



Plain Language Edition

The “profound autism” label hurts autistic people

*This toolkit was made possible with support from
The International Council on Development and Learning (ICDL)*



Words To Know

Communication disabilities

- Disabilities that make it hard to talk, write, or understand language. Non-speaking people have communication disabilities.

Diagnostic and Statistical Manual of Mental Disorders (DSM)

- A book that has a list of signs of certain disabilities. Doctors use this book to help decide whether or not someone has a disability.

Functioning labels

- A wrong idea about how autistic people work. Functioning labels are words that try and show different “types” of autism. “High functioning” and “low functioning” are examples of functioning labels.

Guardianship

- When someone else makes legal decisions for a disabled person. A court chooses someone, usually a parent, to be a guardian.

Home- and community-based services (HCBS)

- Services that help disabled people get the everyday support they need in their own homes.

IACC

- A group of people chosen by the government. The IACC helps decide what autism research the government will pay for. IACC stands for “Interagency Autism Coordinating Committee”.

Intellectual disabilities

- Disabilities that make it harder to learn or do everyday tasks. Intellectual disabilities are called “ID” for short.

Institutions

- Places only disabled people live. People do not get to control their own lives in an institution.

Masking

- Being able to hide that you are autistic.

Profound autism

- A new kind of functioning label. It says that autistic people with many support needs have a different kind of autism than people with less support needs.

What is this toolkit about?

This toolkit talks about autistic community history. It shares some problems that happened before, and how they are happening again now. These problems were about an idea called functioning labels.

This toolkit talks about a new functioning label some people started using recently. This new functioning label is called “profound autism”. We will talk about how the “profound autism” label hurts people. We will also talk about how you can advocate against the “profound autism” label.

What are functioning labels? Why are functioning labels bad?

Functioning labels are a wrong idea about how autistic people work. Functioning labels are words that try and show different “types” of autism, such as:

- “High functioning”
- “Low functioning”
- “Mild autism”
- “Moderate autism”
- “Severe autism”
- “Classic Autism”
- “Asperger’s Syndrome”

Autistic people who act more like non-autistic people get called “high functioning”. Autistic people that can not hide being autistic get called “low functioning”.

Functioning labels don’t help autistic people get what we need. They don’t show how autistic people need help with different things. Functioning labels hurt us. Someone might say autistic people shouldn’t get help if we are low functioning. Or, they might say we don’t need help if we are high functioning.

People called low functioning are treated like we cannot make our own choices. We are spoken over. We are treated badly because we are seen as less “normal”. We are treated badly because we get seen as “the most disabled”.

For example:

Alyssa is autistic, and uses an app on a tablet to talk. Alyssa flaps her hands a lot in public. A lot of people look at Alyssa and know she is autistic. Functioning labels say this means she is “low functioning”. This changes how people treat Alyssa.

People think Alyssa is not smart. They think because she is not smart that she can’t make her own choices. People in public try to talk to Alyssa’s mother or friends instead of her. Alyssa is treated like her ideas about her own life do not matter. This is not okay.

Masking means being able to hide that you are autistic. For autistic people who can mask, the label “high functioning” causes problems. It makes people make bad guesses about our needs. It makes people think we are lying when we ask for help. Seeming “less autistic” based on functioning labels can make getting help we need harder.

For example:

Roger is autistic, and can mask. People usually do not know Roger is autistic right away. Functioning labels say this means he is “high functioning”. This changes how people treat Roger.

Roger has a hard time getting and keeping jobs. He asks a government job program for help. But the program thinks Roger does not actually need help. They don’t believe Roger when he says he needs help. This is not okay.

Functioning labels say that the “less autistic” you look or act, the less help you need. These labels assume that doing some things without help means you can do everything without help. They assume needing help in one way always means you need help with everything else.

This is not how autism works. Functioning labels make these guesses because the people who created functioning labels did not understand autism. Autistic people can need more or less help with lots of different things, like:

- Communication (like using a tablet, or a spelling board & partner)
- Other health conditions (like seizures)
- Self-care (like cooking or showering)
- Home care (like cleaning or home repairs)

Needing help in one way does not mean you need help in all of them. There is not a simple line from “more” autistic to “less” autistic. Autistic people all have our own specific sets of needs. It does not help us to make guesses about what our needs are. It helps us to ask what our needs are. It helps to give us services for the needs we actually have.

Functioning labels are a bad idea. Functioning labels hurt all autistic people. They are a way to avoid listening to autistic people’s actual, specific needs.

