Autism and Safety Toolkit: Safety Tips for Self-Advocates

What Is In This Guide?

We created this guide to give safety tips to autistic people. This guide gives you tips on:

- How to recognize and report abuse and neglect
- What to do if you have been abused
- What to do when someone you know is thinking about suicide
- What to do when you feel suicidal
- How to avoid interacting with the police
- How to make changes in your community so that police will be needed less often
- What to do if you get lost and don't know where you are

Everyone wants to be safe and to live independently in their community. Autistic people want this too. However, lots of autistic people may have extra challenges when it comes to staying safe.

Autistic people are often less safe because:

- We are more likely to be abused or neglected
- We are more likely to have been subjected to therapies that teach us compliance, rather than independence
- We are less likely to be connected to our community and are often segregated against our will, such as in group homes or institutions
- We are more likely to die from suicide
- We are more likely to be targeted by and have bad encounters with the police
- We are less likely to know survival skills that would help us if we got lost, and less likely to know how to find our way back to where we want to be

These things make it harder for us to stay safe.

Sometimes people will say that this means we can't or shouldn't live independently. This is not true. In fact, we are *more* safe when we have control over our lives. **Everyone** has the right to live in the community and be safe in their community.

Many of our tips come from information from other sources, including research articles, relevant websites and policy papers produced by others, and a survey we conducted of autistic self-advocates' and their concerns with respect to autism and safety. In our footnotes, we cite to documents that we got information from so that you can read more. We thank all the autistic self-advocates who took the time to fill out our survey, particularly our ASAN affiliates.

Abuse and Neglect

Abuse and neglect are serious problems in our community. People with developmental disabilities might be more vulnerable to abuse because:

- Many of us do not know what is and is not abuse because we weren't taught how to recognize it
- Many of us have a hard time describing abuse and neglect because we have trouble communicating
- Many of us do not know how to talk about abuse and neglect because it is hard and no one taught us how to talk about it
- Some of us are scared of speaking up when we're abused or neglected by someone who is helping us with something, since that may mean losing that help
- Many of us were taught "compliance," or doing as we are told without questioning why
- We may think we deserve the bad things that are happening to us, even though no one deserves to be abused or neglected
- We have had bad experiences with the police or other authorities and, as a result, we are afraid of reporting abuse and neglect to them
- When we do tell others about abuse or neglect, some people may not believe us
- We don't tell anyone about being abused or neglected because we are afraid that no one will believe what we say¹

This guide explains how to recognize and prevent two kinds of abuse and neglect: abuse and neglect at home or between people and abuse and neglect in schools and institutions/group homes. We talk about how to do it for yourself and how to do it for other people.

Abuse and Neglect at Home or Between People

How can I tell if I am being abused and/or neglected?

First, trust how you feel if someone makes you feel bad when you are around them. Other people might try to downplay it but it is how you feel that is most important!

Does the person you are concerned about:

- Hit you or touch you in ways you do not want to be touched?
- Call you names or insult you?
- Tell you that you cannot talk to your other friends or family members?
- Refuse to be your friend or partner unless you do things that you don't want to do?
- Deny you things you need unless you do things that they want you to do?
- Force you to hang out with them?
- Ignore you?
- If they are your caregiver, do they refuse to help you do things around the house when they are supposed to help you do those things?
- If they are your caregiver, do they refuse to help you eat, drink, or go to the bathroom even though they are supposed to help you do those things?

Much of this list of reasons people with disabilities are vulnerable to abuse comes from Green Mountain Self Advocates' guide Abuse: A Peer to Peer Guide About Domestic and Sexual Violence (2011), http://www.gmsavt.org/wp-content/uploads/2015/07/GM-SA-A-Peer-to-Peer-Guide-About-DV-and-SV.pdf. To read more of Green Mountain Self Advocates' excellent resources, check their Resources page at: http://www.gmsavt.org/trainings-and-resources/.

All of these things are signs of abuse. There are other actions that may also be abuse. Just because a sign of abuse that you have seen does not appear on this list does not mean it is not abuse.

Family members who do these things may also be abusive. Family members do NOT have the right to hurt you or make you feel terrible just because you are related to them. **You have the right to control your own body and your own life.**

What Should I Do If I Am Being Abused or Neglected?

Try, if you can, to have a group of friends or supportive family members around you. If you need to get away from someone else for several days, your friends can help. You might also be able to speak to a therapist, someone at your school, or someone who works for you (i.e. provides you with services and supports that help you to do things in your home or in the community) about what to do next. Keep in mind that all three of types of people (therapists, school staff, and disability services staff) are mandated reporters, which means they might have to tell your state government or your state's Adult Protective Services system that you have been abused.

If you need to leave your abuser and you are able to do so, pack everything you need to live somewhere else for a week and hide it in a safe place. Here are some examples of things you should pack:

- Identification, like ID cards and passports
- Cash and credit cards
- Food and water
- Clothes for a few days
- Transportation cards, like Metro cards (remember to refill these!)
- Medicine if you need it
- Anything you need to communicate, like an iPad or letterboard
- Any proof you may have that you were abused (like text messages between you and your abuser, emails and letters between you and the abuser, recorded conversations if you have them, photographs of your injuries or other physical evidence of abuse, etc.)
- Car registration and driver's insurance if you have a car
- Health records and health insurance cards
- Records of your lease, mortgage, etc. if you have them
- Hygiene products such as menstrual pads or tampons

Some things may not be possible to hide or fit in a bag, but it is still important to take them with you if you have to leave. Make sure that they're in a place where you can get to them. This may include:

- Your wheelchair if you have one
- Medical equipment you need to live (like IV machines or ventilators or dialysis machines) if you have that kind of equipment

If something you need to live is really hard to carry, or if you need help in order to move, you may need to get a friend to help you on the day you move.

Once you are somewhere safe, you and your friends can discuss what to do next. Here are a couple things you could do:

• Ask your local court for a document called a **protective order**, or a **temporary restraining order**, which stops the abuser from meeting with you or seeing you. These kinds of court orders differ from state to state and may be called different things. Sometimes there are consequences to getting a protective order - for example, the court may also tell you that you can't talk to the abuser either. Make sure to look up what protective orders look

like **in your state**. The site <u>Womenslaw.org</u> has information on protective orders and temporary restraining orders that you can view state by state.² These laws can be used by anyone, not just women.

- Tell the police you were abused, if you feel comfortable doing so. In some states you may have to tell the police you were abused in order to get a protective order.
- Make a permanent plan for where you will live and how you will get supports.
- If you have Social Security, tell them to start sending mail to your new address, rather than your abuser's.
- You could contact a protection and advocacy organization (P&A). We talk more about Protection and Advocacy organizations on pgs. 5 and 10 of this guide.

What If I Have No Friends or Nowhere to Go? Who Can I Report Abuse and Neglect To?

Sometimes your abuser takes care of you and you do not have very many friends you can get help from. If that happens, there are still a couple of different places you can go:

- If you need someone to talk to who is not a friend or family member, the web site <u>loveisrespect.org</u> has resources that explain who to talk to if you have been abused.
- You can go to a **domestic violence shelter.** Each state has a network of domestic violence shelters. A list of domestic violence shelters can be found here.3 You could also search your state's name or the name of the town you live in and "domestic violence shelter" on Google or another search engine.
 - Not all shelters are accessible to people with disabilities. Look for accessibility options on the shelter's website. If the website is not clear you may have to call the shelter's number and ask if they are accessible. If the shelter says that they are not accessible, you might be able to ask for an accommodation. Many shelters are required to be accessible, by a civil rights law known as the Americans with Disabilities Act (ADA).
 - A note on LGBTQ (Lesbian, Gay, Bisexual, Transgender, and Queer people) people and domestic violence shelters: The Violence Against Women Act (VAWA) is a national law that gives money to shelters. Shelters that get this money are not allowed to discriminate against a person based on their transgender status, sexual orientation, or gender expression. The Department of Housing and Urban Development (HUD), which also gives money to some shelters, has also passed a rule saying that shelters that accept this money are not allowed to discriminate against LGBTQ people based on these factors. Keep in mind that shelters who have to follow these laws can still decide to be "women-only" shelters and refuse to admit anyone who does not identify as female. Keep in mind that some people who don't identify as female may be able to access the shelter if people think they are female. For example, a non-binary person whose identification card says "female" would probably still be allowed into the shelter.

