

Autistic Self Advocacy Network's Community Living Summit: **What Does "Living in the Community" Mean?**

To Start

The Autistic Self Advocacy Network (ASAN) is a group of autistic people that works on disability rights. ASAN believes that autistic people should have the same rights as everyone else. We should have the same chances to live, work, play, and be free. One important right ASAN fights for is the right to live in the community.

Living in the community or living in an institution?

We have the right to live in the community. This is one of many rights that we have. For example, we have the right to vote, to take the bus where we want to go, and to speak up about what we want.

Some disabled people live in **institutions** instead of their communities. 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. They usually can't spend their free time how they want to, or decide where to take the bus to. They would get in trouble if they speak up about what they want. When someone lives in an institution, it is much harder to use their rights. When someone lives in their community, it is much easier to use their rights.

Why did we write this paper?

The government decides what counts as “living in the community”, so disabled people need to tell the government what it means to live in the community. If we don’t, the government might get it wrong. We should decide what it means to live in the community so we can let other people know what we think.

ASAN had a **summit** about living in the community. A summit is when a lot of people get together to talk about something. At the summit, autistic people decided what living in the community means to us, and talked about the best ways to help us live in the community.

We wrote this paper to tell people what living in the community means to us.

ASAN's Community Living Summit

The Community Living Policy Center (CLPC) gets money from the government to do studies about living in the community. The CLPC wanted to talk with autistic people to find out what autistic people think about living in the community, so they asked ASAN to do a two-day summit about living in the community.

ASAN had the summit on May 3rd and 4th, 2018. At the summit, autistic people decided what living in the community means to us, and talked about the best ways to help us live in the community.

Ten autistic people came to the summit, and they were very different from each other. They needed different kinds of help to live in the community, they were different races, and had different disabilities besides autism. Two of the people who came could not speak, and used **augmentative and assistive communication (AAC)**. AAC is other ways to talk without speaking, like typing or using a letter board. Two people at the summit had intellectual disabilities.

We also talked with four other autistic people who could not come to the summit in person. These people also had a lot of different needs and ideas.

Self-Advocates Decide What “Community” Means

First, the people at the summit talked about what “community” means. They decided it means: *living in the same places as people without disabilities*. A community can be a neighborhood, town, or city - anywhere that disabled and non-disabled people live together. The self-advocates at the summit didn’t want to be seen as “special”. They wanted to live with everyone else - not in a separate place built for them.

“Intentional Communities” are Institutions

The people at the summit also talked about new institutions. People keep building new institutions, but they call them “**intentional communities**.” These places look like regular neighborhoods, but only disabled people live there. The people living there don’t get to be around non-disabled people. They don’t get to decide what to do each day, and they don’t usually get to go outside their neighborhood. Intentional communities are still institutions, and *self-advocates don’t think that neighborhoods only for disabled people are real communities*.

Parts of Living in the Community

Living in the community is more than just having your own home, or just living together with non-disabled people. People at the summit came up with seven big parts of living in the community. These seven parts were:

- **Freedom**
- **Helping each other**
- **Making money**
- **Paid helpers**
- **Unpaid helpers**
- **Finding people and things you like**
- **Being a part of the community**

Freedom

Self-advocates at the summit talked a lot about freedom. They wanted to make choices about their own lives, and freedom means being able to make your own choices. It is also choosing the risks you will take, since freedom means being able to make mistakes. Part of being an adult is making decisions, and sometimes that means mistakes happen. Living in the community means people treat you like an adult, and not like a child. Being treated like a child is not giving us freedom, so it is not living in the community.

Freedom means being able to make *all* choices, not just some. People at the summit talked about how making every choice in your life is important. We have to be able to make every choice every day. Real freedom means *real* choices - both small choices *and* big choices.

For example:

You can choose to eat your cereal with milk or without milk. This is a small choice.

You can choose to move to another city, or stay where you are. This is a big choice.

A lot of institutions say that disabled people living there have choices, but they only have small choices. People in institutions don't have the freedom to make big choices.

Freedom means that you can choose not to do things. You can choose to stay inside, even if other people are going out. You can choose to be by yourself if you want to be.

Someone at the summit gave a good example of this:

Most people in Janet's house want to go to the movies, but Janet does not want to go. In an institution, everyone would have to go, and Janet is forced to go to the movies. In the community, Janet could stay home in pajamas instead.

People shouldn't have less freedom because they need more help. What counts as living in the community should be the same for everyone. The rules shouldn't be different if someone needs more help. Everyone has the right to freedom and to live in the community.

Helping each other

Having freedom is not the same as not needing any help from other people. Helping each other is an important part of living in the community. We all need help from other people, whether or not someone has a disability.

Most people need help with something every day, and get help from friends and family members. We also get a lot of help from people we don't know. We buy food that other people grew. We buy clothes that other people made.

Disabled people may need help with things that other people don't. We should get the help we need, and we can also help others. It's okay to need help, and we shouldn't have to do everything "on our own" to live in the community.

One person we talked to shared a story about this. We'll call this person Sam.

Sam needed help with some chores around the house, like cooking. Sam had a paid helper, but Sam's helper wouldn't do the chores for them. The helper would only tell Sam how to do the chores, and said Sam needed to do the chores on their own. This made it really hard for Sam to live on their own!

It is bad when people tell us that we have to do everything on our own, and can be just as bad as when people say we can't do anything on our own. Both ideas make it hard for us to live in the community. Living in the community means getting the help you need. It doesn't mean doing everything on your own, and it doesn't mean doing nothing on your own.