Studies show functioning labels are wrong and not helpful. Many people in the autistic community also already know functioning labels are wrong. We worked very hard to make the idea of functioning labels less popular.

But now some people are trying to make functioning labels come back with a new name. This new name for “low functioning autism” is “profound autism”. It makes the same bad guesses about autistic people’s needs as “low functioning” autism.

What is “profound autism”?

Profound autism is a new kind of functioning label. It says that autistic people with many support needs have a different kind of autism than people with less support needs. Some people say that profound autism is a different type of autism, separate from everyone else.

Different groups mean different things when they say “profound autism”:

- The Lancet is a research journal that publishes health research. They came up with the label “profound autism” in 2021. They said profound autism means having both a communication disability and intellectual disability.
 - **Communication disabilities** are disabilities that make it hard to talk, write, or understand language. Non-speaking people have communication disabilities.
 - **Intellectual disabilities** are disabilities that make it harder to learn or do everyday tasks. Intellectual disabilities are called “ID” for short.
- In 2025, a conference of autism researchers added more to what The Lancet said. These researchers said profound autism meant people who could not safely be by themselves. They also said people could only be called profoundly autistic if they were over 8 years old.
- A government group called the IACC talked about profound autism in 2026. They said that profoundly autistic people are people with communication disabilities, and people who could not safely be by themselves. They did not say people with ID are part of the “profound autism” label. We will talk more about the IACC later in this toolkit.

These ideas are exactly what some people said about “low functioning” autism years ago. The idea that there is a clean line between being “more” or “less” autistic is wrong. It tries to make autism simpler than it is.

Labeling people as having profound autism makes the same mistake as functioning labels. It makes guesses about how our needs are grouped together instead of asking us. It causes the same problems with treating autistic people with more support needs very badly.

This way of thinking does not help autistic people get the support we need. It is a way to avoid listening to what each of us needs.

Why did people start using the “profound autism” label?

Autistic people have advocated against functioning labels for many years. They got many people to stop using functioning labels. People started using the words “autism spectrum disorder” to talk about all autistic people.

But other people were not happy about this change. Some parents of autistic kids with many support needs got worried. They worried that without functioning labels, other people would not understand their child’s needs.

These parents worked together with some doctors and researchers. They came up with the label “profound autism” to talk about their kids. Now, these groups work together to try and make people start saying “profound autism”.

How does the “profound autism” label hurt autistic people?

The idea of profound autism hurts autistic people in lots of ways. A lot of these problems happen because people don’t agree on what profound autism means. Other problems happen because of how the “profound autism” label makes others feel about autistic people.

Profound autism makes it easier to take away someone’s rights

“Profound autism” is a label that gets put on autistic people with many support needs. Some people believe that if someone has too many support needs, they should not have rights. People could decide that nobody with the profound autism label should have certain rights.

For example, people with the “profound autism” label could get put into institutions more easily. **Institutions** are places only disabled people live. People do not get to control their own lives in an institution. Nobody should have to live in an institution.

Using the “profound autism” label could also make it easier to force autistic people into guardianship. **Guardianship** is when someone else makes legal decisions for a disabled person. A court chooses someone, usually a parent, to be a guardian. Everyone should get to make their own choices, but guardianship stops people from having a say in their own lives.

Profound autism hurts people with ID

Many autistic people also have intellectual disabilities. Some people think everyone with profound autism must have an ID. Other people think ID is a completely separate thing from profound autism. They think nobody with ID should be labeled with “profound autism”.

It does not help to say all autistic people with ID have profound autism. This leads to people not listening to autistic people with ID. Instead, they make bad guesses about what autistic people who have ID can and cannot do. They treat people with autism and ID like they cannot make their own choices because they need lots of help. This is unfair.

Autism and ID are two different things. Autistic people with and without ID have different needs. If profound autism means labeling these two disabilities together as one thing, it would be bad. People would not get the right support for their disabilities.

But it is also bad to leave people with ID out when talking about profound autism. It means that when people talk about support needs, they won’t think about what autistic people with ID need. More and more research is happening that talks about profound autism. People with ID could get left out of autism research.

People of color also get labeled as having an ID more than white people. People of color are already left out of a lot of autism research. If “profound autism” means people without ID, people of color could get left out of autism research even more.

Profound autism makes it even harder for autistic people to get their needs met

Some people think using the “profound autism” label will help autistic people get more services. But this is not true. Making a profound autism label separates autistic people with higher support needs from the rest of the community. Separating people with higher support needs makes it easier for people to hurt them or take away their rights. When someone gets labeled with “profound autism”, people stop looking for other reasons for how someone feels and acts.