Not all shelters are covered by these rules, though, and it's possible that these regulations may be repealed. Not all shelters follow these regulations. LGBTQ people have been turned away from domestic violence shelters because they were male, or because they were trans. LGBTQ people also have LGBTQ-specific concerns in shelters, such as the person who abused them following them into a single-gender shelter (if they are gay, lesbian, or bisexual) or being bullied over their sexual orientation or gender identity. If you are LGBTQ and need to go to a domestic violence shelter, you should plan ahead. If you can, look up the websites of shelters in your area. See if you can find one that specifically states they serve LGBTQ people, or says they serve "all" victims of abuse regardless of gender or sexual orientation.

- You might be able to call your local police department. Use 911.
 - Make sure you plan in advance what you are going to say to the police. The website <u>loveisrespect.org</u> has a resource on how to communicate with the police called "Calling the Police."

Valerie Despres, Know the Laws: Restraining Orders, Womenslaw.org (2008), http://www.womenslaw.org/laws_state_type.php?id=11169&state_code=GE.

Theresa's Fund, Domestic Violence Shelter & Program Search Tool, Domesticshelters.org (2017), https://www.domesticshelters.org/search#?radius=50&page=1.

- You can call a caseworker, doctor, or counselor that you regularly meet with and tell them about the abuse and/ or neglect. Keep in mind that caseworkers, doctors, and counselors may be mandated reporters. That means that they may have to report that you were abused to the police, Adult Protective Services, or if you are under 18 to Child Protective Services. If you're worried about this, you can ask them about whether they are mandated reporters before telling them about the abuse.
- You may be able to call your state Protection and Advocacy Organization (P&A), who may be able to tell you what to do next. P&As are organizations that help advocate for the rights of people with disabilities. You can find a list of P&As and their contact information on the National Disability Rights Network's website: http://www.ndrn.org/ndrn-member-agencies.html.
- You can call Adult Protective Services (APS) in your area. Adult Protective Services caseworkers investigate cases of abuse and neglect when the victim is either elderly or a person with a disability. Adult Protective Services may be called something else. If you don't know what your Adult Protective Services agency is called, look up "reporting elder abuse" or "reporting abuse of people with disabilities" in your state. You can get more information on how APS helps on their national organization's website at: http://www.napsa-now.org/get-help/how-aps-helps/. You can find a list of APS offices using the map at this website: http://www.napsa-now.org/get-help/help-in-your-area/.

- A note on Adult Protective Services and guardianship: Sometimes Adult Protective Services (APS) may be legally obligated to petition your local court to appoint a guardian for you. For example, APS may petition for guardianship if it decides that you cannot take care of yourself or if you are refusing to leave what they perceive as a dangerous or abusive situation.
 - **Guardianship** is when someone is allowed to make decisions for you. A guardian may be able to decide where you live or how you spend your money. It can be very hard to get out of guardianship.
 - In many states, before a court in any state can appoint a permanent guardian for you, the court must hold a hearing, called an **incapacity hearing**.
 - The court must tell you that this hearing is happening in advance. This is called giving you **notice.**
 - You have a right to be at that hearing and to argue that you do not need a guardian.
 - You can show the court **evidence** such as doctor's notes saying that you can make decisions and also bring **witnesses** who can tell the court that you do not need a guardian.
 - In some states, but not all, you also have the right to a jury trial or an attorney.
 - If the court thinks you are unable to make your own decisions, the court must appoint a guardian. Sometimes guardianships are only over certain kinds of decisions, like healthcare. Other guardianships cover all kinds of decisions.
 - Courts usually want to make a family member the guardian. But in cases where a family member is abusive, or in cases where there are no family members, courts may appoint someone else as a guardian. It may be someone you do not know.
 - If Adult Protective Services decides that your life or property is in **immediate** danger, they can also petition for the appointment of an **emergency guardian** for you. This is only supposed to happen if APS sees no other alternative to appointing the guardian. There is usually a short hearing before an emergency guardian is appointed. You would would have the opportunity to argue that you do not need an emergency guardian. But an emergency guardianship hearing is shorter than a normal one and you may not have as much time to find evidence that you don't need a guardian.
 - An emergency guardianship does not last more than a few days in most states. However, emergency guardians often ask the court to become a permanent guardian after that time. The emergency guardian may have the power to move you against your will during the time that you are under emergency guardianship.
 - Guardianship proceedings and guardianship itself can be *very different* from state to state, and APS' level of involvement also differs from state to state. If you want to understand the guardianship laws and proceedings in your state, you should check the National Resource Center for Supported Decision Making's state by state list of applicable guardianship and supported decision making laws.
 - The appointment of a guardian can be a very dangerous situation, as you would lose control over both your life and property. The person who makes decisions for you may be someone you do not know. Before you call Adult Protective Services as a result of abuse, you should **make a plan** to defend yourself from guardianship if you need to.
 - For more information on defending yourself from guardianship, see ASAN's toolkit <u>"The Right to Make Choices."</u>

Autistic Self Advocacy Network, "The Right to Make Choices: New Resource on Supported Decision-Making" (2016), http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/.

What if I depend on my abuser for help?

If your abuser is your caregiver or service provider and you can't find anyone else to provide care, you may be able to get a different caregiver through Medicaid. Most if not all states have Medicaid-funded home- and community-based services (HCBS) waivers, which allow you to get support services in your community. If you are receiving HCBS services from Medicaid, the state's Medicaid program must offer you a choice among service providers. By switching who gives you services using this process, you could replace an abusive caregiver with someone else that you choose.

If you are not currently receiving HCBS services from Medicaid but you are a Medicaid customer, you could potentially apply for these services by applying for a Medicaid-funded HCBS waiver. Although HCBS waiver waiting lists can be very long, some states prioritize the applications of people who have been abused and/or neglected.

What if my abuser is my guardian?

Sometimes, people with disabilities have been placed under **guardianship** by a court. Some people under guardianship are not allowed to decide for themselves where they want to go. This can be a problem if the guardian is abusive. If your abuser is your guardian, you can still call 911, the Protection and Advocacy organization for your state, or Adult Protective Services. Protection and Advocacy organizations are especially good at helping people who are under guardianship determine what they need to do next in order to get away from an abusive guardian. You can also visit the National Resource Center on Supported Decision-Making, which has a <u>list of resources available in each state</u>.⁵

How can I tell if someone I know is being abused and/or neglected? How can I help that person if they are being abused and/or neglected?

When trying to find out if someone you know is being abused or neglected, you should **look for signs of abuse and neglect in that person's life.**

If you see any signs the person is being abused and neglected, or are just worried about them, you can then **set up a time to talk to that person.**

Finally, you can help the person find accessible resources, such as crisis hotlines, authorities they can report the abuse and neglect to if needed, and other people they can talk to.

What are the signs that someone I know is being abused and/or neglected?

Before you talk to the person, you might want to look for signs that something really is wrong. **Here are a few ways you** can do that.

Try to determine how the person is *feeling*. Are they:

- Uncomfortable about something, or sad? Do they seem to be feeling this way often or all the time? Do you know why?
- Angry all the time? Do they appear to be "always on edge," or have a temper they did not use to have?
- Unusually scared of bad things happening to them or their friends, more than they were before?
- Much more nervous than they used to be?
- Saying new things like "Stop" or "Don't hurt me" or "No, please," even when there is no clear threat around, and when they did not say these things before?

