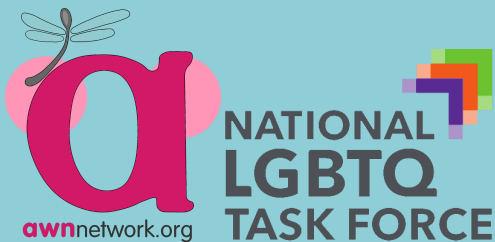


Before You Go:

Know Your Rights & What to Expect at the Doctor and in the Hospital

Tips and advice (life hacks!) for autistic trans people about finding and going to doctors

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Illustrations by Erin Casey [Human]



Research and community storytelling reveal

that autistic and trans people experience major health disparities in access to care, quality of care, and health outcomes for physical and mental health care. Many of us also experience discrimination, prejudice, and bias in doctor's offices and hospitals, even in clinics meant to serve marginalized communities.

For autistic and trans people who haven't had reliable access to health care, the processes of finding providers and knowing how to plan for disability-related access needs can be scary, confusing, and complicated.

The Autistic Women & Nonbinary Network and the National LGBTQ Task Force are excited to share a guide for trans autistic people called *Before You Go: Know Your Rights & What to Expect at the Doctor and in the Hospital*.

This guide will help our trans and autistic community members know better what to expect when going to doctors or hospitals, understand rights and responsibilities, and strategize for safety planning, effective communication, accommodations, and more.

Life hacks!



1. How do I choose a doctor for the first time?

We all need doctors or other health providers at some point. Choosing a new one can be a scary and intimidating experience. First you need to evaluate what kind of doctor you need. Your first one may be a primary care provider (PCP) or general practitioner (GP), or a specialist in a specific condition. Some health insurance plans require you to have a primary provider who then refers you to the specialists.

Your health insurance, if you have one, will include a listing on its website of health providers who accept that plan, usually sorted by specialty. Google is always an alternative, but also look into magazines and directories of recommended providers. For example, in some cities, magazines will have "top doctors" directories by specialty. You can find one by word of mouth (don't hesitate to ask friends in similar situations who they see).

You should call the provider to make an appointment. Before you schedule it, make sure to ask if they're taking new patients and if they accept your insurance. There will usually be paperwork on day one of your first appointment.



2. How do I choose a therapist for the first time? What if I want to see a new therapist?

When you're wanting to choose a therapist, you first have to decide on a couple different things. You need to make for sure you're looking within the parameters of someone who will represent you, and someone you feel will represent your situation. If you're looking for someone who understands about trans issues, you need to research what therapists, if any, in your area do trans work. You have to look for someone who's going to have the experience that you're seeking guidance in. It needs to be a good match. There's a lot of legwork you can do. Sometimes it takes emailing, googling, calling, looking on their websites, looking for reviews, seeing what kind of work they do. Sometimes these extra few minutes you take in the beginning will save you a lot of time in the end.

There's always going to be insurance issues. To save time, make for sure you have your booklet from the insurance company, if it says you only have certain providers. Put their names in the search bar and see what they practice. You're not always going to find someone who's a perfect match. Probably no one will be a perfect match for any of us.

You might want to find someone who specifically understands being nonbinary, having PTSD, and being a survivor of domestic violence - but you might not be able to find someone who understands all of that. But a therapist could eventually recommend someone else who can cover one of the other areas, or even a support group. Sometimes you have to be flexible about who you find. You can go to the therapist and tell them the other things you're looking for, and if they're worth their title, they'll be able to point you to other resources that can help you in the other areas you're looking for. A lot of times, you'll find a therapist who'll even recommend books and invite you to bring in readings to go through together. Prioritization is very important, and you also have to be able to give yourself a break. We can be so deep into trauma that we can't prioritize. We may not have the ability to know what we need most in that moment. It's okay if you can't prioritize to just pick one.

3. Should I choose a doctor or therapist who's better with autistic people? Or one who's better at trans stuff?

For some people, it's more important to find a therapist who understands trans issues. For other people, it's more important to find a pro-neurodiversity therapist who understands autism. Only you know what you need and what would be most helpful for your situation.

Some people decide to focus on finding a therapist who understands trans issues, or even a therapist who is trans themselves. They might feel better about educating their therapist about being autistic than about being trans.

