



Easy Read Edition

Institutions: **The Old, The New, And What** **We Should Do**

Part 4: Living in the Community: **Important Rules and Laws**

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.



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.



Medicaid

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



HCBS Settings Rule

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



The Americans with Disabilities Act (ADA)

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



Supreme Court

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



Olmstead

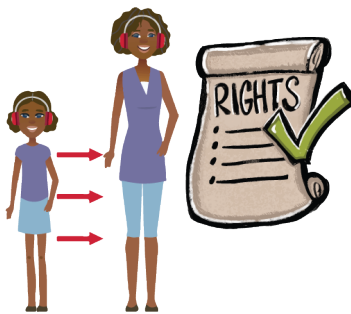
A big court case in 1999. It says that you have a right to live in the community. It says that you don't have to live in an institution.

Living in the Community: Important Rules and Laws

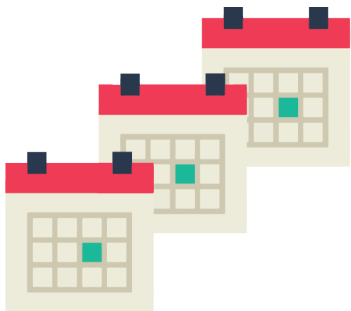
DD Act



The **DD Act** is a law that got made in 1975.



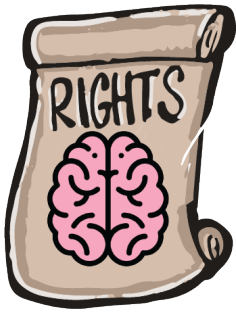
It helps protect the rights of people with developmental disabilities.



It became a law 3 years after people learned about Willowbrook.



It tries to make sure institutions can't hurt people like Willowbrook did



Part of the DD Act is the **Developmental Disability Bill of Rights**.

1 —

2 —

3 —

It lists what rights we have when we get LTSS.



It says that we should get to live the way we want.



It says we should have freedom.



1.=

2.=

It also made rules that institutions have to follow.

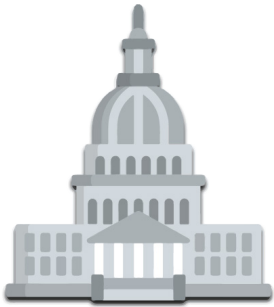


It says that institutions can't get money from the government if they hurt us.

Medicaid and the HCBS Settings Rule



Medicaid is a health care program in the United States.



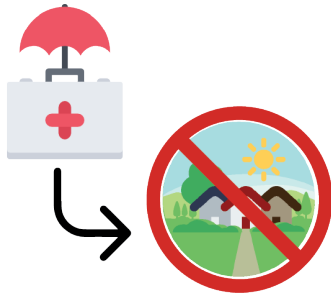
The government runs Medicaid.



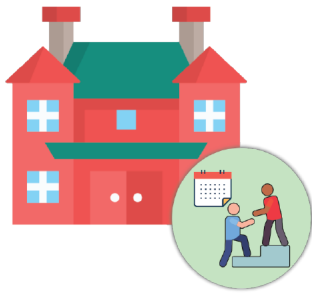
Medicaid helps people with disabilities get health care.



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.



Medicaid wouldn't pay for us to get LTSS in the community.



In the 1970s, more people started trying to live in the community.



They needed LTSS in the community.



They asked Medicaid to help pay.



In 1982, Medicaid started trying to help people live in the community.



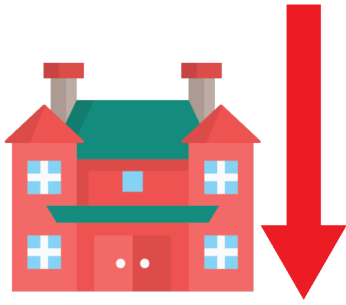
Medicaid set aside some money to give people LTSS in the community.