These all could be signs of abuse and neglect.

The person could also be scared of something that is not dangerous, like perfume or a certain voice, that they were not scared of before. This could mean that the person was harmed and the harmless thing (called a **trigger**) reminds them of getting hurt.

Morgan K. Whitlach et. al., *In Your State*, National Resource Center for Supported Decision Making (2012), http://supporteddecisionmaking.org/states.

Check to see if there's **anything** *different* about the person. Here are some examples of things that could be different:

- If they are normally well dressed, are they now looking messy or wearing dirty clothes all the time?
- If they are normally excited about activities they like (like board games, video games, sports, etc.), are they now not excited about these things?
- If you ask them why they're not doing things they used to do, do they say that they're "not allowed anymore" to do those things?
- Are they unable to do something, like wash dishes, that they used to be able to do?
- Do they have any odd marks, cuts, scrapes, bruises, or other obvious physical injuries? Do they have no explanation for these injuries?

These all could be signs of abuse and neglect.

Look to see if anything has changed in the person's life.

- Is someone else in their life always angry at them? Are they scared of this person?
- Do you rarely get to see this person now, even though you used to do things with them often? Are they not showing up at social events, parties, church, etc.? Are they absent from school or work a lot more often than before?
- Does the person seem to not have any money when they used to have money?
- Is the person doing something odd they were not doing before, like checking clocks all the time?

These are all signs that the person could be in an abusive relationship.

If a lot of the signs on this list are happening at the same time, there is a possibility that something is wrong. **Set up a time to talk with them and try to find out what is happening.**

What should I do during the talk?

Talking to someone about abuse or neglect can be hard. Here are some suggestions for how to talk to someone who may be abused or neglected.

Make sure to try to talk to the person privately. Make sure that there are no other people around who might be an abuser or might be someone the person does not trust (see page 10 for advice on situations where this may be hard - such as if you suspect a person's communication partner of abuse).

You may want to start your talk by asking them if they are feeling comfortable and relaxed, and start by saying that what you are about to say might make them uncomfortable or sad.

Talk to them them in the way that works best for them. Here are a few examples of different ways you could speak with them:

- Ask them in person if someone has been hurting them.
 - Try to use their preferred language which may be spoken or signed.
- Send them an email saying that you are worried about them. Explain what you are concerned about and ask to talk to them.
- Write them a letter, print it out, and hand it to them.
- Use forms of communication that are specific to the person or to your relationship with them.
 - For example, some people communicate by playing YouTube videos that express what they're saying.
 - Others like to use specific sentences or phrases with particular people, especially when talking about difficult or sensitive topics.

Regardless of which method you use for talking with the person, you should try to talk slowly and carefully. We recommend giving suggestions and offering support, but not forcing the person to do anything. People who are being abused or neglected often need to feel like they can make decisions for themselves.

If the person has trouble communicating, make sure to give them time to answer.

What if I can't think of anything to say to them?

While every person and situation is different, we can provide you with the following brief example script. If you want to use this script, tailor it to your specific circumstances.

[Sample 'opening' script: "Hi, I was wondering if I could talk to you about something that may be hard to talk about. Is this a good time?" "Okay." "I noticed that you have been acting scared around your girlfriend sometimes, and she seems to be saying mean things to you a lot. I'm worried that maybe you're not safe. Is there any way I can help?"]

What if the person doesn't want my help? Are there any resources or groups of people I could point the person to?

Sometimes the person might say they are being abused or neglected, but that they love the abuser. People who feel this way might not want to leave the abuser right away. You can help by saying that abuse and neglect are not how people show love. If the person is not ready to change how they feel about the abuser, it may help to remind them that their safety comes first.

Sometimes the person does not want to leave or report their abuser for other reasons. For example, they may not want your help. Or they may feel like there is nothing that they can do to stop the abuse. In this situation you may want to suggest that they talk about it with someone else.

- This could be another friend or a professional.
- This could also be an abuse hotline in their town or a national abuse hotline. Hotlines are numbers people call when they are in trouble. For a list of hotlines that you could direct them to, you can look at PleaseLive's list of national abuse hotlines at http://www.pleaselive.org/hotlines/. You can also look up your local area's abuse hotline online by searching "abuse hotline" and the name of your town.
- You can also suggest that they call their local P&A and ask what they should do. You could also discreetly ask the P&A what to do yourself but we recommend that you talk to the person first. You can find a list of P&A phone numbers at this website: http://www.ndrn.org/ndrn-member-agencies.html.

Note on assisted communication: Some people need help communicating. This means that it is hard to communicate with them without the help of a staff member, family member, or assistant who helps them. This person is often called a communication partner. If you believe that a communication partner is abusive, try to find out out if there are any alternative forms of communication that the person can use. For example, the person may be able to type without the partner's help, or use sign language that you can understand without the partner's help. Even if a person is only able to answer "yes or no" questions without the communication partner, this could be good enough. Find a time when the communication partner is not present and explain your concerns to the person. Give them opportunities to tell you whether they'd like help. Also give them the opportunity to tell you that they don't want to talk about the issue or that they would like to talk about the issue later.

You can also try to find out whether anyone other than that specific communication partner can do the partner's job. Often a person may have a few different people who can help them communicate. If someone else can be the person's communication partner, try to set up a time to talk with the person at a time when they'll be with that other communication partner. However, keep in mind that the person may not feel comfortable disclosing abuse and neglect in front of this communication partner either - especially if the communication partner is connected in some way with the abuser. You may want to tell the person that you are concerned, and also suggest ways that they can contact you in the future if they want to talk later - with the communication partner or method of their choice.

If you can't find a way to communicate with the person without the communication partner, it may be necessary to ask others who know the person. See the next section for tips on how to do this.

What if I can't talk to the person about what is happening?

The best way to find out if a person is being abused is by asking them. But if that is not possible, you could also **ask trust-worthy people you know** who know the person well, like friends and classmates.

Keep in mind that you should only do this if you are having a lot of trouble communicating with the other person - for example, if they have disappeared and you cannot contact them. If they have said they do not want to talk to you about the issue, asking others could be invading their privacy.

In an extreme situation, where you think the person is going to get seriously hurt if you do nothing, you could call Adult Protective Services. As we noted earlier in this guide, Adult Protective Services can go by different names in different states, so you should search for terms like "Elder Abuse reporting" or "how to report abuse of people with disabilities" to find the correct people to contact. Adult Protective Services has the power to investigate criminal abuse and neglect of adults with disabilities.

Keep in mind that calling Adult Protective Services may result in police or other authorities coming to the person's house. This may be dangerous, especially in a mental health crisis. The police are not trained mental health professionals. For more on alternatives to police in mental health crises, see page 18.

Sometimes Adult Protective Services will decide that a person needs to be removed from their house or placed under guardianship. For more information on Adult Protective Services and guardianship, see page 6. In other situations, however, Adult Protective Services can help someone get the services they need to escape an abusive situation. Deciding whether it is a good idea to call Adult Protective Services can be a difficult balance.

You may also be able to call the Protection and Advocacy organization - especially if the person who you are worried about is under guardianship or in a group home. Protection and Advocacy groups are less likely than Adult Protective Services to respond by trying to put the person under guardianship. For more information on Protection and Advocacy organizations, see page 5.

Abuse and Neglect in Schools, Institutions, and Group Homes

Abuse and neglect can also happen outside the home - such as in school, college, an institution, or a group home. Abuse in these places can take many forms, including:

- Bullying,
- Abuse by staff, or
- Seclusion and restraint.

About Bullying

Bullying is a significant problem for autistic people. We are bullied at higher rates than non-autistic people and can suffer adverse health effects from the bullying. For more research on bullying, see our <u>Research Section</u>.

What can I do if I am being bullied?

1. Reporting the bullying

It may help to tell the school that you are being bullied. Public secondary schools (like high school) often have a way for you to tell the school that you are being bullied.

