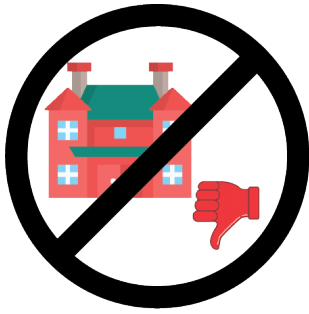
They decided to give Blackwell's island more money.



They hoped it would help the institution get better.



They also said the government would come check the institution more.



They would make sure it didn't get bad again.



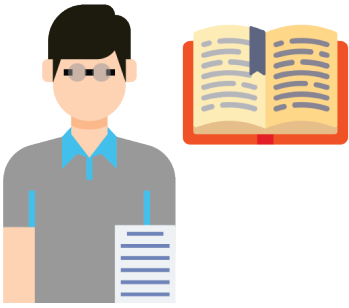
But then the money ran out.



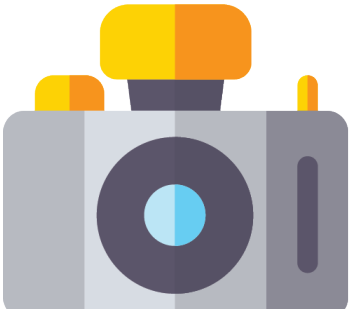
The government stopped coming to check Blackwell's island.



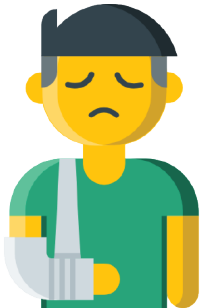
Things got bad again.



In 1948, Albert Deutsch wrote Shame of the States.



He went to 12 institutions and took photos.



He showed how the institutions hurt people with disabilities.



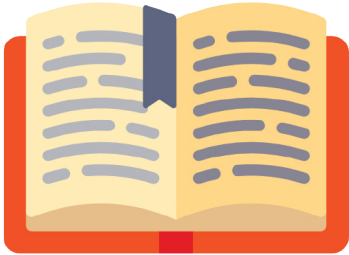
He said institutions should be more like a good hospital.



He said institutions should try and make people with disabilities better.



He said institutions should help us go back to the community.



A lot of people read Albert's book.



Some new institutions got built in the 1950s.



They were supposed to be better.



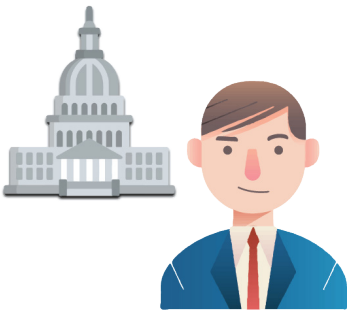
They were supposed to be like what Albert said.



But then they got worse again!



President John F Kennedy had a brother.



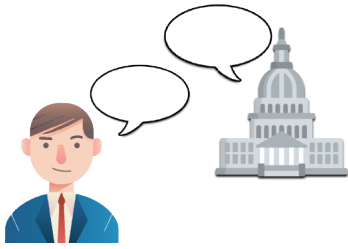
His name was Robert Kennedy. He also worked for the government.



In 1965, he took a tour of an institution called Willowbrook.



He 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.



He wanted to make sure people at Willowbrook got taken care of.



But not much at Willowbrook changed for 7 more years.

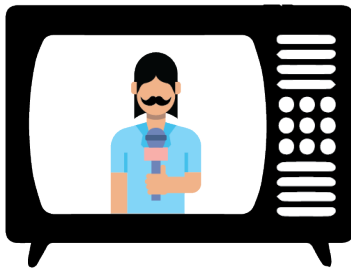


Things started to change in 1972.