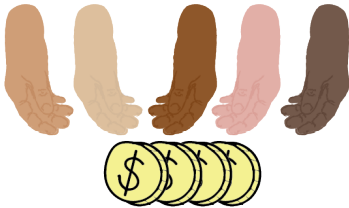
More people got LTSS in the community.



So more and more people got to live in the community.



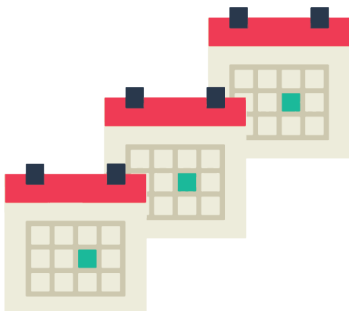
Institutions started getting smaller.



But there wasn't enough money for everyone to get LTSS in the community.



Many people with disabilities got put on waiting lists.



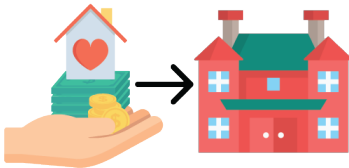
They had to wait years to get LTSS in their communities.



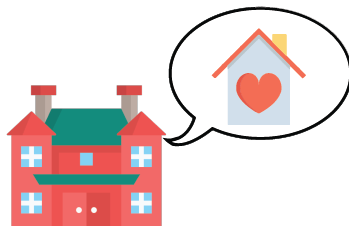
Lots of people are still on waiting lists.



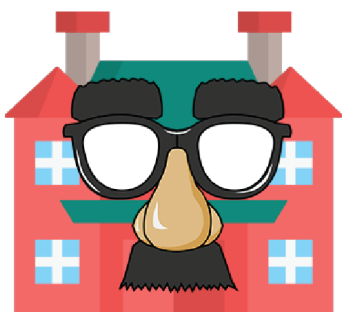
And there was another problem.



Institutions took some of the money
Medicaid set aside.



They said they helped people live in the
community.



But they were lying. They were still
institutions.



Institutions used up some of the money
Medicaid set aside.



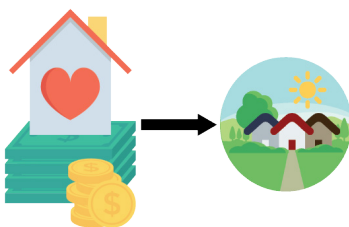
So there was less money to actually help us live in the community.



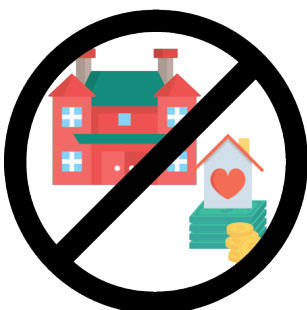
The government wanted to make sure that stopped happening.



They made a rule called the **HCBS Settings Rule**.



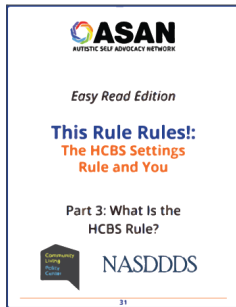
This rule makes sure that Medicaid money only goes to LTSS in the community.



It makes sure institutions can't take money meant for living in the community.



The rule hasn't started working yet. It starts in 2022.



You can learn more by reading the ["This Rule Rules!" Toolkit](#).

The ADA and Olmstead



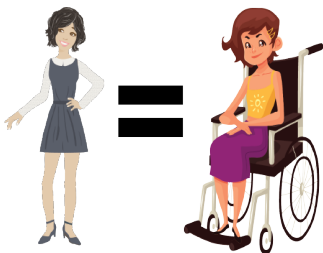
The **Americans with Disabilities Act** is a law that came out in 1990.



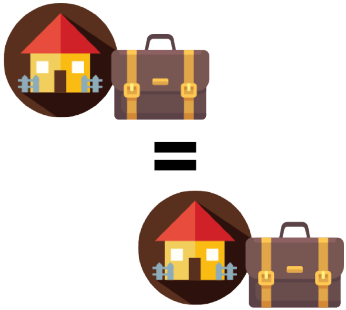
People call it the ADA for short.