For example, in Maryland, Montgomery County Public Schools has a <u>Bullying, Harassment, or Intimidation Reporting</u> <u>Form</u>. You can give the form to a teacher or the principal.

Colleges often have a department you can go to if someone is harming you. For example, the University of Maryland has an <u>Office of Civil Rights and Sexual Misconduct Office</u>, which you can call if you are being harmed.

- If your school system does not have a special form, you can also write a letter describing the bullying.
- You can also talk to school counselors, psychologists, or social workers.
- If you are able, be sure to write things down and keep all your writings and documents together in one place. This includes notes about when you are bullied. It also includes notes about what happens in your meetings with school officials.
- It can help to write your meeting notes into an email (including the things that you said and the information you gave them) and send them to school officials after the meeting. This way, the school or organization will have a difficult time claiming that they were unaware of the bullying.

Sometimes the school staff do not listen to the person with a disability. If your complaint is being ignored, try contacting your school's disability rights group or organization. If you want to know how to start a disability rights group in college, you can look at ASAN's Disabilities.

2. Due Process Complaints

If you are in high school or are not yet in high school, and if the school you go to is a public school, you could also file a document called a **due process complaint**, saying that the school broke a law called the **Individuals with Disabilities Education Act (IDEA).** Under the IDEA, public schools have to give people with disabilities a "free and appropriate public education," or FAPE. If something at school -- such as bullying -- is stopping you from getting a good education and the school does not do anything about it, the school may be breaking this law.

Paul R. Sterzing et al., Bullying Involvement and Autism Spectrum Disorders: Prevalence and Correlates of Bullying Involvement Among Adolescents with an Autism Spectrum Disorder, 166 Arch. Pediatr. Adoles. Med. 1058, 1061 (2012) (bullying); Catherine Cappadocia et. al., Bullying Experiences Among Children and Youth with Autism Spectrum Disorders, 42 J. Autism & Dev. Disord. 266, 270-71 (2011) (adverse health effects of bullying).

You must file the document with the county agency and state agency that runs your school. Here is an example of the form you must file, for the schools in the District of Columbia: https://osse.dc.gov/publication/due-process-complaint-form

3. Filing an ADA Complaint

You might also be able to say that the bullying is so bad that it counts as discrimination on the basis of disability - especially if the bullying is based on your disability. This would break a law known as the **Americans with Disabilities Act** (ADA).

One part of the ADA, Title II, says that state government agencies cannot discriminate against people with disabilities. State government agencies include public school districts, public schools, and state colleges, community colleges, and universities. Another part, Title III, says that "places of public accommodation" cannot discriminate against people with disabilities. This includes most private schools, including elementary schools, middle schools, high schools, colleges, and universities. It does not include religious schools. It would also apply to privately run group homes, institutions, and residential treatment centers.

Not every type of bullying violates the ADA. Bullying may violate the ADA if it is based on your disability. If your bullies are your peers or fellow students, you may also have to prove that the school has not done enough to help you and that the bullying makes it very hard for you to get the same education that other students are getting. If the school does less to protect its disabled students than it does to protect nondisabled students, that may also be discrimination under the ADA.

Where to file an ADA complaint depends on what kind of school you are at.

If you are at a **public school** or at most kinds of **college or university,** you can send a complaint to the Department of Education Office of Civil Rights (OCR). For more information on how to file such a complaint, go to OCR's website at https://www2.ed.gov/about/offices/list/ocr/complaintintro.html.

Regardless of where you go to school, if it is covered by the ADA then you can also send the complaint to the Department of Justice (DOJ). You can file the complaint at https://www.ada.gov/filing_complaint.htm. OCR and the Department of Justice talk to each other. That means that if they think you sent your complaint to the wrong place, they will send it to the right place. So if you send your complaint to the Department of Justice, you may hear from an investigator from OCR.

A note on filing IDEA and ADA complaints

Both filing an IDEA due process complaint and an OCR complaint might put you in a position where you have to fight against your school or school district. This means that you should file a complaint only if you have already tried to report the bullying to the school, or if you are sure that the school will not otherwise do anything about your complaint.

There are **time limits** to filing complaints under the IDEA or ADA. This means if you file a complaint about a bullying incident that happened years ago and don't mention anything that happened more recently, your complaint may be thrown out. The time limits are called **"statutes of limitations."** The statute of limitations for an IDEA complaint is two years. The statute of limitations for the ADA is different in each state. Look up your statute of limitations before filing a complaint.

You can also file an IDEA or ADA complaint through a **private lawyer**. A lawyer could help you file a lawsuit in court. It may be hard to find an affordable lawyer. However, in special cases, some lawyers are willing to represent people *pro bono* (for free) or *on contingency* (which means they are only paid if they win you money). Note that before going to court under the IDEA, the lawyer would usually have to start by filing a due process complaint.

For more information on which types of schools are covered by Title III of the ADA, you can read the Department of Justice's Title III Technical Assistance Manual at: https://www.ada.gov/taman3.html.

About Abuse and Neglect by Staff

People with disabilities are abused and neglected by staff members at schools, institutions, residential treatment centers, and group homes at higher rates than people without disabilities. We discuss the data on abuse and neglect in more detail in the <u>Research section</u> of our safety toolkit.

If a staff member at a school, institution, or group home has done something illegal, you can report it:

- To another teacher or staff member
- To a school guidance counselor
- To a case manager
- To the school's or institution's nurse or doctor

In many states, doctors and people who work at schools or group homes are **mandated reporters**. This means that if you tell them about abuse, they may have to report it to:

- The police,
- Child Protective Services if you are under 18
 - Child Protective Services can go by different names in different states. For example, in Massachusetts it is called Department of Children and Families (DCF) and in Texas it is Department of Family and Protective Services.
- Adult Protective Services if you are over 18
 - Adult Protective Services also may be called different things in different states.
- Your state health department's abuse and neglect hotline.

You can also report the abuse and neglect to these groups directly.

Another place to report abuse in schools, group homes, or institutions is the Protection and Advocacy organization. P&As are organizations that help advocate for the rights of people with disabilities. You can find a list of P&As and their contact information on the National Disability Rights Network's website. Protection and Advocacy organizations have special powers to investigate abuse in group homes and institutions. If the abuse is happening in a group home or institution, they may also be able to help you leave and go somewhere safer.

Seclusion and Restraint

Seclusion and restraint are when staff at a school, group home, or institution:

- Uses their body to hold someone down or stop them from moving;
- Uses straps, pads, or other "mechanical" restraints to hold someone down or stop someone from moving; or
- Forces a person into a locked room away from other people.

Are Seclusion and Restraint Illegal?

In many states, there are no laws specifically saying that restraint and seclusion is illegal. In other states, there are laws against restraint and seclusion but only in some situations. For example, staff may be able to use some restraints (like using their body to hold someone's arms) but not others (like tying someone to a chair or locking someone in a room). Or staff may only be allowed to use restraint and seclusion when you are doing something that would be dangerous for you or someone else. You should check the applicable laws in your state. The Department of Education has a <u>summary of these laws</u> on its website.⁹

⁸ U.S. Gov't Accountability Office, GAO-08-146T, Residential Treatment Programs: Concerns Regarding Abuse and Death in Certain Programs for Troubled Youth 2, 3 (2007) (residential treatment centers); Council of Parent Attorneys and Advocates, Unsafe in the Schoolhouse: Abuse of Children with Disabilities 5-9 (May 27, 2009) (schools).

⁹ U.S. Dep't of Educ., Laws & Guidance: Seclusion and Restraints, States and Territories Summary, https://www2.ed.gov/policy/seclusion/seclusion-state-summary.html#co (last updated Oct. 17, 2013).

Even if there are no laws in your state specifically about seclusion and restraint, it still may be illegal. For example, seclusion or restraint may be violate laws against assault, abuse, or disability discrimination. If the school is a public high school, you can say that seclusion and restraint violate the IDEA, because their use makes it impossible or much more difficult for you to get an education, as described on page 11 of the "Bullying" section of this guide.

