



ASAN

AUTISTIC SELF ADVOCACY NETWORK

Settings

Rules Resources

**Who can I talk to if someone
isn't respecting my rights?**



Who can I talk to if someone isn't respecting my rights?

All your providers should respect your rights. But sometimes, providers don't respect your rights. It is never your fault when a provider doesn't respect your rights.

If a provider isn't respecting your rights, you have lots of options. You can decide to talk to the provider directly. You can decide to get someone like a friend or family member to talk to the provider for you. You can also decide not to tell the provider at all.

If you want to talk to your provider:

You can talk to the provider if you want to. You can tell the provider how they are not respecting your rights. You can tell the provider what you would like them to do differently.

If you want to talk to your provider, make a plan for how you will do it. Decide how you will tell them they are not respecting your rights. Decide how you will tell them what they need to do differently. If it will help, write down what you want to say. That way, it will be easier to remember what you want to say.

You can always ask someone else, like a friend or family member, for help. This person can help you by:

- Helping you come up with what you are going to tell the provider.
- Role-playing as the provider so you can practice what you are going to say
- Helping you write down what you are going to tell the provider
- Talking to the provider for you, if you want

Here is a script for talking to providers when they don't respect your rights. You can add in your own details to this script. You can also change this script however you want.

"I'd like to talk to you about something that happened. When you do [thing they did that didn't respect your rights], it's hard for me. It makes me feel like you don't respect my rights. My rights are very important to me. I want you

to respect my rights. In the future, I want you to do [thing you want them to do that respects your rights]. This will help me feel better. It will make me feel like you respect my rights. Do you have any questions? Is there anything you want to talk about?"

Try to talk to the provider when you are both free to talk. Don't try to talk to the provider when one or both of you is very busy. Try to be gentle when you talk to your provider. They may not know how you feel. They may not understand what they did was wrong. Be gentle, but be firm. You are talking about how you feel. Your provider doesn't get to tell you how you feel.

For example: Liliana goes to a day program. One of the staff at the day program is always making fun of Liliana. Liliana wants to talk to the staff member. But she isn't sure what to say. So Liliana talks to her sister. Liliana's sister helps Liliana write down what she wants to say. Liliana's sister also helps Liliana practice what she is going to say. Then, Liliana talks to the staff member. This is what she says:

"I'd like to talk to you about something that happened. When you make fun of me, it's hard for me. It makes me feel like you don't respect my rights. My rights are very important to me. I want you to respect my rights. In the future, I want you to stop making fun of me. I want you to treat me with respect. This will help me feel better. It will make me feel like you respect my rights. Do you have any questions?"

The staff member listens to Liliana. The staff member agrees that they will stop making fun of Liliana.

You should try to talk to your provider about what they did as a first step. But sometimes, talking to your provider doesn't help. Your provider might keep doing the same thing. Or, you might be scared to talk to your provider. This could be because the provider is very mean to you. Or, it could be because the provider has hurt you physically.

In these cases, you might want to file a grievance. We will talk more about grievances in the next section.

What is a grievance?

If a provider isn't respecting your rights, you can file a grievance. A grievance is an official complaint. You can talk to your provider about your grievance. Or, you can file a grievance with your state's **Developmental Disability (DD) Agency**. Your state's DD Agency is the part of the state government that runs the state's Medicaid program.

If you want to file a grievance against your provider, talk to your case manager first. In most cases, your case manager will know the process for filing a grievance. Your case manager can help you file a grievance. But your case manager might not know what the steps are to file a grievance. Or, you might be trying to file a grievance against your case manager. In those cases, here are some steps you can take to file a grievance.

How can I find my provider's grievance process?

A grievance process is the steps that you have to go through in order to file a grievance. Remember, you can file a grievance with your provider. Or you can file a grievance with your state's DD Agency. We will go over the steps on how to file your grievance with either your provider or your state DD agency.

Providers' grievance processes

Providers typically work for agencies. An agency is a group or company that manages providers. Every agency will have a different grievance process. You can do a web search for "[your provider's agency's name] grievance process." Many agencies have an online form you can use to report grievances. The form might ask for things like:

- Your name
 - What kind of services you receive
 - What your grievance is about
 - What steps you have taken to make your problem better. (For example, if you have already talked to your provider about what they can do to respect your rights.)
-

The form might also tell you how long it will take for someone to respond to your grievance.

For example: Rudy has an in-home helper. The in-home helper is one of Rudy's providers. Rudy wants to file a grievance against the in-home helper. The in-home helper doesn't listen to Rudy. The in-home helper calls Rudy mean names. Rudy's in-home helper works for an agency called Great Oaks Services. So Rudy does a web search for "Great Oaks Services grievance process." Rudy finds a webpage with a form to fill out. Rudy fills out the form about his grievance against his in-home helper.

What if I can't find a grievance form?

If you can't find a grievance form for your provider's agency, you still have options for filing a grievance. You could try talking to your provider's supervisor, if they have one. Your provider's supervisor is their boss. You can ask your provider for their supervisor's name and contact information.