The ADA gave people with disabilities rights.



It says we have the same rights as non-disabled people.



It says we have the right to go to the same places as non-disabled people.

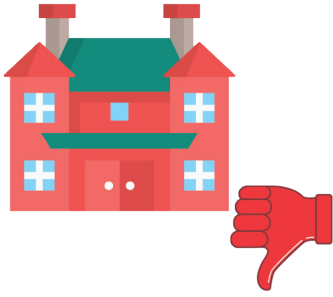


It says we have the right to live and work in the same places as non-disabled people.



In 1999, two women were living in an institution.

Their names were Lois Curtis and Elaine Wilson.



They didn't want to live in an institution.



They wanted to live in the community.



Lois and Elaine said the ADA gave them the right to live in the community.



They fought for their rights from the ADA.



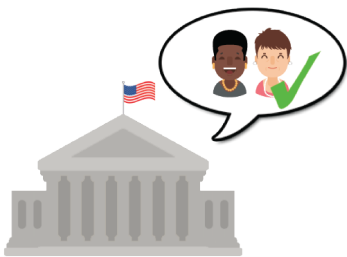
They went to the **Supreme Court** to fight for their rights.



The Supreme Court is the biggest court in the United States.



They have 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.

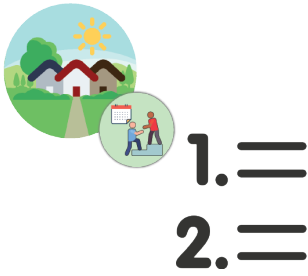


It says that you don't have to live in an institution.



You have the right to get LTSS in the community.

Institutions Today



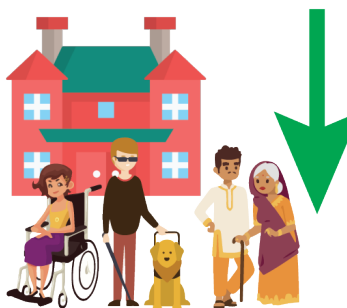
These rules and laws helped us get LTSS in the community.



They helped us move out of institutions.



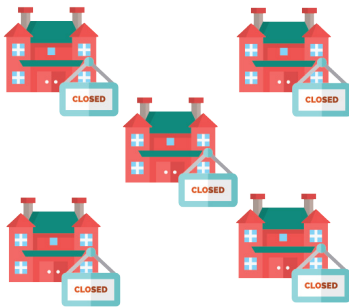
More and more people with disabilities got to live in the community.



So now, less people live in institutions.



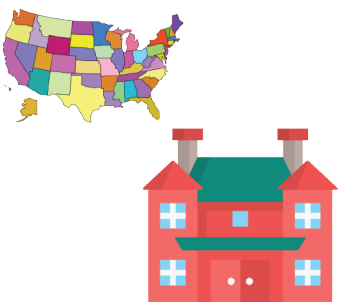
Some states started closing institutions in the 70s and 80s.



In the 90s, some states closed all of their big institutions.



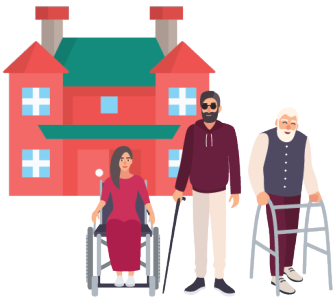
Today, 17 states have no big institutions.



But most states still have at least one.



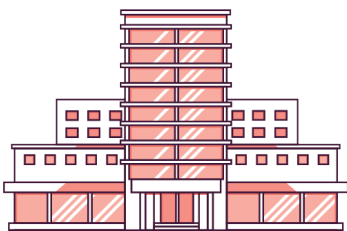
Today, most people with disabilities live in the community.



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.

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