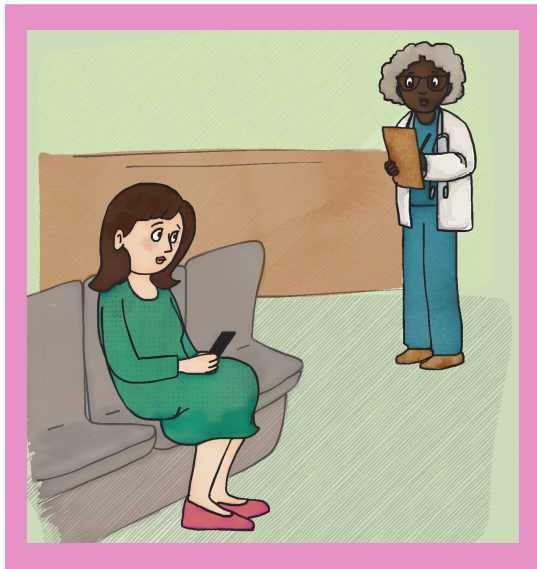
Other people decide to focus on finding a therapist who understands autism, or even a therapist who is autistic themselves. They might feel better about educating their therapist about being trans than about being autistic.

You can also decide to change therapists if you decide your current therapist isn't helping, or if your current therapist makes you feel unsafe.

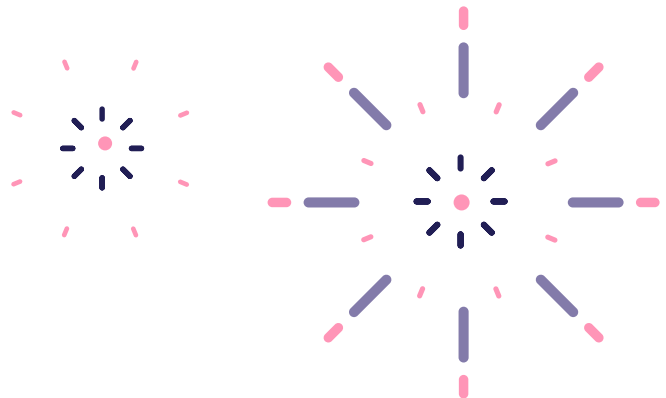


4. What is low-cost or sliding-scale care? How can I find out if a doctor offers this?

Sliding-scale fees are based on income and household size (e.g. two parent households with five kids). Some places will go farther than that. Many people don't know to ask but there are also some places (but not all) that take into consideration your expenses.



Many places that offer sliding-scale fees will advertise this information. You can find out right away with a phone call or looking at the website. If you know you need any kind of care, treatment, or therapy at sliding-scale, find out first by making a call or sending an email about whether they offer the fee.





5. What is urgent care? When should I think about going to urgent care?

Urgent care is different from a regular doctor. Urgent care is meant to help if you get sick and you can't see a regular doctor (because you're on vacation, or you don't have a regular doctor). It's not meant to be a replacement for regular care. It's one step above an emergency room. If you go to urgent care, they'll tell you if you have to go to the emergency room instead. When you call to get in, you can ask what the basic cost is to see the doctor before you go, and if they take your insurance.

A primary care physician (PCP) if you have one, is your main contact. Always try to call and get an appointment with your PCP. But if you call your doctor, and they don't have an appointment for a week and you're really sick or leaving town and want to know if you're OK to travel, then you could go to urgent care.

Sometimes people use urgent care offices as intermediate care. Urgent care is there for people who can't get into their doctor the same day and want to be seen. It's also there for people who don't have a doctor at all, or who are traveling. Urgent care usually accepts insurance, if you have it. However, unfortunately, because not everyone has insurance, many people are forced to use urgent care or emergency rooms as primary (or regular) care.

Other people use urgent care even if they have a regular doctor because it's convenient.



6. When do I know if I should call 911? Can I go to urgent care instead?



A lot of people think that urgent care is the same as the emergency room. But urgent care offices usually won't help with medical emergencies. If you go to an urgent care, they will send you to the emergency room if you have a serious medical emergency.

Sometimes it's better to go straight to the emergency room instead of to urgent care first. For instance, if you're having severe chest pain, dizziness, and shortness of breath, you should probably go to the emergency room instead and they will tell you what kind of help you need.

If you're in doubt and you don't know for sure if you need help right away, err on the side of caution and go to the emergency room.

If you feel you need treatment right away, go to the emergency room.

If you have an injury, severe pain, or severe sickness that needs treatment right away, go to the emergency room.