Or, you can look on the agency's website for your provider's supervisor's information. Sometimes this information isn't listed on the website. But you may be able to find contact information for the person who supervises all the providers in the agency. That person will also know who your provider's supervisor is. You can contact that person and ask for your provider's supervisor's contact information.

You can also talk to the **Human Resources (HR) department** at your provider's agency. The HR department is part of an agency. One of the jobs of the HR department is to handle grievances. You can look on your provider's agency's website for how to contact their HR department. Then, you can contact the HR department.

Here is a script for talking to your provider's supervisor or an agency's HR department. You can fill in this script with your own information. Then, you can use the script for things like phone calls and emails.

Hello,

My name is [your name] and I get services from [agency name]. I am having trouble with my provider, [your provider's name]. [Describe the problems you are having here. Try to be specific and give details.] I would like to file a

grievance against [your provider's name]. Could you tell me how to do that?

(If you are trying to find the name and contact information of your provider's supervisor:) Could you please give me the name and contact information for [your provider's name]'s supervisor so I can contact them?

Thank you for your time and help,

[your name]

What if my provider doesn't work through an agency?

Usually, when you get HCBS, you get assigned to an agency. The agency then assigns you providers, like support workers. You usually don't get to choose who your providers are.

For example: Marv gets HCBS. When Marv started getting HCBS, his case manager assigned him to an agency, CareOne. CareOne then assigned Marv a support worker. Marv doesn't get to choose who his support worker is. He just gets whoever CareOne assigns to him.

But some people who get HCBS don't work with providers through an agency. These people who get HCBS hire their own providers by themselves. This is sometimes called "self-directed services" or "consumer-directed services." When you hire your own provider, you can also choose to fire your provider directly. **Firing** a provider means you tell them you don't want them to work for you anymore. You always have the right to fire a provider, even if you get services through an agency. But if you hire your providers yourself, you don't have to go through an agency to fire your providers.

You should try and talk to your providers before you fire them. Tell the provider what they did wrong. Tell them how they can make it better. But if you have already talked to your provider and it didn't help, you can choose to fire them. Or, maybe your provider did something really bad. Then, you could choose to fire them without talking to them first.

Here is a script for firing providers: "I'd like to talk to you about something that happened. When you do [thing they did that didn't respect your rights], it's hard for me. It makes me feel like you don't respect my rights. My rights are very important to me. I want you to respect my rights. [I've already talked to you about

this problem, but it hasn't seemed to help.] OR [What you did was really wrong and made me feel really bad.] Because of this, I don't think we can work together anymore. I will be finding another provider to replace you. I'm sorry for doing this, but I felt I didn't have another option. Do you have any questions? Is there anything you want to talk about?"

For example: Jessica gets HCBS. Jessica gets self-directed services. Jessica doesn't work with an agency to find providers. Jessica hires her own providers, like support workers, directly. When she wants to hire a new support worker, she puts an ad in the newspaper and on Facebook. Jessica's case manager helps her make sure her support workers are paid on time. Jessica is having problems with one of her providers. The provider is always late to work. No matter how many times Jessica tells the provider to come to work on time, the provider always shows up late. So Jessica decides to fire the provider.

Jessica talks to her provider. This is what she says:

"I'd like to talk to you about something that happened. When you show up late to work all the time, it's hard for me. It makes me feel like you don't respect my rights. My rights are very important to me. I want you to respect my rights. I've already talked to you about this problem, but it hasn't seemed to help. Because of this, I don't think we can work together anymore. I will be finding another provider to replace you. I'm sorry for doing this, but I felt I didn't have another option. Do you have any questions? Is there anything you want to talk about?"

States' Grievance Processes

Your state should have a way to file grievances directly. The state needs to say what this way is in their transition plan. The way to do this in every state is different. It might be hard to find the right way to file a grievance to the state. The way your state has to file grievances might be hard to use on your own. There are people who can help you file grievances using your state's system. In the next section we talk about some of the people who can help you.

Who can help me file grievances?

Filing a grievance can be hard. It can be hard to know who to talk to. It can be hard to know what to say. There are several people and groups who can help you if you have a problem with your provider. This can include helping you file a grievance.

Your case manager

If you have a problem with one of your providers, talk to your case manager. Your case manager cannot be one of your providers. Your case manager can help you. Your case manager could talk to your provider for you. Or, your case manager could help you talk to your provider. Or, your case manager could help you file a grievance with your provider or the state.

Your state's Protection and Advocacy organization (P&A)

Protection and Advocacy organizations (P&As) help people with disabilities fight for our rights. P&As make sure states and other people or groups, like providers, follow disability laws. There is a P&A in every state. You can find your P&A by going to <https://www.ndrn.org/about/ndrn-memberagencies/>

Your state's P&A can help you file a grievance with your state. Your state's P&A also can help you get a lawyer if you need to go to court to fight for your rights.

Your state's Long Term Care Ombuds

An ombuds (also called an ombudsman) is a person who looks into complaints and grievances people make. An ombuds also helps people resolve problems or disputes they have with others. A Long Term Care Ombuds (also called a Long Term Care Ombudsman) is a state government official. They look into grievances people make about long term care facilities. Long term care facilities can be places like institutions and hospitals. They can also be places like group homes and assisted living facilities. Remember, the HCBS Rule says that places like group homes and assisted living facilities can count as HCBS.