For example:

Dev is a non-speaking autistic person. Their parents say Dev has profound autism.

Dev starts getting very bad headaches. They don't have an easy way to communicate this to their parents. Dev grabs their head and bangs it against the wall whenever they get headaches.

Dev's parents and doctors don't try to figure out why Dev is acting this way. Instead, they say it is just a part of Dev's profound autism. That means Dev never gets help for their headaches.

Labeling someone with profound autism makes it harder for them to get services and supports. People might think the problems that “profoundly autistic” people have can't be solved. They might think there is no point in trying to help because profoundly autistic people are “too disabled”. This makes it harder for autistic people:

- In school
- At jobs
- To get good health care
- To stay in the community

- In many more places and situations

Using the label “profound autism” could also be bad for autistic people who don’t get that label. The government could decide that only people with profound autism can get services. Some autistic people with higher support needs might not fit into the “profound autism” label. They could have more trouble getting the services they need.

Many autistic people with high support needs don’t get enough services. That is not because other autistic people are getting services. And it is not because autistic people are getting services they don’t need. It is because the government is not giving enough money to support autistic people. Taking services away from some autistic people will not help other autistic people.

Profound autism takes advantage of people who want to help autistic people

Sometimes people who are trying to be helpful will use the wrong words. Sometimes people do not understand why some ideas are harmful. This is true about profound autism, too.

People who use the “profound autism” label want their ideas to be normal. They want other people to believe what they believe. Getting other people to believe what you believe is the goal of any advocate.

Some people who use the “profound autism” label say they believe in disability rights. They try to make it seem like saying profound autism will help disability rights. For example, they might say “Using the profound autism label will help support people who need the most help.” Some autistic people have even started saying they have profound autism.

Some people really believe using the “profound autism” label will help autistic people. Others just use disability rights language to convince more people the “profound autism” label is right. They might say they are our allies. They might have worked with us on important issues before. But that does not mean saying profound autism is the right thing to do.

Autistic people with a lot of support needs usually do not get the help they need to live their best lives. Many people who use the “profound autism” label are frustrated. They see that autistic people with higher support needs have not been able to get the care they need. Their family members and caregivers feel alone. They feel like nobody is listening. They think that making a “profound autism” label will make people pay attention to their needs.

But the people who want to split the autistic community are not doing it to help autistic people. They are doing it because of what they believe about our rights. They think that “profoundly autistic” people are too disabled to have rights. And they think “not profoundly autistic” people are not disabled enough to get the services and supports they need.

Profound autism makes people pity autistic people who need lots of help

Another problem is that people think profound autism means “the most disabled”. They think everyone with profound autism is part of a big group of people who need pity. People give disabled people a lot of pity in general. That means people who are “more disabled” are treated with more pity. Pity is bad because it means people think you aren’t able to do anything. It means people are sad that you exist. It means people think you live a sad life.

But this is not true. Disabled people have problems just like everyone. But we can be happy too. We can make choices. We can do things, even if sometimes the way we do them is different. We can do things even if we need help to do things. It is okay for us to need help.

Being treated with more pity gives you less power. It takes away the chance for you to make choices. That is why it is bad to treat people with pity. It is bad to treat people who need lots of support with pity.

Profound autism makes autism research and policy worse

Some researchers are trying to say autism research should focus on profound

autism. This is a bad idea because it isn't a good way to separate autistic people in research. There is no proof that profound autism is any different from other kinds of autism. That makes it harder to do good research.

For example:

Janet wants to understand if there are other disabilities that lots of autistic people have. She has talked to other autistic people who are curious about this. Janet has lots of autistic people fill out a survey about what other disabilities they have. She starts by grouping certain autistic people together to see what they have in common.

Janet let people choose on her survey if they have "profound autism". She looks only at people who mark themselves as having "profound autism". But she does not see a lot in common between those people. She realizes that different people have different ideas about what profound autism means. She decides questions about profound autism aren't helpful for her survey.

She looks at the answers from all of the autistic non-speakers instead. She sees that there are a few disabilities that are more common in this group. She can use this information when she explains how her study went. This way, lots of other scientists can try to do this study. They can find out what disabilities are more common for autistic non-speakers.

Some people who want a "profound autism" label say that no one with profound autism can advocate for themselves. If researchers believe this, they won't try to talk to autistic people who need more services. This would also make autism research worse.

The government has also started to talk about profound autism. Profound autism came up in IACC meetings in April and August 2026. IACC stands for "Interagency Autism Coordinating Committee". We call them the "IACC" for short.