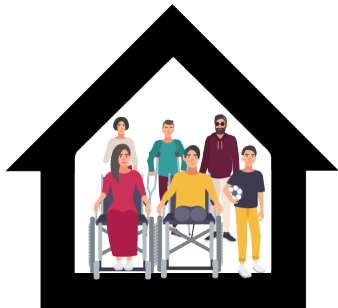




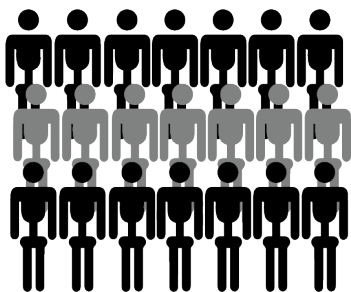
A reporter named Geraldo Rivera took some videos of Willowbrook.



He put the videos on the news.



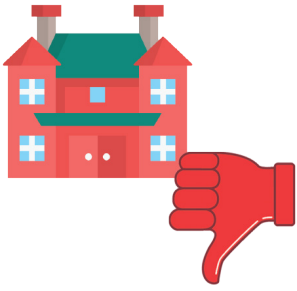
It showed people crowded together in dirty rooms.



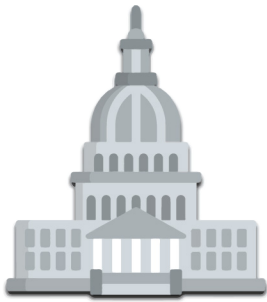
People were starving and very skinny.



Nobody was around to help them.



That is when everyone realized how bad institutions were.



The government decided institutions needed to be changed.

*Support for this toolkit was provided by The Community Living Policy Center at Brandeis University. Funding for this center is provided by the National Institute on Disability, Independent Living, and Rehabilitation Research (grant number 90RTCP0004). However, the contents of this brief do not necessarily represent the policy of the federal government.*



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# The Cycle of Institutions

Part 4:

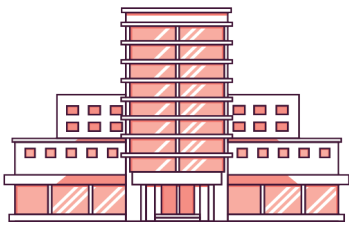
The Second Cycle: ICFs and  
Group Homes

# Words to Know in Part 4



## DD Act

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



## 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.



## Group homes

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

# The Second Cycle: ICFs and Group Homes

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## What rules got made to help institutions get better?



1. =
2. =

The government made rules that institutions needed to follow.



The biggest one was a law called the Developmental Disabilities Act.



We call it the DD Act for short.

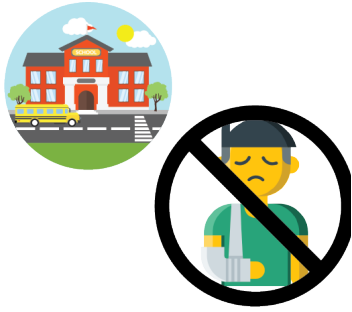


The DD Act got made in 1975.

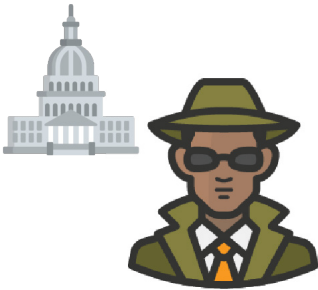




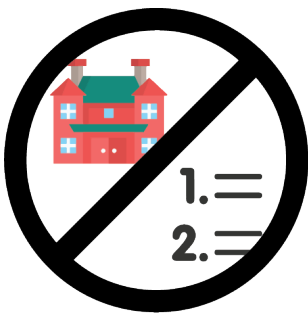
It said that institutions had to try and help people with disabilities.



They have to help us go to school. They aren't allowed to hurt us.



The government also said they would check institutions more.



Many old institutions couldn't follow these rules.



So they got closed down.



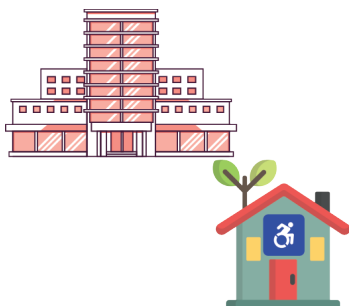
But it was still hard to find help in the community.