Seclusion and restraint practices may be covered by the Americans with Disabilities Act or Rehabilitation Act. The ADA bans disability discrimination by state agencies (including public schools and universities) and public businesses (including non-religious private schools). The Rehabilitation Act bans disability discrimination by any program that gets money from the federal government - which also includes public schools, universities, and most group homes and institutions. Seclusion or restraint may be considered discrimination under the ADA. If you want to file a complaint under the ADA, see instructions in our Bullying section above.

Suicide

Autistic people attempt suicide and die of suicide at higher rates than non-autistic people worldwide. We talk about the data on this heightened suicide risk in the Research section of our safety toolkit. The following suggestions are for autistic people who are struggling with suicidal thoughts.

What do I do if I have thoughts of suicide?

If you are struggling with thoughts of suicide, **you are not alone.** The autistic community has a lot of people in it who have thought about suicide. If you are feeling suicidal, there are ways that you can keep yourself safe. You deserve to live and deserve to have a long and good life.

If you are having suicidal thoughts and are worried about your safety, here are a couple of ideas that might help:

If you have not already, talk to your doctor or see a therapist. A good therapist can help you talk about what is bothering you and help find ways to feel better. Not everyone finds therapy helpful, but it does help many people. Sometimes it can take time to find a therapist who really understands you and works well with you. Therapists may be legally required to have you hospitalized if you say you are going to seriously hurt yourself or someone else. But if you are struggling with thoughts about hurting yourself, a good therapist will talk to you first and try to come up with a safety plan. For example, they will help you think of things to do to stay safe when you are thinking seriously about hurting yourself. They may ask you to promise to call them if you don't feel safe.

Consider group therapy. Group therapy can be helpful for many people who are having thoughts of suicide. Keep in mind that not all group therapy sessions are accessible (or are friendly to autistic people). If it is not working for you, try looking somewhere else.

Reach out to religious leaders and organizations, or other strong community groups you may belong to.People from these groups likely have a lot of experience talking to people who are having thoughts of suicide. Some people prefer to talk to clergy than to therapists or doctors.

Reach out to friends who can support you. When you feel like you are struggling, it is best to have friends who you can talk to. Your friends can also stop you from doing something dangerous.

• When you are having serious thoughts of self-harm, try calling someone you know well and asking them to come over. They might be able to help you think of something else instead.

Reach out to the autistic community. Being part of a community can help in the long term. Autistic community groups may be a good place to find friends who understand what it's like to be autistic. In some areas you can find in-person support groups, such as the <u>Asperger-Autism Network in Massachusetts</u> or a <u>local ASAN affiliate</u>. Your local DD Council or Independent Living Center may also be able to help you find a group. Groups such as the <u>Autism Women's Network</u> may be good ways to find other autistic women or gender minorities. You can also find autistic support groups online.

• Keep in mind that autistic community groups may not be prepared to help people who are in a major crisis, especially people who are new to the group.

Make a plan for who you want to be around you when you are feeling very bad. Pick the people who you do not have to be anything but yourself around. Also pick people who know how to make you feel better and who can stop you from hurting yourself if they need to. Make sure to think of more than one person, in case the first person you call is not able to help.

Tatja Hirvikoski et al., *Premature Mortality in Autism Spectrum Disorder*, 208 Br. J. Psychiatry 232, 234-35 (2016) (describing the high mortality rate of autistic people, and that one cause of death contributing to this rate is our higher likelihood of committing suicide).

Tell the people close to you who to call if you are having a mental health crisis. This will help ensure that they don't panic or call someone who you don't want to be called.

If you are worried that you may hurt yourself, try to get rid of any objects in your house that could be used to seriously hurt you. It might be impossible to get rid of everything. Consider giving these objects to a friend until you feel safe again. Some people put dangerous objects in a locked box and give the key to a trusted friend.

Create a safety plan. Having a plan for what to do when you are thinking about suicide or in a crisis makes it easier to remember what to do. Your plan could include:

- The name and phone number of your therapist or clergy
- Things to think about that will make you want to stay alive
- A list of objects to get rid of or give to others when you are not feeling safe
- The name and phone number of friends or family who can help you
- Safe places that you can go, and
- Any other things that help you.

Creating a list of specific things to do in a specific order might make the list easier to follow. You can use a form that is available here.

Consider calling or texting a suicide or mental health crisis hotline. If you can't call people because you have trouble speaking, you can use a text crisis hotline like http://www.crisistextline.org/faq/. If you want more links to mental health crisis hotlines you can call, you can check the Resources section at the end of this toolkit.

Consider going someplace safe. This could be friend's house, place of worship, or community center. Some states have a network of **respite centers.** These are places you can go for a short time when you are not feeling safe. Note that some respite centers are better than others. It can help to ask others who have been to your local respite centers about their experiences. That way, you can know in advance which center would be best.

Be careful about calling the police if you are having a mental health crisis. The police are not trained mental health professionals. They are trained to "control the situation," which can make mental health crises worse or put people in danger. If you feel that you need to go to a hospital, consider asking a friend to come drive you instead of calling 911. However, if you are seriously hurt and need medical attention, you may want to call 911 so they can send an ambulance.

Hospitals. If you don't feel safe and nothing else helps, psychiatric hospitals or wards are a last resort. However, while some people find hospitals helpful, others do not. Some hospitals are better than others. To find out which psych wards would be best for what you need, you can visit a review site such as https://psychwardreviews.com/. This site does not have reviews for every hospital, so you may also want to talk to people in your community about which one is best for autistic people, or people with problems similar to yours. Some hospitals also have reviews on sites like Google or Yelp. Tell people close to you in advance if there is a hospital that you prefer over others, or if there is a hospital that you absolutely don't want to go to.

Keep in mind that if you say you are suicidal, a hospital may be able to keep you in the hospital for several days. They will be able to keep you in the hospital even if you decide you want to leave. If you go to a hospital, make sure to tell people where you are going and how to contact you. Make sure to bring things you might need in the next few days. Hospitals may take away things that they think are dangerous, like sharp objects or long strings. They may also take away cell phones. This is one reason it helps to bring activities to keep you busy, such as books. You should also bring a written list of phone numbers of family and friends.

Write a psychiatric advance directive. If you are worried that you will have a mental health crisis in the future, you can write down instructions on what you do and don't want to happen. This is called a **psychiatric advance directive.** Psychiatric advance directives can include instructions on:

- Who you want to make decisions for you if you can't make them yourself
- Who you do and don't want to visit you if you are in the hospital
- Which hospitals you prefer or don't prefer
- What medications to try or not try (including a list of medications that you know don't work well for you)
- Whether or not you consent to electroconvulsive therapy (ECT). ECT is sometimes used for people with very serious depression.

Different states have different laws about how to write a psychiatric advance directive. For more information visit the <u>National Resource Center on Psychiatric Advance Directives</u>.²

Nat'l Resource Ctr. on Psychiatric Advance Directives, http://www.nrc-pad.org/ (last visited Oct. 11, 2017).

Avoiding Unnecessary Police Interactions, Creating Alternatives to Policing and Making Better Police Forces

As we note in our Research guide, people with disabilities - especially people of color - may face discrimination by police. Police may criminalize people with disabilities for our disabilities and use excessive force when interacting with people with disabilities. Many counties and cities are also relying on the police as first responders for mental health crisis situations rather than funding social services and crisis teams that would be safer to use as first responders. This makes people with disabilities less safe. Self-advocates can **try and advocate for a better police force, for improvements to our communities that make them safer places to live,** and for **community-based methods of solving problems that reduce or eliminate the need for police involvement.**

Setting up a Safety Plan¹⁵

Sometimes we need help in order to keep us safe in an emergency. However, you might not feel comfortable calling the police. If you want to, you can set up a safety plan to minimize phone calls to the police. The safety plan can describe various things that you would like your friends, family, or relatives to do in the event that something dangerous is happening. This group of people is called your *support network*. Having a support network during a mental health crisis or other significant crisis helps.

