

# Autistic Self Advocacy Network's Community Living Summit: **What Autism Researchers Should Study**

## Introduction

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### **What is ASAN?**

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.

### **What is Living in the Community?**

**Living in the community** is 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, and we aren't kept apart from people without disabilities.

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. If we don't live in the community, it makes it harder for us to use our other rights.

We say more about [what "living in the community" means here](#).

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## ***What are institutions?***

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.

## ***How can studies help us live in the community?***

We face a lot of problems when we fight for our right to live in the community. One problem is that **researchers** do not know a lot about autistic people. Many researchers do not know what life is like for autistic adults, because they have not spent time studying what life is like for us.

The government makes programs to help autistic people, and researchers help the government pick which programs to make. The government pays for **services** for autistic adults, and uses studies to decide which services to pay for. If researchers knew more about autistic adults, it would help the government make better programs and services.

The government wants to know more about autism, so it put together a group called the **Interagency Autism Coordinating Committee (IACC)**. The IACC keeps track of studies about autism. The IACC found out that there is not a lot of money for studies about services. *Only 2%* of all money for autism studies goes to studying services. Another 2%

of money goes to studying what life is like for autistic adults. Most of the money goes to studying why people are autistic, or how to get rid of autism - not to studies that find out how to help autistic people. That makes it harder for us to live in the community.

The government gives money to programs that help autistic adults, but the government does not know how many autistic adults there are. The government counts autistic kids, but they don't count autistic adults. It's a problem that the government doesn't know how many autistic adults there are, because they don't know how much money to give to help us. If the government doesn't give enough money, autistic people may not get the help we need.

There are not a lot of studies about what kind of services autistic adults need. There are programs that are supposed to help autistic adults, like **Medicaid**, which give us services (for example, help with cooking or other daily tasks). Medicaid needs to know more about what services help autistic adults, so they can get better at helping us. Programs like Medicaid will have trouble helping us if they don't know about us.

We also need to know how to support autistic people with different needs. For example, we need to know what is the best way to support people who do not talk. No one has studied this yet.

We want to make sure people who do not talk get everything they need to live in the community, but it's harder to do this when no one has studied what they need.

But autistic people know a lot about autism. We know what we need, what our lives are like, and what will help. Autism researchers should work with autistic people, so we can tell them what we need and what would help us. This will make the studies better.

We already know this works because of a group called the **Patient Centered Outcomes Research Institute (PCORI)**. The government put this group together to make sure that researchers talk

to people. PCORI found out that when researchers talk to people, their studies get better.

For example, researchers talked to people with heart problems, and asked them what they wanted. When the researchers learned what people with heart problems want, they got better at studying heart problems. Now their studies are more helpful to people with heart problems.

If autism researchers talked to autistic people, it could make autism studies better. We could learn ways to help people live in the community.

# ASAN's Community Living Summit

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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. CLPC asked ASAN to do a **summit** about living in the community. A summit is when people get together to talk about something.

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.

# About The Research Questions

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During the community living summit, ASAN came up with lots of questions about studying autism and living in the community. The people at the summit came up with most of the questions.

After the summit, ASAN thought about what they said, then came up with some more questions.

The questions don't have easy answers. People who study autism should think more about these questions, so they can find answers to these questions. They can talk to people about what they learned, and help make programs that work better for autistic people.

We came up with seven big questions:

1. How can we help autistic people live in the community?
2. What is the autistic community like?
3. How should we study autism?
4. How can we help autistic people stay on track?
5. Where should autistic people live?
6. How can we help autistic people communicate?
7. How can we help autistic people be free and safe in the community?

All the questions on this list are very important to autistic people. They are questions about autism that have not been studied a lot, and some have not been studied at all. Our list is a good start for autism researchers who want to work with autistic people. Together, we can help more autistic people live in the community be free, and have better lives.

# Research Questions

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## *How can we help autistic people live in the community?*

- **How do we help autistic people when we get older?** Right now there aren't good programs that help older autistic people. How can we make sure autistic people can get help no matter what age we are? What if what we need changes when we get older?
- **How should we support people who hurt themselves?**
- **How should we support people who hurt other people?**
- We know about some good ways to support people. For example, some people use **microboards**. A microboard is a group of people someone knows and trusts, that helps them control their services. Good ways to help, like microboards, can take a lot of time, money and friends. **What if someone doesn't have enough time, money, or friends? Can we make the same things happen for them?**
- **What are the best ways to use supported decision-making?** **Supported decision-making** is when disabled people get help to make our own choices. When should we use supported decision-making? Can paid helpers ever help with supported decision-making? How can supported-decision making work the best for each person?
- How can helpers make sure autistic people are free to make our own choices? What if the helper doesn't like the choice?
- **What makes someone a good helper?** What do good helpers have in common? How can we tell if someone is a good helper?

- Autistic people need to be in charge of our own helpers. **How do we know if someone is in charge of their helpers?**
- Sometimes helpers try to control us. For example, a helper might try to tell us what to eat. **What makes helpers try to control us?**
- **How can we stop helpers from controlling people?** Can we teach them to stop controlling people? Would it help if we made new rules for helpers? Do we need to make big changes to the way people get services?
- **What can we learn from other countries about how to help autistic people?**
- **Does making your own choices make your life better?** Does it make you healthier?
- **How can we help autistic kids grow up to make their own choices?** For example, is it easier to make your own choices if you have always felt good about yourself?
- It's good when autistic people can help *each other*. **How are we already doing this?** How can we help more autistic people help each other?