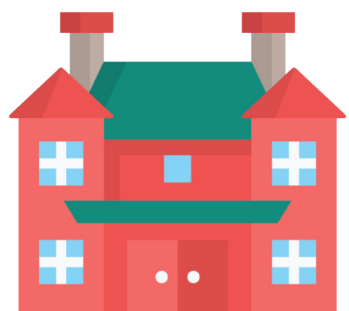
There weren't a lot of places to help people with disabilities.



So new places got made to replace institutions.

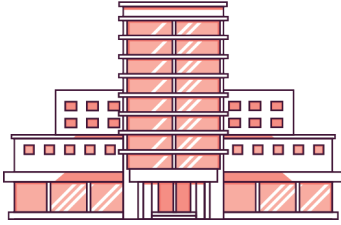


They were called ICFs and group homes.



They looked a little different. But they were still institutions.

## What are ICFs?



**Intermediate care facilities** were one new kind of institution.



We call them **ICFs** for short.



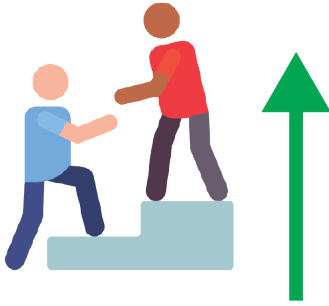
ICFs got made to take care of people with disabilities.



They were for people who need more help with everyday life.



ICFs look a lot like hospitals.



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.



State schools used to have houses just like this.



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.



They 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.



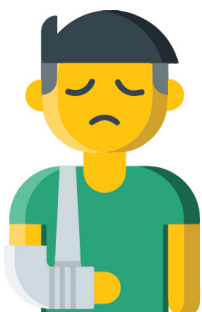
Sometimes, group homes are in houses in the community.



But people with disabilities might not be allowed to go out.



They might not get to 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.



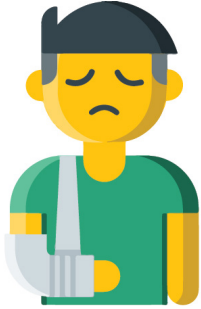
But a lot of ICFs became group homes.



And they both still keep people with disabilities separate from everyone else.



They still don't try to help us live better lives.



They still hurt people with disabilities.



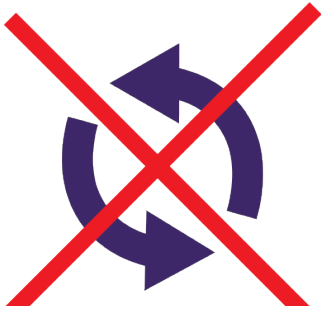
They are still just institutions.



People still sometimes notice how bad ICFs and group homes are.

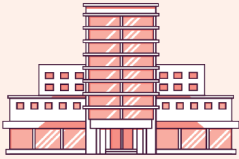


They tell other people about it.

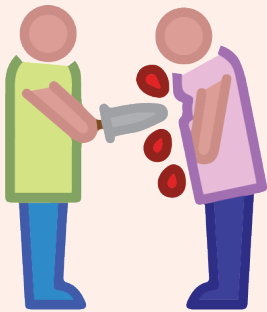


But not much has changed to make these institutions better.

For example:



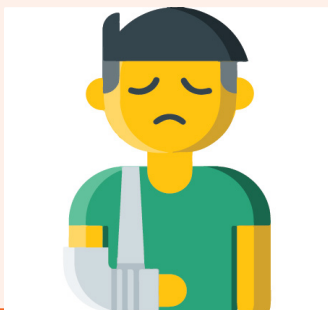
California has some ICFs called developmental centers.



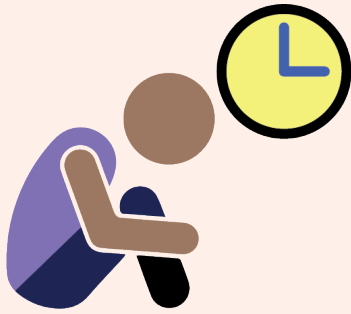
People got killed at the developmental centers.



They didn't get help when they got sick.



They got hurt by staff.