Some examples of what could go into the safety plan are:

- The best ways to calm you down when you are very angry or very sad and are reacting in a way that might be dangerous to you or someone else
- Which people to contact if you get lost, have a mental health crisis, get into a fight with someone else, or are somewhere dangerous and are having trouble getting away
- A step by step list of instructions that you want people to follow which explains, if you need it, which hospitals to take you to and which treatments to use in the event of a mental health crisis (often called a **psychiatric** advance directive)
- If you have dependents or pets of any sort, also include who should take care of them in the event you are unable to temporarily care for them.

Your safety plan should reflect your personal circumstances. For example, you may create a safety plan that you *only* use when you are harming yourself or others or at risk of harming yourself or others. You could also create two different safety plans: one to use when you are suicidal and one to use when you are having a meltdown or other crisis, but are not suicidal.

Using medical ID bracelets

It can help to be able to show police officers or other first responders that you have a disability, especially if you are non-speaking or lose your speech when you are tired or frightened.

See David M. Perry, Lawrence Carter-Long, The Ruderman White Paper on Media Coverage of Law Enforcement Use of Force and Disability: A Media Study (2013-15) and Overview, Ruderman Foundation 5-8 (2016), http://rudermanfoundation.org/white-papers/media-coverage-of-law-enforcement-use-of-force-and-disability/; Ruth Marcus, Virginia's governor should keep an autistic man out of prison, The Washington Post (Jan.8, 2015), https://www.washingtonpost.com/blogs/post-partisan/wp/2015/01/08/virginias-governor-should-keep-an-autistic-man-out-of-prison/?utm_term=.29058fba03c8 (Neli Latson's case).

See Boris Sanchez and Kevin Conlon, North Miami shooting: Man, wounded caretaker reunite, CNN (July 28, 2016, 7:24PM), http://www.cnn.com/2016/07/28/health/north-miami-police-shooting-reunion/; San Diego District Attorney's Office, Officer-Involved Shooting Review: Analysis of Cases Reviewed by the San Diego County District Attorney's Office 1993-2012 (December 2014); Nadja Popovich, Police shooting of mentally ill woman reaches U.S. Supreme Court: Why did it happen at all? The Guardian (Mar. 23, 2015, 7:15AM), https://www.theguardian.com/us-news/2015/mar/23/police-shooting-mentally-ill-teresa-sheehan-supreme-court.

Kate Hamaji et. al., Freedom to Thrive: Reimagining Safety and Security in Our Communities 1, 3 (Jul. 5, 2017), https://static1.squarespace.com/static/5500a55ae4b05a69b3350e23/t/595cf69b1b631b031e0542a5/1499264677929/Freedom+to+Thrive+Web.pdf [hereinafter "Freedom to Thrive"].

 $We got parts of this suggestion from Rose City Copwatch, \textit{Alternatives to Police} \ (2008), \ \underline{\text{https://rosecitycopwatch.files.word-press.com/2010/03/alternatives-to-police-draft.pdf}}.$

Some people suggest carrying an "autism ID card" to take out when talking to police. We do not recommend this because police may assume that people reaching for a card are actually reaching for a weapon.

Medical ID bracelets might be a better option. If you are wearing a medical ID bracelet, all you have to do to show you have a disability is hold up your wrist. This does not look like you are reaching for a weapon. The bracelet has a special symbol that lets first responders know that you have a disability or medical needs. You can have information about your disability written on the inside of the bracelet. Once first responders know you have a disability, they are likely to be understand why you are having trouble talking or following directions. They may also be more receptive to alternative methods of communication you use, if any (such as augmentative and assistive communication device (AAC) or a phone keyboard).

Helping Advocate for Better City Budgets and Investments in Community and Social Services

Many cities and counties rely on the police to respond to mental health crises. These jobs could be better done by a city's social services. Many cities also do not spend enough money on infrastructure, community centers, mental health services, and schools that improve community safety. In part because local governments are relying on police to do jobs that should be done by social services, they end up spending a lot of money on police. That money could be spent on other things.

One way to change that is by adding your voice to **participatory budgeting** councils and planning committees. Participatory budgeting is a way for community members to help decide how a city or town spends its money. They do so by bringing the community together to vote for what the city will fund. One example of participatory budgeting is the Hartford, Connecticut project, "Hartford Decides," in which citizens 13 and over decided how to spend \$1.25 million in Capital Improvement funds, which would be invested into the city's infrastructure. ¹⁸ People voted for everything from improved park lighting to better security at the city's senior wellness centers. ¹⁹ Hartford Decides, for its Year One project, ultimately decided to use the city's Capital Improvement funds to install 14 murals in each of Hartford's neighborhoods. ²⁰ The Participatory Budgeting Project's website and Annual Report says that participatory budgeting has been used to redirect funds towards new technology at schools and libraries, as well as improved local bike lanes, playgrounds, and other aspects of communities. ²¹

If you want to get involved with participatory budgeting, the Participatory Budgeting Project provides examples of projects in major United States cities. It also offers suggestions for how to start a project if there aren't any where you live. You can find these materials on its <u>website</u>.²²

Freedom to Thrive at 3.

¹⁷ Freedom to Thrive at 3-4.

Vinny Vella, Hartford Inmates Help Decide How City Spends 1.25 Million, Hartford Courant (Mar. 30, 2016 5:25PM) http://www.courant.com/community/hartford/hc-hartford-inmates-voting-0330-20160330-story.html.

¹⁹ Id.

²⁰ Hartford Decides, *Paint the City*, http://www.hartforddecides.org/paint-the-city (last visited Oct. 8, 2017).

Participatory Budgeting Project, Our Impact, https://www.participatorybudgeting.org/impacts/ (last visited Oct. 8, 2017).

Participatory Budgeting Project, Participate in PB, https://www.participatorybudgeting.org/participate/ (last visited Oct. 11, 2017).

Advocate for Greater Police Accountability

National advocacy organizations across the country have made policy recommendations for creating a safer and more effective police force. For example, Campaign Zero, founded by the organization We The Protesters, has created a 10-point list of policies²³ that would create more accountable, better trained, de-militarized police forces. The Center for Popular Democracy also created a toolkit on police accountability²⁴ that recommends similar policies. These policy changes include:

- Creating **independent or special prosecutors' offices.** These are state agencies separate from both the regular state prosecutor's office and the police department. They prosecute cases where a police officer appears to have committed a crime.²⁵ Campaign Zero also calls for investigators of police misconduct complaints that are independent of the police department that is being investigated.²⁶
- Reforming or eliminating laws against very minor offenses, such as jaywalking, disorderly conduct, or loitering (staying in the same public place for too long without a good reason).²⁷ These reforms would also stop people from being arrested for minor school disciplinary issues. This phenomenon is called the **school-to-prison pipeline.** For more information on the school-to-prison pipeline, see page 12 of the <u>Research Guide</u> of this toolkit.
- Banning racial, ethnic, religious, or immigrant status profiling by changing state laws, regulations, and police trainings. These new rules would not allow police officers to stop, arrest, or otherwise profile people based on their race, ethnicity, apparent or actual religion, and immigrant status.²⁸ We believe these rules should also cover profiling based on disability.
- Creating civilian oversight commissions or boards. These are agencies made up of citizens of a particular city
 or municipality who can recommend a course of action when a police officer is accused of police misconduct
 towards a person in that city or municipality.²⁹
- Revising laws or regulations regarding police use of force, so that use of force is only authorized in extreme situations where there is a high risk of harm.³⁰
- De-militarizing the police, such as by passing local laws that prohibit them from using or acquiring military-grade weapons.³¹

These policies, if enacted, may make it less likely that you and people like you will encounter excessive police use of force or police violence. One way to fight for these policies is to join with organizations that are fighting for policies like these. You can contact your own state government to fight for these policies as well. Campaign Zero itself lists different ways that civilians can take action on the bottom of its website.