If it's after normal business hours and you know your doctor's office is closed, go to the emergency room. Most urgent cares are also closed after business hours.

If you don't think you can get yourself to the emergency room, and you don't have anyone who can take you, you can call 911.



7. What happens if I call 911?

When you call 911, a person will answer the phone (called a dispatcher) who will ask what your emergency is. It helps to tell them clearly what is happening and what you need help with.

Sometimes, you can ask for the type of help you need - medical, fire, or police. Other times, calling 911 will always result in police being sent to you. For many trans and autistic people, being around the police is not safe, so some people might not feel comfortable calling 911. In other situations, it might feel more important to get help in an ambulance, since the people who work in the ambulance are trained medical professionals.

If you're taking in an ambulance to a hospital, and you don't have insurance, you might end up with a very large bill later because of insurance laws.

You should make a decision for yourself whether it makes sense to call 911 or not.

If you're worried about calling 911, you can set up a safety plan with people you know and trust in advance, so you have someone else safe to call.



8. How do I tell a doctor that I'm trans or autistic? How do I know whether I should disclose?

At some point in your patient/provider relationship, there will be a need to decide if to disclose you being autistic, or trans, or both things. It is worth keeping in mind at this instant, why are you seeing this doctor? Some providers have denied transition related care like hormones to trans autistic people on the basis of their being autistic. If you're seeking transition-related care, you need to weigh the pros and cons of their knowing of your autistic status. Not all providers who understand trans health issues understand autism and vice versa. Other times, many providers have refused to treat patients because of their being trans.

One consideration is, how easily can you switch a provider? You may be able to just find another primary care doctor, or they may be the only one taking new patients with your insurance. Or you may be inside a hospital seriously ill where you can't just walk away and find a new provider. If what you're seeking care for does not affect either of those things, you may decide to play it safe and not disclose.

Sometimes it helps to ask doctors or nurses to accommodate a specific need, instead of telling them about a disability or diagnosis. For example, it can be easier to ask medical professionals to tell you before they touch you and only touch you where you can see them, than to say you have post-traumatic stress disorder or sensory aversions.



9. How do I ask for accommodations for my disability? How do I know what accommodations I need?



At a doctor's office:

If it's your first-time visit, you're going to have to let them know if you need the lights turned down, for instance, as a sensory accommodation. A lot of times, you can fill out your medical information ahead of time before your first visit, and you can arrange for this request ahead of time. A lot of doctor's offices have this option online too. Try to take care of as many accommodation requests as you can in advance.

Since nurses and other staff can change a lot at doctor's offices, you'll often have to remind the receptionist to tell the nurse or other employee about your requests, like having the lights turned down or having a blanket.

If you feel you get stressed out at appointments, you might want to bring someone with you to your appointments to help ask for accommodations for you. We can sometimes forget to ask for what we need and want when we're under stress. But we can tell someone we trust what we want them to ask for when we get there.

In a hospital:

Usually when you're in the hospital, it's because of an emergency or because you're very sick. It's good to have a sheet you've filled out ahead of time that explains your disabilities and what accommodations you need. You can use SABE's resource - you can also consider having a medical bracelet. You can use a medical bracelet for any condition it's important to tell other people about.

10. What do I do if I'm worried that speaking up for myself will backfire?



You should feel affirmed and validated when seeing a provider, and your concerns should be addressed. However, this doesn't always happen, and some providers are better than others. Some providers may not pay enough attention to your concerns, or ignore them altogether. You should be firm in repeating your questions, or if you need to do so, seeking second opinions. You may be asked if you have further questions, at which point you should always use the chance to do so. If the provider shifts the question to unrelated issues (like, your gender identity or being autistic, for example), you should always try to deflect back to the reason you came here in the first place. That said, always be polite and courteous. Self advocate without pissing off people with the ability to kill you through negligence or malice.



11. What if I'm deadnamed or misgendered in a doctor's office or hospital?

This can happen in many ways, be it because your provider in the examination insisted on referring you by your deadname or wrong pronouns, or because the receptionist at the lobby loudly calls you by your deadname. When you choose a provider to begin with, if you're either confident they're trans friendly, or willing to take the risk of disclosing, make sure to let the intake person know your preferred name. If the doctor misuses it in the appointment, say "actually, I prefer x. Y is my legal name that I don't use" or something to that effect. Again, weigh the pros and cons, and be ready for the possibility of having to change providers or self-advocate if they refuse.