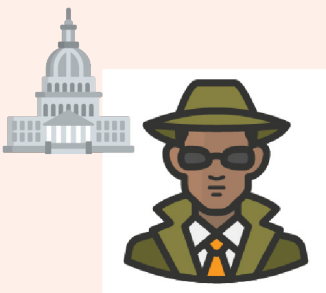
They got left alone for too long and died.



The California government didn't do anything about it for a long time.



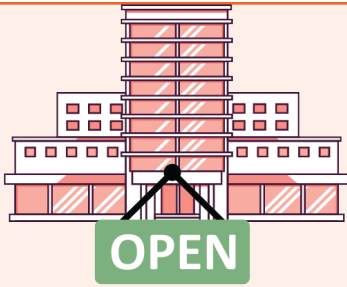
Then, the news talked about it in 2012.



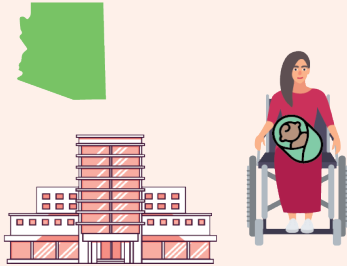
So the government checked the institutions.



They said they would close all the developmental centers.



But some of them are still open today.



In 2019, a disabled woman living in an ICF in Arizona had a baby.



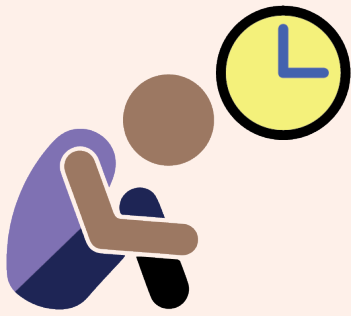
None of the institution staff noticed she was pregnant.



Some of the people living there were covered in bugs.



Nobody helped clean them.



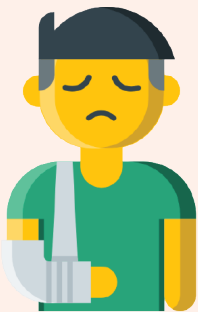
They got left alone for days at a time.



In 2016, a newspaper called the Chicago Tribune wrote about group homes.



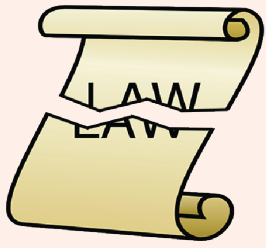
They looked at group homes in Illinois for 5 years



They 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.



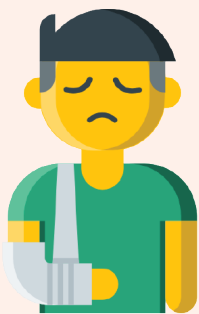
That is against the law, but it happened anyway.



The group homes never got in trouble.



The U.S. government also looked at group homes in 2018.

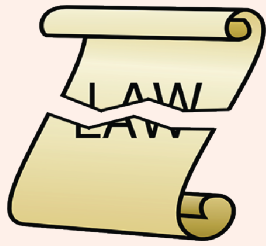


They found out that group homes were hurting people.



And most group homes didn't tell anyone when people got hurt.





That is against the law. But it still happens today.

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# The Cycle of Institutions

Part 5:

The Third Cycle: Intentional  
Communities

# Words to Know in Part 5



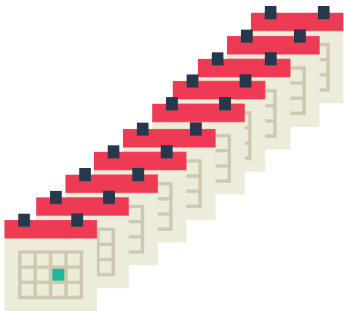
## Intentional Communities

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

# The Third Cycle: Intentional Communities

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## What are Intentional Communities?



In the past 10 years, a new kind of institution showed up.



The people that make them are mostly parents of disabled kids.



They saw how bad ICFs and group homes are.



They want their kids to live in a nicer place.



