Healthcare Self-Advocacy Tools

for Women of Color with Intellectual & Developmental Disabilities

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INTRODUCTION

These eight tools are meant to help Women of Color with Intellectual and Developmental Disabilities in:

Speaking up for their needs during healthcare appointments

Being the leader of their healthcare decisions

Addressing unfair treatment due to race, gender, and disability

They can be used by **anyone** looking for help with navigating care and advocacy during healthcare appointments.

INTRODUCTION

All tools are available digitally, but **it may be helpful to print physical copies and fill them out by hand.**

If you would like to share the **provider focused resources** and training materials with your healthcare provider, they can access that resource packet using this link or QR code.

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A GUIDE TO

DIRECT TO CONSUMER HEALTHCARE SERVICES

This guide helps you understand and use direct-to-consumer (DTC) healthcare services. It focuses on helping you learn about different types of DTC healthcare services, make informed and cost-effective choices, and more.

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**DTC = Direct to Consumer*

FAQ's

What are direct to consumer healthcare services?

While there is no single definition of what constitutes a DTC health care product or service, it typically involves consumers initiating the process of **ordering a product or service sometimes with little to no direct involvement from a healthcare professional.**

What is this guide for?

This guide helps you understand and use **direct-to-consumer (DTC) healthcare services**. It focuses on helping you:

- Learn about different types of DTC healthcare services
- Make informed and cost-effective choices
- Compare DTC services to your regular healthcare
- Compare benefits and risks before signing up
- Feel confident self-advocating for your needs
- Reflect if a service meets your need

FAQ's

Who is this guide for?

- People with disabilities or chronic health conditions
- People with limited or high-deductible insurance
- Anyone wanting faster, easier, or more DTC healthcare access

Why might you use DTC services?

These services can add to your regular healthcare. They may give you easier or faster access to care, especially if you live far away from providers, don't have certain specialists nearby, or want to avoid long referral processes

Helpful Questions to Ask

- Is the provider licensed or credentialed?
- Can you use insurance or coupons?
- Is this a one-time or ongoing service?
- Is it meeting a **real need** — like faster access, lower cost, or better fit for your schedule?

FAQ's

What else should you be aware of?

- If possible, **check with your main healthcare provider** before starting new treatments and tell them what you're planning on using

  Ask: "Does this make your healthcare easier or more confusing?"

- **Research the company.** Look at patient reviews, their website, and their privacy and security policies
  - Is the company licensed or regulated?
  - Are provider credentials clear and easy to find?
  - Look for accessibility features — like video captions, plain-text instructions, or disability-friendly support.

- **Focus on the services that truly help you and improve your quality of life**. You don't need to use everything they sell — remember, these companies are businesses making money.
  - Is pricing transparent?
  - Is it a subscription, insurance-based, or one-time payment?
  - Compare speed, cost, and long-term value.
  - Is there customer support?

Examples of DTC Services

Direct to Consumer Prescription Providers

Companies that give you access to medications directly through an app or website. You usually fill out a form or talk with a doctor online.

Examples:

- Hims / Hers – sexual health, hair loss, skincare
- Wisp – birth control, STI treatment
- NURX – low-cost birth control and emergency contraception

Pros: Fast and private access. Easy online processes. Often cheaper for common medication.

Cons: You might not build a long-term relationship with a doctor. Oversight and quality can vary between companies.

Questions to ask:

Are prescriptions doctor-reviewed? What happens if you have side effects? How is your data and privacy protected?

Examples of DTC Services

Prescription Services Linked to Insurance

These services help you save money or make it easier to get prescriptions through insurance or discounted programs.

Examples:

- GoodRx – medication coupons and telehealth
- Cost Plus Drugs – low-markup prescription prices
- Capsule – free delivery from local pharmacies (in some cities)

Pros: Can lower prescription costs. Keeps your regular pharmacy involved.

Cons: Discounts may vary depending on insurance or where you live. Not all medications qualify.

Scenario Example:

You need affordable acne medication. You check **GoodRx** for coupons and compare that to a prescription through **Curology**. This helps you find the lowest-cost option

Examples of DTC Services

Telehealth and Specialist-Focused Practices

Online clinics that connect you with **dietician and mental health specialists** — like therapists, psychiatrists, or dietitians — for ongoing care.

Examples:

- Nourish – medication coupons and telehealth
- Headway, Alma, Octave – low-markup prescription prices
- Plume – Gender-affirming healthcare services and hormone therapy

Pros: Can lower prescription costs. Keeps your regular pharmacy involved.

Cons: Discounts may vary depending on insurance or where you live. Not all medications qualify.

Scenario Example:

You're managing cholesterol. You meet a **Nourish** dietitian online once a month, and insurance covers it. You can share reports with your primary doctor.

Examples of DTC Services

Concierge or Membership-Based Care

Private or "direct primary care" services where you pay a monthly or yearly fee to access your provider more easily.