12. What if I want to bring someone with me to the appointment/hospital?

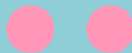
When you go to a doctor's office or a hospital, you can bring a friend, partner, family member, or support person with you. Usually, doctors won't say anything about your health in front of someone else though. Sometimes, you can tell the doctor it's okay with you to talk about your health with someone you trust in the room.

If you want the other person to be able to access all your information, it can be safer to sign a document called a release or waiver form that gives written permission for everyone in a doctor's office to share information with the person you trust. You should only do this if you trust this person with knowing private information about you. (You can also take back your permission by signing a different form later if you change your mind.)



13. What if I'm deadnamed or misgendered by my insurance company?

Many insurance companies require sex-assigned-at-birth information. There isn't any federal law that mandates how insurance companies collect information. Unfortunately, this means that doctor's offices can usually see this information too. If you feel comfortable, you can ask your doctor's office to use the name and pronouns you actually go by instead of the name and sex marker information on your insurance paperwork.



14. What's the difference between private insurance and Medicaid? Are there other kinds of insurance or ways to get insurance?

There are different kinds of insurance offered depending on your age, whether you're in college, or so on. If you're still in college and under 30, many companies will still let you be covered under your parents' plan if they have insurance. For other college students, including grad students, schools will sometimes offer a student insurance plan. For other people, it's common to get insurance through their job if they have a full-time job with benefits.

Currently, there is also an open market where you can fill out your personal information and income details, and then you can find out if you are eligible to buy a plan there or if you're eligible for a state Medicaid program.



Medicaid is a program for people who are low-income and/or have disabilities. There are also a few other groups of people who are eligible for Medicaid.

Medicare is a different program for people who are low-income and/or are elderly and/or have disabilities. Most people can become eligible for Medicare when they turn 65.

One of the biggest differences between Medicaid and Medicare is that Medicaid will sometimes cover "long term supports and services," like disability support important to many autistic trans people.



15. What is a power of attorney? What is an advance care directive? Why should I have them?



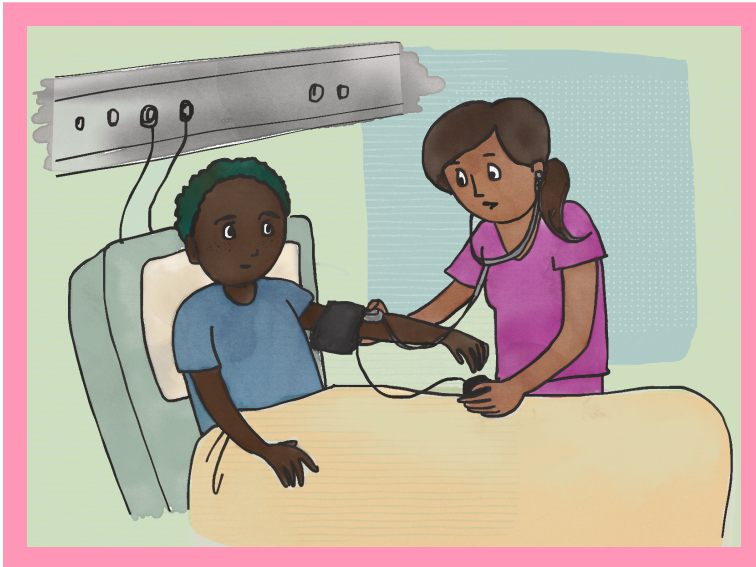
Power of attorney goes by many names, but usually, it means that you've created and signed a document giving someone else the authority to act on your behalf as far as the making of medical decisions goes. For example, if something happened that you can no longer make those decisions because you're unconscious, that person would be in charge of making them. This can be end of life care, or psychiatric care in a commitment, or even emergency situations arising from accidents or such. Normally a next of kin (family, spouse) will make these decisions. But if you don't want your blood family or spouse to be making those decisions in such a situation, you can assign someone else. This varies from state to state, and many states have forms that you can use to create power of attorney, so you should always research your circumstances and if possible consult an attorney in your home state or territory.