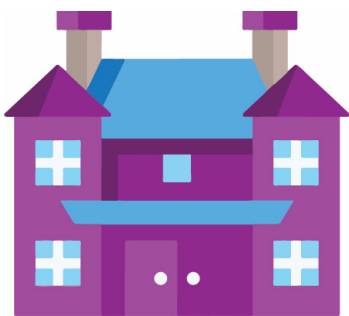
They want their kids to feel like they have a community.



But these parents still think their kids can't live in the community.



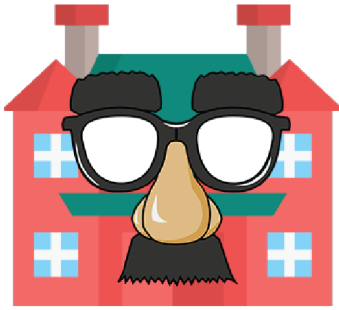
They want their kids to live somewhere just for people with disabilities.



So they built something called "intentional communities"



Intentional communities are a new kind of institution.



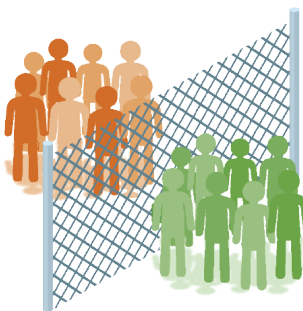
They try to hide that they are institutions.



Some of them try to look like actual communities.



Intentional communities make people with disabilities live together.



They 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.



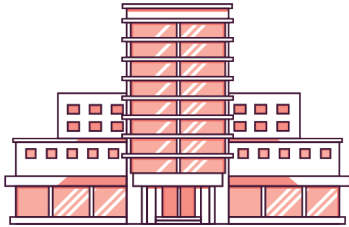
Or it could be on a farm.



Just like state schools.



Or it could be in a big building.



Just like ICFs.



Intentional communities say they will teach us things.



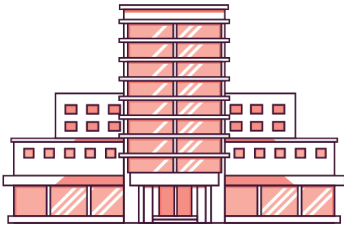
They will teach us how to work.



Just like state schools.



Or they will teach us how to get ready for the community.



Just like ICFs.



Intentional communities are very new.



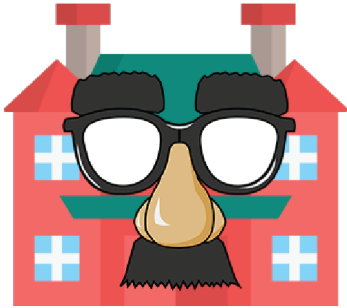
So we don't know too much about them yet.



But we know that they look a lot like group homes.



They look a lot like state schools.



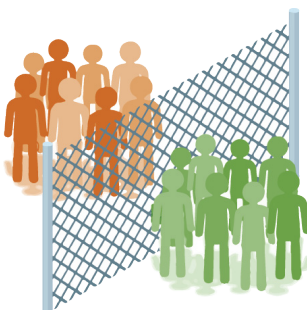
Intentional communities are not real communities.



They are institutions.



State schools, ICFs, and group homes didn't help people with disabilities.



They kept us separate from everyone else.



They thought we needed to be kept separate.



They thought that was what's best for us.



But they didn't help us. They even started hurting us.



Intentional communities will do the same thing.

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# The Cycle of Institutions

To Learn More

1

[Disability History Exhibit.](#) By the State of Alaska Governor's Council on Disability and Special Education.

2

[Farms for Disabled People Aren't A New Idea.](#) By Kit Mead.

3

[Forging a Federal-State Partnership: A History of Federal Developmental Disabilities Policy.](#) By Robert M. Gettings.

4

[Parallels in Time: A History of Developmental Disabilities.](#) By the Minnesota Council on Developmental Disabilities.



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# The Cycle of Institutions

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.



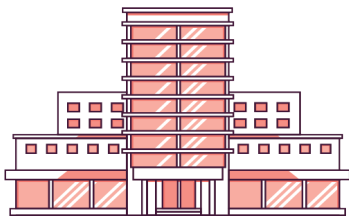
## Institutions

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.

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