Getting Help

People are more likely to get help if they have a lot of people they can ask. We should be able to ask for help from people in the community, and live near friends and family that can help us. But friends and family can't do everything for us on their own. For example, if your parents get older, they may not be able to help as much. You might not have a family or friends right now, or have someone that can help you all the time.

You might need help with something your family can't do.

Example: Molly needs help getting into her wheelchair, since her mom hurt her back and can't do it safely. Molly gets a paid helper who has a strong back. She has been to classes about how to pick people up safely. Now Molly can get into her wheelchair, and her mom's back is better.

Having paid helpers is important, and living in the community means having the paid helpers we need. Living in the community means we choose who we pay to help us. There are government programs to help people hire helpers, but the programs can be confusing. The government should make it easier to get helpers.

Making Money

We can't live in the community without money. We need money to buy food, to take the bus, and get a good place to live. Most people make money by getting a good job. A good job helps people be a part of their community. You usually work with other people and businesses while doing a job, so working is an important part of living in the community.

We talked with someone who told us about her job:

She said her job changed her life, since before her job, she didn't have a lot of money. She couldn't pay for the kind of food she liked, and she couldn't pay for a good place to live that was near a grocery store. She got a job, and then she could move to a better place to live. She could also eat the foods she wanted to.

We should be able to get good jobs in the community if we want them. Some of us can't work enough to pay for everything we need, and that's okay. You shouldn't have to work to live in the community. There are government programs to help, but some of these programs have problems.

One program is called **Medicaid**, which pays for people to have helpers. But most people can only get Medicaid if they are very poor. It is hard to live in the community if you are very poor, but many people can't pay for helpers without Medicaid. Lots of disabled people have to choose between making money or having helpers. We think disabled people should not have to make that choice. We think the government should make it easier for disabled people to pay for what we need.

Finding people you like

Living in the community means meeting new people. It means having the chance to make new friends or fall in love. We should be able to hang out with whoever we want, and no one should tell us who we can and can't talk to.

Sometimes, helpers will try to choose which people we can see. They may not let two married people with disabilities live together, or they won't let a disabled person see a friend. This make it harder to live in the community. We should be able to date, have sex, get married, and have kids if we want to. Everyone makes choices about love and family, and we should be free to make those choices too.

Going Where You Want

You should *always* be able to leave your house when you want to. You should be able to go anywhere people without disabilities go. If you like video games, you should be able to go to the arcade, and if you like books, you should be able to go to the library.

Helpers shouldn't try to stop you just because they don't want you to go. For example, you might get hungry late at night.

You could decide to go to a burger place that is always open. Your helper shouldn't stop you just because they think it's too late, or just because they think burgers are bad for you. Your helper's job is to help you. You decide where to go.

If you need help to go out, a helper should always be there to go with you. You should be able to have your helper work at night if you need them, and your helper should always be ready to go out with you. If you can't go out when you want, then you aren't really living in the community.

Not everyone wants to go out all the time. We should be able to choose to stay home if we want to. We should be able to choose not to have helpers if we don't want them.

Everyone has different ways they live in the community, but how we live in the community should always be our choice.

Putting it all Together: What is Living in the Community?

"Living in the community" means a lot of things, and it is not something we can explain in one sentence.

"Living in the community" means living in the same places as people without disabilities.

Living in the community means freedom, and being able to make our own choices. We need to be able to make real choices, and not just small choices like what color shirt to wear. We need to be able to make big choices, about things like our job or where we live. We need to be able to make choices all the time, not just once. We should make our own choices every day.

Living in the community means getting help when we need it, and helping each other.

We get help from the people we care about, and the people we care about get help from us, too. Every disabled person knows themselves best - we know what kind of help we need to live in the community. Nobody should force us to get help we don't want, or force us to do anything just because we need help.

Living in the community means being with people we care about, and getting the chance to meet new people. We choose the friends we make and the family we see.

We take care of each other when we live in the community together.

Sometimes, we need help from paid helpers. Paid helpers should be there when we need them. Having paid helpers is part of living in the community. We should have the money we need to pay for them, and we shouldn't have to use all our money to pay for helpers. This is part of our right to live in the community.

Living in the community means having money to pay for the things we need. We can get money from a job, or help from the government.

Living in the community means being able to go out when you want to. You can go to the store, the gym, a museum, or wherever you want. You can also choose to stay home if you want to.

Living in the community means being able to take risks and make mistakes.

It means being treated like an adult.

Living in the community lets **you** decide what you do, and who you will become.

Last Thoughts

Autistic self-advocates have a lot to say about living in the community, and we hope this paper shows what living in the community means to us. It's important to listen to self-advocates. We want to live good lives and make our own choices, just like everyone else. You can help us live in the community by listening to us.

Words to Know

Augmentative and Alternative Communication (AAC)

Ways to talk without speaking, like typing or using a letter board.

Institutions

Places where a lot of disabled people live. People living in institutions usually did not decide to live there. They were usually put there by someone else.

Intentional Communities

Institutions that look like regular neighborhoods, but only disabled people live there. The people living there don't get to be around non-disabled people.

Living in the community

When disabled people have our own places to live, that we control. Living in the community means we live and work in the same places as everyone else.

When we live in the community, we aren't kept apart from people without disabilities.

Medicaid

A program the government made to help disabled people. Medicaid gives people services. It also gives people health care.

Summit

When people get together to talk about something.

To Learn More

To learn more about Medicaid, look at ASAN's Medicaid Toolkit at <https://autisticadvocacy.org/policy/toolkits/medicaid/>

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