Advance care directives tell doctors what you want to happen to you if you become unable to express your choices or preferences - for instance, if you end up in a coma, or you aren't able to communicate but are on life support. You can decide if you want doctors to try to save your life and keep you alive. You can also decide if you'd prefer doctors give you palliative care (try to make you comfortable, and decrease pain) but otherwise let you die naturally. You can also decide if there are specific types of medical treatment or interventions you're okay with or not okay with. If you have strong preferences about what you'd want to happen to you if you end up in this situation, it can be important to make an advance care directive to make sure doctors follow your wishes. If you have one, you should tell people you trust where it is.

16. Can I bring a list of contacts with me to the hospital?



If you know you're going to the hospital, you can take a phone and/or a printout with important people's contact information. This can be a good idea especially if you're worried about how doctors or nurses might react to how you communicate, or if you know you'll need help advocating for yourself.



If you go to the hospital in the middle of an emergency, you might not have time to do this. You might also not be conscious! It can be helpful to have a card with important emergency contacts in a wallet in general, just in case there's an emergency.





17. What is safety planning? Can I do this before a doctor's appointment? What about before going to the hospital?

Safety planning is how you strategize about your comfort and safety. People make safety plans for all sorts of reasons. Sometimes, people make safety plans when going to protests. Other times, people make safety plans for leaving an abusive relationship.

Safety plans are practical and specific to you and your situation.

You can make a safety plan for going to a doctor. You can also make a safety plan for going to a hospital, if you know in advance you're going to go. These kinds of safety plans can include telling people you trust when you're going. You can also plan to bring someone you trust with you. You can plan to have someone you trust call you partway through the appointment to check how you're doing. You can also plan how you'll get to the appointment and how you'll get home.

Safety planning for emergencies can include setting up power of attorney, advance directives, and release/waiver forms that give permission for information sharing.



18. How can I plan to see a doctor or therapist if I'm living with an abuser?



You have to make a safety plan to see a doctor or therapist if you're living with an abuser. Seeking any medical treatment or therapy can be hard in an abusive relationship, because an abuser can try to convince you not to see someone or can try to call a professional and say you are crazy.

If your abuser is a parent, and they get medical guardianship over you, it can be unsafe to talk to a doctor. But it can - at least sometimes - be safer to tell a therapist that you are being abused.

If you're in a gay, lesbian, or same-gender relationship with an abuser, it can be harder to be taken seriously if you tell someone about the abuse.

Sometimes it is safer not to tell a doctor or therapist about abuse. In some cases, abusers can attempt to get and use your medical or therapy records to use against you, which can make it safer to keep information out of those records.



18a. What are my privacy rights?

Most medical privacy law is governed by HIPAA. In short, HIPAA is a federal law that requires that in the majority of instances, health providers cannot disclose your health information to others without your consent. Exceptions to these include when the provider thinks life or safety is in danger (for example, they may report to 911 if they believe you're suicidal), if you're a minor (in which case they can talk to your parents), or if you're under guardianship (again, with your guardian). This is neither exhaustive nor legal advice, and if you think your HIPAA rights are being violated you can make a complaint at the Health and Human Services Office of Civil Rights, or try to seek legal aid.

18b. How can I safety plan for telehealth appointments if I'm living with an abuser?

It's important to use a telehealth provider who lets you decide when to call in. That way you can know when it's safe to call the doctor.

During the COVID-19 pandemic, it can be even harder to safely plan for telehealth - and sometimes it might be impossible - because abusers at home are more likely to be at home all day.



19. Who should I tell if I'm being abused?

It isn't always safe to tell someone else right away. However, the safest person to talk to can be someone at an intimate partner violence shelter (sometimes called a domestic violence shelter). People at shelters are trained in confidentiality and how to help and support people being abused by any other person in their life - a romantic partner, a spouse, a parent, a friend, or someone else.



20. What happens if someone calls police to do a wellness check on me?

If a friend, family member, acquaintance or health provider is worried for your safety, they may decide to call 911 and ask the police to do a "welfare check". In theory, this means that they will come to your home and check that you are okay. They may or may not decide to take you to the psych hospital. Interacting with law enforcement can be dangerous, and even deadly especially if you're trans, autistic, and/or a person of color. To that effect, always be calm, speak softly, keep your hands where they can see them. While it is extremely unpleasant, do keep in mind you're dealing with people with guns and a history of using them.



21. What happens if I get taken to a psych ward, and get committed?



Sometimes, you can get committed to a psychiatric ward or hospital when someone calls police on you because of a mental health crisis. Sometimes, you can also get committed to the psychiatric ward even if you go to the emergency room for a mental health crisis on your own.