The IACC is a group of people chosen by the government. The **IACC** helps decide what autism research the government will pay for. [You can learn more about the IACC with our plain language resource here.](#)

The IACC voted on changes they thought the government should make about autism. One thing they voted on is that researchers and policy-makers should look into profound autism. They said “profound autism” should get listed as a new kind of autism for research and policy projects.

This would be really bad. Many autistic people would get left out of research and policy about profound autism. And nobody has decided exactly what profound autism actually means. That makes it impossible to do good research or make good policies.

Researchers and policy-makers should listen to autistic people. They can learn about what supports and services we need. They can learn about what autistic people want autism research to focus on. Good research and policy needs to ask specific questions and focus on specific needs.

What can we do?

We can fight back against the “profound autism” label. Here are some ways how:

1. Change how autistic people talk about each other. That can help change how other people talk about us. This matters because people need to understand each other. How we talk about autistic people changes how we understand autism.

Remember that All means all. When we talk about autism we should talk about all kinds of autistic people. That means we need to talk about people who need more support.

When a problem affects people who need the most support, we should say so! We can do this by being specific about who a problem hurts. We can help others learn how to help, instead of seeing someone’s support needs as a problem.

For example:

Recently, the government has been trying to cut home- and community-based services (HCBS). **HCBS** helps disabled people get the everyday

support they need in their own homes. News reporters and elected officials need to hear from autistic people about this problem. Some things you could say are:

“Cutting HCBS hurts autistic people! There are autistic people who use HCBS to eat safely at home. For example, if an autistic person has a feeding tube.”

“There are autistic people who use HCBS to go to work or school. There are autistic people who use HCBS to fill their medications every week.”

“Without HCBS, many autistic people could lose the supports that help them live at home. All autistic people deserve to live in the community.”

2. Sometimes, groups will say things that try to split up the autistic community. This can be on accident or on purpose. Either way, it is important to say something if this happens. This lets people know it is not okay.

Here are some ways to spot when groups are using these bad ideas:

- The group uses the word “profound” autism or “low functioning” autism.
- The group is not willing to think about what autistic people have to say.
- An example is saying “Your opinion on what helps autistic people matters less than mine as a parent. That’s because you are not the same kind of autistic as my child.”
- The group says that people need the “choice” to live in an institution.
- The group says that some autistic people cannot make our own choices or need guardianship.
- You can use this toolkit to figure out what you want to say to these groups. For example, you can write a script about the problems with the “profound autism” label. You can also send groups this toolkit to read themselves.

3. You can send in written comments to the IACC. The government reads these comments for each IACC meeting. You can say that you don't think the government should use the profound autism label. You can tell the government why saying profound autism hurts autistic people.

ASAN has a webpage that posts updates about when each IACC meeting will happen. The page has instructions about sending comments to the IACC. You can check out this page at: <https://autisticadvocacy.org/2026/02/interagency-autism-coordinating-committee-iacc/>

4. You can advocate to keep the "profound autism" label out of the new DSM. **The Diagnostic and Statistical Manual of Mental Disorders (DSM)** is a book that has a list of signs of certain disabilities. Doctors use this book to help decide whether or not someone has a disability.

The new version of the DSM will be made soon. It is called DSM 6. Some people are advocating to add "profound autism" to the DSM 6. ASAN will share chances to advocate against this soon.

This is not just about the words "profound autism"

We do not just want people to stop saying "profound autism". The words "profound autism" are not the only problem. The ideas that made people start using the words "profound autism" are the big problem.

Right now, many people with power in the government have very harmful ideas about autism. They think autism needs to be cured. They want to force autistic people to live in institutions instead of in our communities. They do not want autistic people to be born or to live in the world.

We know that a lot of autistic people who need the most support are not getting the help we need. Putting us into a separate group will not let us get the help we need. We know this because this happened before with different functioning labels.

Making systems that listen to autistic people and our loved ones will get us the supports and services we need. That means fighting for help that we can get at

home and in our communities. That means training doctors to listen to us instead of making bad guesses about what we need. That means protecting autistic people from being hurt and separated from others at school and work. That means making sure we can always get health care.

The autistic community is stronger together. We have to focus on helping autistic people who need the most help. People who need the most support are an important part of our community. They should not be separate from our community.

Separating people with many support needs into a different group hurts them. It hurts the people who love them. And it hurts the autistic advocacy movement. We must fight for a world where all autistic people can make choices about our lives and futures.