Examples:

- One Medical, Tia, Carbon Health – subscription-based primary care
- Well Theory, AgelessRx – wellness and pain management services

Pros: Tend to have fewer patients per doctor than traditional practices, it can be easier to get same-day or next-day appointments.

Cons: If you rarely use primary care, you may end up paying more over time with a monthly membership than you would if you just paid per-visit under traditional insurance.

Scenario Example:

You pay $100/month for a direct primary care doctor. You can message them anytime and get prescriptions at cost-plus rates.

Examples of DTC Services

At-Home Diagnostic or Lab Testing Services

Services that let you order lab tests from home or online, such as bloodwork or allergy testing.

Examples:

- QuestDiagnostics
- Everlywell
- Color Health

Pros: Private and convenient. Lets you see results without a full doctor's visit.

Cons: Some results may still need doctor review. Privacy and data handling differ by company. Out of pocket cost of ordering your own labs. Without consulting with a provider you may end up ordering an unnecessary or inappropriate test.

Scenario Example:

You order an Everlywell allergy test at home. You get results in a week and discuss them with your doctor to confirm next steps.

Support Organizations

You don't have to make health decisions alone. These trusted organizations can help you find answers, report problems, and get advocacy or accessibility support.

Disability and Health Advocacy Help

- **The Arc** - thearc.org

  Supports people with intellectual and developmental disabilities (I/DD) with advocacy, healthcare navigation, and self-advocacy resources.

- **National Council on Independent Living (NCIL)** - ncil.org

  Local Centers for Independent Living offer peer support and help with healthcare access.

- **Autistic Self Advocacy Network (ASAN)** - autisticadvocacy.org

  Provides plain-language health materials and peer-led training for self-advocates.

- **National Black Disability Coalition (NBDC)** - blackdisability.org

  A network centering Black disabled people in health, education, and advocacy.

Support Organizations

Legal and Patient Rights Help

- **Disability Rights Centers (DRCs)** - Find your local DRC at https://nacdd.org/

  Can be found in every U.S. state; offers free help if your rights are violated.

- **Patient Advocate Foundation** - patientadvocate.org

  Provides free help for people managing medical bills, insurance denials, or medication costs.

Accessible Health Communication

- **Plain Language Action and Information Network (PLAIN)** - plainlanguage.gov

  Offers guidance on understanding and creating plain-language materials.

- **CommunicationFIRST** - communicationfirst.org

  Advocates for people who use AAC or other communication supports in healthcare

Support Organizations

Peer Support and Community Spaces

- **Sins Invalid -** sinsinvalid.org

  Disability justice arts collective centering disabled people of color — offers resources and workshops about body autonomy and health.

- **Crip Camp Online Community**

  Peer group focused on disability pride and access.

If You Feel Unsafe or Exploited

If a company pressures you, asks for personal data that feels wrong, or seems dishonest:

1. **Stop sharing information.**
2. **Save any emails or receipts.**
3. **Report the issue** to your local Disability Rights Center or to the Federal Trade Commission (FTC) at reportfraud.ftc.gov.

Support Organizations

Emergency or Crisis Help

- **Call 911** for emergencies.
- **988 Suicide and Crisis Lifeline -** Call or text **988** for free confidential support (available 24/7, all languages, and accessible formats).
- **The Trevor Project (LGBTQ+ Youth) -** Text **START** to **678678** or call **1-866-488-7386**

MAKING A HEALTHCARE APPOINTMENT

A FILLABLE GUIDE

This guide will help you make a healthcare or doctor's appointment. It shows you what steps to take and gives you space to write down important information. Some parts may not fit your needs, and that's okay—you can skip them.

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MAKING AN APPOINTMENT

When you call the doctor's office, you may need to share some basic information. If a machine answers, ask to talk to a real person. If you are a new patient, it helps to have this ready:

Your Contact Information

- Name: _____
- Phone Number: _____
- Email: _____
- Address: _____

Emergency Contact

- Emergency Contact's Name: _____
- Emergency Contact's Phone Number: _____

Support Person's Contact *(if you have one)*

- Support Person's Name: _____
- Support Person's Phone Number: _____

Your Schedule

- Days of the week that work for you: _____
- Times of day that work for you: _____

MAKING AN APPOINTMENT

Accomodations (You may need help)

Examples: ramp, written notes, translator, bus pass, or parking

Reasons for the Appointment

- Symptoms: _____
- Concerns: _____
- Others: _____

Health History

Sometimes you'll be asked for general health history while making appointments or in online patient portals. Have any important health information ready to share.

- Allergies: _____
- Recent cold, flu, or COVID symptoms (fever, vomiting, runny nose, etc: _____
- Relevant imparment or diagnoses: _____
- Recent Menstrual Cycle/Period Date: _____
- Family Health History to note: _____

DOCTOR & INSURANCE INFORMATION

Doctor's Contact

- Doctor's Name: _____
- Office Name: _____
- Office Phone Number: _____
- Office Address: _____
- Other (ex: websites, patient portal access, login info):

  _____

*If you have insurance, check if the doctor accepts it ("in-network"). You can look online, call your insurance, or ask the doctor's office.