When you are taken to a psych ward, the staff will often take your phone or tablet. In some hospitals, you can keep your phone, but it depends on the specific hospital. It can be hard to have private conversations with anyone while you're there.

In every state, you have the right to a hearing if the hospital wants to keep you there for longer than a few days (usually 72 hours or three days). If the hospital wants you to stay longer but you want to leave, they have to file a petition to commit you. A judge will schedule a hearing to decide whether or not to commit you. You will have the right to a lawyer to represent you. In many states, this is someone from the public defender agency.

To successfully commit you, the hospital usually has to prove that you are dangerous to yourself or others because of a mental illness. The specific laws are different in every state. People often get committed if they attempt suicide, or if someone else thinks they might attempt suicide. Sometimes people also get committed if they are acting violently toward other people, making threats against other people, or if other people believe they're acting violently.

Often, hospitals will file the petition and create a hearing date, but will then let you go right before the hearing. This is not what the law is meant for, but it is technically legal.

While you're in the psych ward, the doctors might want you to take psychiatric medications, even if you don't normally take any. You can tell the doctors if you don't want to take the medications. If the doctors want to legally force you to take medications, they have to file a separate petition in court.



Other Resources



1. No Body is Disposable: Know Your Rights Guide to Surviving COVID-19 Protocols

No Body Is Disposable is a campaign by disabled, fat, queer, trans, people of color, and other marginalized communities facing discrimination because of COVID-19. This group published a free guide to prepare and safety plan for getting COVID-19 and going to the hospital.

2. National Queer and Trans Therapists of Color Network

The National Queer and Trans Therapists of Color Network is an organization of mental health professionals who are queer and trans people of color. They have an online directory of QTPOC therapists and other mental health providers.

3. Open Path Collective

Open Path Collective is a membership network of therapists across the United States who provide therapy for \$30-\$60 per session to people who have some financial need but can still pay something. You can join Open Path Collective for a lifetime membership fee of \$59.

4. Legal Aid

There are a few different types of nonprofit law offices that help people for free or for low cost with legal problems.

One type is a general legal aid office. Most cities, counties, or regions in a state have a legal aid office. General legal aid offices can usually help anyone in their area who is low-income with issues like housing, employment, or healthcare discrimination.

Another type is a community-specific legal aid office. Not every city, county, or region in a state has these. These offices help specific groups, like immigrants, Asian Americans, transgender people, day laborers, or people with disabilities. If you belong to the group the office helps, you can ask for help.

Another type is an issue-specific legal aid office. Some of these are also law clinics based in law schools, where students work with lawyers to help people with legal problems related to one area only. One example is Health Law Advocates, which helps people in Massachusetts with legal problems related to health care. Another example is the Network for Victim Recovery of DC, which helps people in Washington, DC with legal problems related to intimate partner abuse and related issues.

If you're trying to get legal help, you can sometimes ask your state's bar association or pro bono resource center to give a referral. Referrals can be to a nonprofit law office, a private law firm, or an individual lawyer who might be able to help.

5. Protection and advocacy agencies

Protection and advocacy agencies, often called P&A's, are an important type of community-specific legal aid office. They are federally funded offices that give free legal help to disabled people. There is a P&A for each state and territory, one for the District of Columbia, and one for Native people in the Four Corners region. Most P&A's are known as "Disability Rights" and then the state's name. Not all P&A's handle every type of legal problem a disabled person might have. Some will be more understanding of trans issues than others. You can find your P&A on the National Disability Rights Network directory.

6. Civil Rights Complaints

When you've been discriminated against by doctors or therapists, you can sometimes file civil rights complaints. In some cities and counties, you can file a complaint with a Human Rights Board or Office. In every state, you can file a civil rights complaint with the State Attorney General, and with your state's health services department (it might have a slightly different name). You can also file federal complaints with the [U.S. Department of Justice, Civil Rights Division](#), and/or the [U.S. Department of Health and Human Services, Office for Civil Rights](#).

7. Public Defender Agencies for Commitment Defense

In many states, public defender agencies provide free legal representation when people are committed to a psychiatric unit or hospital. In some of these states, the public defender agency might have private lawyers help take commitment cases. If you have general questions about civil commitment in your state, you can try to find out if your public defender agency has a mental health division.