## *What is the autistic community like?*

- **How many** autistic adults are there? **What** are autistic adults like?
  - What do we need help with?
  - What ages are we?
  - What races are we?
  - How much money do we have?

### **Can we find out all of these things at the same time?**

- Some people have a hard time getting what they need to be healthy. For example, it's hard to be healthy if you don't have somewhere to live, if people are mean to you, or if you can't get to the doctor. Autistic people can have trouble with all of these things. **How does this hurt our health?**

## *How should we study autism?*

- **How do we figure out which studies help autistic people?**
- There are lots of different kinds of autistic people. Some autistic people talk, and some autistic people don't talk. Some autistic people have intellectual disabilities, and some autistic people don't. **How do we make sure that all autistic people can understand autism studies?** Should there be easy-to-read study papers? What would these papers have in them?
- **How can we make sure that autistic people and autism researchers work together?**
- **How do we help autistic people study autism ourselves?**

## *How can we help autistic people stay on track?*

- Autistic people sometimes need help to stay on track. Staying on track means things like: following a plan, starting something new, stopping what you are doing, remembering what to do next, and moving on to the next thing. **What are good kinds of help for staying on track?** How can we make sure people know about good kinds of help?
- **Different things help different people stay on track. Why?**
- **What apps can help autistic people stay on track? Apps** are programs on a computer or iPad. There are lots of different kinds of apps. People use apps to make lists, read maps, set alarms, and so much more!
- There are lots of different ways an app could help autistic people stay on track. For example, the app could talk to the person, text them, show them a picture, vibrate, make a sound, or do other things. It could also do all of these things at once. How many different ways are there? **Will different ways be more helpful for different people?**
- Can we make one app that does everything someone needs? **Can apps do the same jobs helpers do?**

## ***Where should autistic people live?***

- Some people get labeled because of their disability. For example:
  - Sheila does not have a disability. Sheila has a bad day, and yells at her sister. People say, “Sheila was being mean today.”
  - Renee has a disability. Renee has a bad day, and yells at her sister. People say, “Renee is aggressive.”

**How do these labels change where someone lives?** Is Renee more likely to get sent to an institution?

- **Do autistic people usually live in the same place our whole lives?** How often do we move to other places? How often do we move to places that give us more freedom? How often do we move to places that give us less freedom?
- We know that a home needs a ramp to be accessible to wheelchair users. **What makes a home accessible for an autistic person?** Can we make a list of rules for what an accessible home looks like?

## ***How can we help autistic people communicate?***

Communication means telling people what you want and need. There are lots of ways to communicate, like talking, pointing, moving around, or making faces. Communication is very important for living in the community.

- **How can we make sure all autistic people have a way to communicate?**
- Sometimes, an autistic person will communicate by doing something. For example, someone might cover their ears if it's too loud. **How do we help others understand that?**
- Augmentative and Alternative Communication (AAC) are tools for autistic people who can't speak. Some types of AAC are typing on a computer, pushing buttons on an iPad, pointing to letters or pictures on a board, or using sign language. **What kinds of AAC work best?** Do different kinds of AAC work better for different people?
- **How can we help more people get AAC?**

## *How can we help autistic people be free and safe in the community?*

- Sometimes, unsafe things happen no matter how hard we try. We want autistic people to be free and safe at the same time. **How do we protect our freedom without giving up too much safety?**
- Sometimes, helpers will get blamed for unsafe things happening, and might take away our freedom to try and keep us safe. **How do we show helpers that freedom is very important?** Will it help if we make sure that helpers don't get blamed for every unsafe thing?
- Sometimes people hurt us. **How do we make sure autistic people won't get hurt, but can still be free?**
- Each state has a group called Adult Protective Services, that works to stop people from getting hurt. **What should Adult Protective Services know about autistic people?**

# Words to Know

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## **accessible**

When something is made in a way that works for disabled people. For example, a building with a ramp would be accessible for someone in a wheelchair.

## **apps**

Programs on a computer or iPad. There are lots of different kinds of apps. They can help people with disabilities in many ways.

## **Augmentative and Alternative Communication (AAC)**

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

## **communication**

Telling people what you want and need.

## **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.

## **Interagency Autism Coordinating Committee (IACC)**

A government group that keeps track of studies about autism.

## **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.

## **microboard**

A group of people someone knows and trusts. The microboard helps the person make decisions about their services.

## **Patient Centered Outcomes Research Institute (PCORI)**

A government group that works to make sure that researchers talk to people.

## **researchers**

People whose job is to study something and write papers about it.

## services

Things or programs that help disabled people live our lives. Some kinds of services are:

- Job training
- Paid helpers
- Help with cooking or shopping

## summit

When people get together to talk about something.



## To Learn More

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To learn more about IACC and what they found out about autism studies, go to

[https://iacc.hhs.gov/publications/portfolio-analysis/2015/portfolio\\_analysis\\_2015.pdf](https://iacc.hhs.gov/publications/portfolio-analysis/2015/portfolio_analysis_2015.pdf)

To learn more about what PCORI does, go to

<https://www.pcori.org/research-in-action>

To learn more about PCORI's study of people with heart problems, go to

<https://www.pcori.org/research-in-action/less-invasive-way-replace-heart-valve-newer-better>