Campaign Zero, Solutions, https://www.joincampaignzero.org/solutions/#solutionsoverview (last accessed Oct. 23, 2017) [hereinafter "Campaign Zero"].

Center for Popular Democracy, Building a Movement from the Ground Up: A Toolkit for Promoting Justice in Policing (2015), http://populardemocracy.org/news/building-momentum-ground-toolkit-promoting-justice-policing, [hereinafter "Center for Popular Democracy"].

²⁵ Campaign Zero.

²⁶ Id.

²⁷ Id.

²⁸ Campaign Zero, Center for Popular Democracy at 19.

²⁹ Center for Popular Democracy at 25.

³⁰ Id.

³¹ Id.

Becoming Part of Advocacy Groups That Help Reform The Police

The report *Freedom to Thrive* describes how activists in cities all across the country are fighting for better city police forces.³²

- In Baltimore, the Campaign for Justice, Safety, and Jobs (CJSJ) successfully advocated for a change in the law that would make sure police officers were trained better.³³ They also made sure people had a way to report if they were mistreated by police.
- In Chicago, activists helped create a Civilian Police Accountability Council that helps keep police accountable, among other major reforms.³⁴

You could try to become part of similar groups in your city or town. It's important that these movements hear from people with disabilities, especially people of color with disabilities.

You could also join national organizations with the same goals. Here is a brief list of just some of the national organizations and different ways you can get involved with them, as well as a link to a much larger list of such organizations.

Black Lives Matter

The Black Lives Matter Global Network is an organization that works to end violence and racism against Black people worldwide.³⁵ Black Lives Matter is also the name of a larger international movement. The Black Lives Matter Global Network has many chapters in United States and Canada. Chapters organize protests and advocate for policies that reduce systemic violence against Black people, including the reduction of police violence.³⁶

You can join a Black Lives Matter chapter by <u>searching their map for a chapter near you.</u> You may also be able to <u>sign</u> <u>up for their action alerts.</u> While using the hashtag #BlackLivesMatter does not automatically make you a member of the organization, it may help you connect with other advocates for reduced police violence and systemic racial justice.

National Police Accountability Project

The National Police Accountability Project is a nonprofit organization made up of lawyers, nonprofit attorneys, paralegals, and other advocates who combat excessive police use of force.³⁷ It helps people find lawyers and access resources if they have been the victim of police violence. The lawyers involved work on police misconduct case, including cases that involve jail and prison guards.³⁸ They also give information to the public about police misconduct, support attorneys working on police misconduct cases, and support broader legislative reform efforts that reduce the risk of police violence.³⁹

If you are a lawyer yourself, you can volunteer to join the project's listserv. You can also <u>find a lawyer on the project's</u> <u>website</u>.

Freedom to Thrive at 4-74.

Freedom to Thrive pg. 16.

Freedom to Thrive pg. 22.

Black Lives Matter, What We Believe, https://blacklivesmatter.com/about/what-we-believe/ (last visited Oct. 18, 2017).

Black Lives Matter, Find a Chapter, https://blacklivesmatter.com/take-action/find-a-chapter/ (last visited Oct. 18, 2017).

National Police Accountability Project, *About Us*, https://www.nlg-npap.org/about (last accessed Oct. 19, 2017).

³⁸ Id.

³⁹ Id.

Funders For Justice List

The website <u>Funders for Justice</u> keeps a list of police reform organizations, both national and local.⁴⁰ The list contains the contact information and names of many of these organizations, both local and national. You can click on any name in the list to get a brief description of what the organization does and a link to the organization's website. From the organization's website, you can find out how to get involved.

Many of these groups have made resources that you can use to advocate for policies locally. See the Research Guide of this toolkit for more information.

Funders for Justice, Organizations Addressing Police Accountability and Racial Justice, http://fundersforjustice.org/organizations/ (last visited Oct. 19, 2017).

What to Do If You Get Lost

Sometimes you might find that you have gotten lost, and you do not know how to get home or what to do next.

A lot of parents and professionals are very worried about this. They have suggested things like:

- Putting tracking devices on autistic people
- Giving us special disability ID cards that would go in our wallets. These might be a problem if an autistic person reached into their pocket to get the ID card in front of a police officer, who might think they're reaching for a gun instead
- Stopping us from going where we want to go

Being lost can be scary. But most of us would rather be able to get help if we get lost, instead of being stopped from going where we want to go. Here are some ways that you can stay safe if you are lost and don't know where to go.

Make A Plan for What to Do If You Get Lost

If you get lost often, one thing you should probably do is make **a plan** for what to do when this happens. Here are some ideas for what could be part of your plan.

Contacting your friends or family

- Carry a phone everywhere you go with the phone numbers of people you know. Make sure that your phone is charged. That way, if you get lost, you can call someone or text them for help.
- If you do not have a phone, carry a written list of phone numbers. If you get lost, you can borrow a phone to call or text for help.

If you have a smartphone with a GPS, you can download a **personal safety app** that lets you tell your loved ones where you are. If you are lost, you can tell the app to text your location to a specific person. The app will only text the people you want to text, and only when you want to let that person know where you are. You can find a list of personal safety apps here,⁴¹ or search for yourself online.

Asking for help

Sometimes you may need to ask a bystander for help. This can be hard if you are scared or overwhelmed, or if you have communication needs.

- If you use an augmentative and assistive communication (AAC) device or several AAC devices to communicate, you can program a scripted message into your device(s) that you can use when you get lost. This way, you don't have to write a new message when you are lost and feeling overwhelmed. The script could state your name and your disability and explain that you are lost and need help getting back to where you need to be.
- You could also print out a card with a message to show bystanders if you are lost. Again, however, you may need to be careful when pulling out cards during encounters with police officers.
- Carry some form of identification around. Make sure the ID includes your name, your address, and an emergency contact. People will be able to check it if there is an emergency.
- Bring credit cards or money with you when you go out, in case you have to get a taxi home.
- Don't accept rides home from strangers who aren't uniformed first responders, especially if you don't have your phone with you. Avoid going into strangers' houses or otherwise going anywhere alone with them especially if you can't tell your friends where you are first. Use a taxi or rideshare company, or call a friend to pick you up.
- It is also okay to ask a stranger for directions when you're both in a public place.

Fox Van Allen, 5 Free Personal Safety Apps that Can Call For Help, Techlicious (July 15, 2016), https://www.techlicious.com/tip/free-personal-safety-apps/.

- If a stranger offers to guide you from one public place to another, that also may be okay. Avoid following them into areas where there are no people around, like back alleys. Ask to stay on the main streets.
- If you feel nervous about where a stranger is guiding you, start by telling them politely that you would rather go a different way, or would rather find your way on your own. If they keep trying to lead you somewhere you feel unsafe, tell them that you want them to leave you alone. **Don't worry about sounding rude or getting loud**. Someone who was really trying to help would respect your wish not to go somewhere you don't feel comfortable.
- If you have trouble recognizing the faces of people you know, listen to their voice and mannerisms and ask them for their name.

When using a taxi, Uber, or Lyft:

- Be familiar with taxis in your area. In most places, taxis have to have a sign on top of the car (called a **medallion**), or must be painted in a special way. Anything else is not a real taxi.
- If you get the chance, check the Uber or Lyft driver's phone to see if your name or your address appears on it.
- Most Uber or Lyft drivers will repeat both your name and the address of the place they are taking you. If they do not, ask them for both pieces of information. If you can't ask questions verbally, write those questions down or put them into your AAC device before your ride arrives. That way you can ask before getting in the car.
- Check that the license plate on the back or front of the car that is picking you up is the same one listed on the Uber or Lyft app. If you have trouble reading the number or remembering it, you could ask someone nearby to read the number out loud for you.