8. Trans LifeLine

Trans Lifeline is a helpline specifically aimed for the trans community. As part of its practices, its volunteer operators are all trans themselves, and it does not practice active rescue (i.e., call the police for wellness checks) without the caller's consent. Their hotline is 877-565-8860 in the United States and 877-330-6366 in Canada.

9. Trevor Project

The Trevor Project is a support hotline aimed specifically at LGBTQ people under 25, but it does not turn away people older than 25. They do practice active rescue (meaning they sometimes send police or ambulances). Their hotline is 866-488-7386. They also have a text-based helpline that you can reach by texting START to 678-678. They also have a chat on their website.

10. AWN Health Provider Survey & Resource List

AWN offers a resource list of gynecologists/intimate care providers who offer accessible and sensory-considerate health care. If you have a doctor who would be good to add to the list, especially if they're supportive of trans people, you can suggest that AWN adds them here.



Disclaimer

All information in this pamphlet is for general informational purposes only.

The information in this pamphlet is not medical or psychiatric advice, and should not replace any information given by a medical professional. If you consult a medical professional who gives different advice from the information in this pamphlet, follow the advice of that professional instead. If you need help addressing a specific medical condition or question, you should consult a medical professional for advice.

Likewise, the information in this pamphlet is not legal advice, and should not replace any information given by an attorney. If you consult an attorney who gives different advice from the information in this pamphlet, follow the advice of that attorney instead. If you need help addressing a specific legal issue or question, you should consult an attorney for advice.



Victoria M. Rodríguez-Roldán

Victoria M. Rodríguez-Roldán is the Senior Policy Manager for AIDS United, where she brings her own unique intersectional specialties to the fight against the HIV epidemic. Particular areas of expertise and focus are the intersections of issues affecting people living at the intersections of transgender identity, disability and mental illness from a social justice lens. She frequently speaks on discrimination issues impacting the trans and disability communities. She has been profiled in multiple national media outlets and has been published in multiple academic outlets.



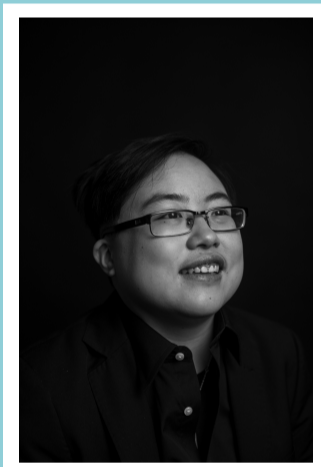
Prior to joining AIDS United, she was senior policy counsel at the National LGBTQ Task Force where she led the Trans/GNC Justice Project and the Disability Justice Project. She currently serves in the board of directors of HIPS, an organization dedicated to harm reduction for sex work and drug use in the District of Columbia and of Equality New York, New York State's leading LGBTQ equality organization. Victoria holds a B.A. in psychology with honors from the University of Puerto Rico, and a J.D. from the University of Maine School of Law. She lives in the Washington, DC area.



Lydia X. Z. Brown

Lydia X. Z. Brown is AWN's Director of Policy, Advocacy, & External Affairs. Previously, Lydia served on AWN's Board of Directors for six years, and led a partnership with AWN to publish *All the Weight of Our Dreams: On Living Racialized Autism*, an anthology they co-edited with Morénike Giwa Onaiwu and E. Ashkenazy.

Outside their work with AWN, Lydia teaches in the disability studies program at Georgetown University, and is volunteer director of the Fund for Community Reparations for Autistic People of Color's *Interdependence, Survival, & Empowerment*. They are also out and proud as a nonbinary, genderqueer, and genderless trans person.



Sharon daVanport

Sharon daVanport is Founder and Executive Director of the Autistic Women and Nonbinary Network (AWN). Sharon represents AWN on both the National Disability Leadership Alliance (NDLA) steering committee, as well the Consortium for Citizens with Disabilities (CCD), and serves on the self-advocacy advisory board for Felicity House. They have spoken before the United Nations and the White House on disability and autism forums and received recognition from the Autistic Self Advocacy Network for their contribution to the self-advocacy movement.

Sharon is co-editor of AWN's first anthology written by autistic people addressing topics ranging from education to gender and sexuality. The Autism Society awarded the anthology for outstanding publication in 2016, and the book was picked up by Beacon Press for republication in 2021. Outside of Sharon's work in autistic and disability activism, they have nearly a decade of experience as a social worker, and they are a parent of four diversely neurodivergent adults.