Long Term Care Ombuds mostly look at places that older adults live in, like nursing homes and assisted living facilities. But people with disabilities of all ages can live in these places, too. And Long Term Care Ombuds can also look at places that

mostly serve people with disabilities, like group homes.

You can talk to your state's Long Term Care Ombuds. You can file a grievance with them. You can find your state's Long Term Care Ombuds here: https://theconsumervoice.org/get_help

Some states also have an ombuds for people with intellectual and developmental disabilities. These ombuds might have different names. States call these ombuds things like:

- IDD Ombudsman
- Residential Facilities Ombudsman
- Ombudsman for Mental Health and Developmental Disabilities

Not every state has an ombuds for people with intellectual and developmental disabilities. You can do a web search for "developmental disabilities ombuds [your state name]." If there isn't an ombuds for people with intellectual and developmental disabilities in your state, you can contact the Long Term Care Ombuds for your state. They may be able to help you with your grievance. Even if they can't, they may be able to tell you the right person to file your grievance with.

Your state's Developmental Disability (DD) Council

DD councils work to help people with developmental disabilities. They figure out problems that the state can fix. Every DD council has to have people with developmental disabilities on it. That way, we can let our state know what problems we think are important.

Your state's DD council can give you resources for how to file a grievance. Your state's DD council can tell you who to talk to in your state to file a grievance.

Your state or local chapter of The Arc

The Arc is an advocacy group for people with intellectual and developmental disabilities. The national group is called The Arc of the United States. There is a state chapter of The Arc in each state. There are also many local chapters of The Arc within states. You can find your state or local chapter of The Arc here: <https://thearc.org/find-a-chapter/#>

Your state or local chapter of The Arc can give you resources for how to file a grievance. Your state or local chapter of The Arc may also be able to give you an advocate to help you file a grievance.

What if I'm scared of getting in trouble for filing a grievance?

You might be scared to file a grievance. That's okay. It can be scary to speak up about your rights not being respected.

But you have rights when you file a grievance!

You have the right to file a grievance anonymously. "Anonymously" means that you do not have to tell your provider you filed a grievance. If you file a grievance with your agency, you can ask that the agency not tell the provider who filed the grievance. If you file a grievance with your state, the state won't tell your provider who filed the grievance, either. Being anonymous can protect your identity. It means that your provider doesn't have to know that it was you who filed the grievance. It also means you can keep the grievance a secret.

You have the right to protection from retaliation when you file a grievance. Retaliation is when someone punishes or hurts you for filing a grievance.

For example: Say you file a grievance against your provider with the provider's agency. The agency then says you can't get services from that agency anymore. That would be a type of retaliation.

You can request anonymity so your provider won't find out you filed the grievance against them. But your provider might still figure out that you filed the grievance. This happens sometimes. It is not your fault if your provider figures out you filed a grievance against them. A provider cannot retaliate against you for filing a grievance, even if they figure out it was you. Providers are not allowed to punish you for filing a grievance.

For example: Lydia works with a job coach at work. Her job coach is one of her providers. The job coach does not respect Lydia's rights. So Lydia decides to file a grievance. Lydia files a grievance with the job coach's agency. The agency promises Lydia that the job coach will not find out that Lydia files the grievance. But the job coach figures out that Lydia filed the grievance. The job coach gets mad at Lydia for filing a grievance. This is not okay! The job coach

is not allowed to get mad at Lydia for filing the grievance.

What can I do if a provider retaliates against me for filing a grievance?

If a provider retaliates against you for filing a grievance, you can file another grievance. You should file this grievance with your state. Follow the steps in the section "State DD Agencies' Grievance Processes."

You should also contact your P&A. Your P&A can help you file a grievance with your state. Your P&A might also be able to file a grievance for you.

Remember, you can always fire providers who do not respect your rights. If you get services through an agency, you can ask the agency for a new provider. If you self-direct your services, you can fire a provider directly. You can read the section "What if my provider doesn't work through an agency?" for more information.

For example: Let's go back to Lydia's grievance against her job coach. Lydia's job coach got mad at Lydia for filing the grievance. This is retaliation. This is not okay. So Lydia decides to file a grievance with her state. She uses her state's DD agency's grievance form to file a grievance. Lydia also talks to her state's P&A. She asks the P&A for help with the grievance process. Finally, Lydia decides to fire the job coach. She tells the agency she does not want to work with the job coach anymore. She asks for a new job coach.

What do I do if I'm not getting the services that I should?

If you are not getting services that are in your person-centered plan, you should file a grievance. A person-centered plan is a plan for all the services you will get. A **person-centered plan** talks about how these services will be provided to you. If a certain service is in your person-centered plan, you should be getting that service.

Talk to your case manager about the services you are not getting. Your case manager can help you file a grievance. You can also talk to the people and groups we already talked about, like your P&A or chapter of the Arc. They can help you file a grievance as well.