Helping people find you

- Create a list of places you go to a lot and then show the list to someone else. That way, if someone comes to find you, they know where to look.
- If you are going somewhere with a group, decide on a meeting place where you and other people will go if you get lost or need to get away. That way, you can go to that place and people will know where to look for you.
- If you are very lost in a building, head towards the front entrance of the building and look for the nearest person. You might be able to find someone who can point you in the right direction. If you are very lost outside or on the street, head towards an area with a lot of people and ask someone for directions.
- If you are lost outdoors where there are no other people, stay close to where you got lost so that people know where to find you. If you are near a body of water, like a lake or a stream, sit next to it. First responders are more likely to look for people near bodies of water. You should **not** go into the water or try to drink from it, as most bodies of water are not safe to drink from or swim in.

Know how to get around and how to use safety skills

Whenever you are going somewhere new, you generally need to know:

- Traffic safety skills
- How to use the local public transportation and/or get a taxi
- How to communicate with people when you are lost in a crowded area

If you are going near water, you may also know how to swim.

If you have these skills, it will be easier to get around wherever you want to go. But sometimes we may not have learned these skills because nobody taught them to us.

It's never too late to learn the skills you need to get around. There are a couple different ways you can learn them. You could ask your friends or family to teach you how to do some of these things. You can also take a class for some skills, like swimming.

Some skills, like traffic safety skills, are best learned by doing. You can ask people you know if they would be willing to do trial runs with you. For example, you could go out on a crowded day with your friend and they could show you how to cross the street and talk to people. Another person with the same disability or combination of disabilities would be best for this, since they are the most likely to notice which difficulties you might have and offer good solutions. A family member or friend who knows you very well is another good option.

When learning how to use public transportation, it is best to bring someone else along during the first few trips on a bus or city Metro train. Both buses and trains might require you to time your actions correctly to get off where you want to go.

You might also be able to learn about your city's public transportation system by participating in a **travel training program.** For example, the Washington Metropolitan Area Transit Authority (WMATA) runs something called the MetroReady Travel Training program, which teaches people with disabilities about the Metro and MetroBus buses and their accessibility features. To look up travel training programs in your area, you can search "travel training programs" and the name of either your city or its transportation authority.

To know how to use public transportation, you also have to know which buses and station lines will take you where you want to go. This may mean learning how to read a transportation map. For example, in the Washington, D.C. area, if you want to go somewhere on the Metro you generally need to know the closest Metro stop, which line the closest Metro stop is on, and any buses that you will need to take after you get off the Metro. Take some time to memorize your route on a day when it will not be a problem for you if you have trouble. For example, if you want to memorize your route to work, try going there on a weekend. Keep in mind that on weekends there may not be as many trains or buses, and there may not be as many people as during the weekday.

If you're getting help learning how to navigate outside, make sure the person helping you doesn't do everything for you. Once you feel like you understand how to do something, ask them to stand back and let you try. Doing something yourself is very different from being told how to do it.

Examples

- Sally likes the water and wants to go swimming in her neighbor's pool. Sally does not know how to swim, so she is worried that she might get hurt if she steps into the pool. Sally decides to take adult swimming lessons with her friend Joan. Sally learns how to swim after two months and can go to the pool.
- Mi Sun wants to learn how to use public transportation. She wants to know how to take a bus to work. Mi Sun calls her friend Imani, who knows how to take the bus almost anywhere. Imani teaches Mi Sun how to get on the right bus, pay the bus fare, and stop the bus nearby work. Mi Sun is able to get to work using the bus.

Be Prepared for the Unexpected

Sometimes, something might happen that is not normal.

Sometimes the Metro station near your work could be closed due to an accident.

Sometimes you miss your stop.

Sometimes an ambulance is driving through when you try to cross the street, and it does not stop when the traffic light is red.

Sometimes it is raining hard outside and so the stream you like to hang out by is way too dangerous to hang out by.

When the unexpected happens, take a moment to figure out what to do. You may need to go back home or go somewhere else so that you can think things through. If you cannot go somewhere else, try to contact someone you know. They might be able to tell you what to do next.

You could also go over some of the most common unexpected situations with another person. There are certain things you should always do in response to an unexpected situation.

• For example, always wait until an ambulance passes out of sight before crossing the street, even if the "Walk" sign is lit.

You could also come up with what to do in the event that you cannot do something that you planned to do. Many of us are disappointed when we cannot do something we want to do, but there may be alternatives. For example:

- If it is raining hard outside and you can't visit your favorite stream, you could go out into your backyard instead in a raincoat and play with the water there. You could also enjoy a relaxing bath.
- If you need to get somewhere and the way to get there is sometimes blocked (such as when the Metro station is closed due to an accident), you could come up with an alternative way to get where you need to go. For instance, in the 'Metro is closed' example, you could look up a bus route that also gets you to your destination.

Resources

For more information on any of the subjects we talked about in this guide, you can go to the websites and read the documents we list below.

On Abuse and Neglect

- Domestic Shelters.org's list of domestic violence shelters: https://www.domesticshelters.org/search#?radius=50&page=1
- Green Mountain Self Advocates' self-advocate resources: http://www.gmsavt.org/trainings-and-resources/resources/
- Loveisrespect.org: http://www.loveisrespect.org; their resource on calling the police: http://www.loveisrespect.org; the police: http://www.loveisrespect.org; the police: http://www.loveisrespect.org; the po
- National Disability Rights Network's list of Protection and Advocacy organizations: http://www.ndrn.org/ndrn-member-agencies.html
- National Adult Protective Services Association's list of Adult Protective Services agencies: http://www.napsa-now.org/get-help/help-in-your-area/

On Suicide

- PleaseLive's list of abuse hotlines: http://www.pleaselive.org/hotlines/
- Crisis Text Line: https://www.crisistextline.org/faq/.
- Psych Ward Reviews: https://psychwardreviews.com/
- Example of a personal safety plan: http://www.sprc.org/sites/default/files/resource-program/Brown_StanleySafetyPlanTemplate2.pdf

On Bullying, Abuse, Neglect, and Restraint and Seclusion in America's Schools and Segregated Settings

- Department of Justice's Title II of the Americans with Disabilities Act Technical Assistance Manual: https://www.ada.gov/taman2.html and Title III Technical Assistance Manual: https://www.ada.gov/taman3.html
- Information on How to File a Department of Education Office of Civil Rights Due Process Complaint: https://www2.ed.gov/about/offices/list/ocr/complaintintro.html
- ASAN's "Empowering Leadership: A Systems Change Guide for Autistic College Students and Those with Other Disabilities": http://autisticadvocacy.org/wp-content/uploads/2013/08/Empowering-Leadership.pdf
- U.S. Department of Education's summary of restraint and seclusion laws by state and territory: https://www2.ed.gov/policy/seclusion/seclusion-state-summary.html#co

On Strategies to Improve Policing and Finding Alternatives to Calling the Police

- Freedom to Thrive: https://static1.squarespace.com/static/5500a55ae4bo5a69b3350e23/t/595cf69b1b631b031e0542a5/1499264677929/Freedom+to+Thrive+Web.pd
- Alternatives to Police by Rose City Copwatch: https://rosecitycopwatch.files.wordpress.com/2010/03/alternatives-to-police-draft.pdf
- Participatory Budgeting Project: https://www.participatorybudgeting.org/participate/

On Safety In Your Community

- Examples of personal safety apps: https://www.techlicious.com/tip/free-personal-safety-apps/
- Organization for Autism Research's Guide to Safety: https://researchautism.org/resources/a-guide-to-safety/
- WMATA's MetroReady Travel Training program: https://www.wmata.com/rider-guide/new-riders/Travel-Training.cfm
- MTM's D.C. Travel Training program: https://www.mtm-inc.net/public-transit/dc-travel-training/