People with intellectual and/or developmental disabilities (IDD) sometimes need help with their everyday lives. They might need help with things like:

- Getting dressed
- Making food
- Going to work
- Keeping a job

When people have help with these things, this is called long-term supports and services (LTSS).

Getting LTSS can be hard. Most people get LTSS paid for by Medicaid. Both the U.S. and state governments pay for Medicaid. But, the governments do not give Medicaid LTSS to everyone. Most people have to be very poor to get Medicaid. It can be confusing to try and get Medicaid. So, many people with disabilities don’t have Medicaid. They may have to wait for a long time for LTSS, even if they need them. Lots of families of people with IDD do not get help from the government. More than 3 million families said they do not get help from state IDD agencies.
People with disabilities want to live in their communities. They do not want to live in institutions. But, Medicaid makes it hard to get LTSS in the community.
Medicaid will give LTSS to people who qualify and live in an institution. But, Medicaid will not always give people LTSS when they want to live in their own homes or in their community.
People may have to wait to get LTSS in their community.
Many have to go on a waiting list.
The Arc talked with families of people with IDD. We found out that 1 in 4 families are stuck on waiting lists.
Some people have been on waiting lists for 10 years.
They are still waiting to get LTSS in their communities.

Some people in the government want to save more money. They want to spend less money on Medicaid. So, they try to change how Medicaid gets paid for. They want to pay for Medicaid with block grants or caps on the amount of money on the U.S. government pays.
Block grants or caps means Medicaid would get less money.
Less people would get Medicaid LTSS.
More people would be put on waiting lists for LTSS. And, the workers who help people with disabilities would be paid less.
All these changes would make it harder for people to get the help they need.