Insurance (if you have it)

- Insurance Name: _____
- ID Number: _____
- Group Number: _____

*You can call the number on your card to ask what is covered and what your copay/payment is at the time of the appointment. The doctor's office can also help tell you some of this information.

HELPFUL PHRASES TO USE

Scheduling the Appointment

- "Hello, my name is _____. I'd like to make an appointment with _____."
- "The reason for my visit is..."

- "My insurance is _____."
- "I'm available on _____."
- "Please send reminders to _____."

Confirming the Appointment

- "Can you confirm the date and time of my appointment?"
- "What is the office address?"
- "Can you email me a map of the campus/building? Which building or room do I go to?"

HELPFUL PHRASES TO USE

Getting Ready for the Appointment

- "Are there any ramps or elevators?"
- "I may need some help, like..."

(Examples: telehealth visit, quiet room, support person, translator)

- "Do I need to fill out papers before my visit or on my online patient portal?"
- "Is there anything I should bring?"
- "How long will the appointment take?"
- "Who do I call if I have questions later?"

THINGS TO BRING FOR A HEALTHCARE VISIT

A CHECKLIST

This worksheet will help you prepare the things you need for your next healthcare visit. Included in the checklist are paperwork, personal needs items and more.

PAPERWORK

Personal Documents

- [ ] Your name, address, photo ID, wallet/payment *(if needed)*
- [ ] Address and directions to the office *(if needed)*
- [ ] Your health insurance card *(if you have one)*

Medical Documents

- [ ] A symptoms worksheet, if you filled one out
- [ ] Any health logs you keep, like blood sugar or blood pressure records, or symptom trackers
- [ ] A list of questions or topics you want to talk about with your provider
- [ ] Anything your provider has asked you to bring
- [ ] Paperwork or instructions from any ER visits, hospital stays, or other providers since your last appointment
- [ ] All your current medications in their containers, or a written list of them *(include any new or changed medicines)*
- [ ] Names and contact information for people involved in your care *(for example: emergency contact, Healthcare Power of Attorney, guardian, or anyone who helps you communicate)*
- [ ] Other: _____

PERSONAL NEEDS

Personal Items

- [ ] Accommodation needs or strategies to help make visits go more smoothly *(examples: assistive devices, easy to remove clothing for physical examination, etc.)*
- [ ] Sensory items *(examples: sunglasses, chewing gum, headphones)*
- [ ] Something fun to do in case you have to wait *(examples: book, puzzle, fidgets, music player)*
- [ ] Masks, bottle of water, an extra sweater and food/snacks

If this is a visit with a new provider, also bring:

- [ ] A short summary of your medical history *(Include records of routine screenings like mammograms or colonoscopy, and vaccinations)*
- [ ] Old medical records *(if you have them)*
- [ ] Names of your past or current healthcare providers, like your primary care doctor or specialists
- [ ] Intake form *(if you filled one out at home)*
- [ ] Any release of information documentation needed from other providers
- [ ] Other: _____

OTHER NOTES

Please use this space to write down any other notes you want to remember:

SCRIPTS TO SUPPORT SELF-ADVOCACY

DURING HEALTHCARE APPOINTMENTS

This handout is meant to help you ask common questions and prepare for the conversations that usually happen during healthcare appointments. Some of the suggestions might not match your exact situation, so you can skip as needed. For support in making appointments, please use our Making an Appointment handout.

SCRIPTS FOR DURING THE APPOINTMENT

General Health & Check-ups

- "What screenings or tests do I need at my age/with my history?"
- "Are my vital signs (blood pressure, temperature, pulse, etc.) in a healthy range or range that makes sense with my conditions?"
- "What vaccines should I be up to date on?"
- "What is the normal range for my lab values and where are my results in this range?"
- "Are there lifestyle changes (nutrition, movement, stress, sleep) I should focus on right now?"

Symptoms

- "What could be causing these symptoms?"
- "Are these symptoms normal for my condition/disability?"
- "Are there any specific changes I should look out for?"
- "How urgent is this concern – do I need to take action now or just keep monitoring?"
- "What tests would help us understand this better?"
- If you have insurance: "What of those tests are covered by my insurance?"

Diagnoses

- “What exactly does this diagnosis mean?”
- “How many cases of this have you treated? Is there a specialist you can refer me to?”
- “Is it possible this could be something else?”
- “Where can I learn more?” (example: websites, pamphlets, support groups)
- “How does this diagnosis affect other conditions or diagnoses I might have? Does it replace them, or is it an additional condition I need to learn about and manage?"

Medications

- “What is this medication you are prescribing me for?”
- “How does this medication work?”
- “What are the possible side effects, and what should I do if I notice them?”
- “How long will I need to take this medication?”
- “Are there any other medications I can take instead of this one?”
- “Is there anything I should know about this medication given my condition/disability?”
- If you have insurance: “Does my insurance cover this medication?”

Treatment Options

- "What are all of my options?"
- "What are the risks and benefits of each?"
- "What is the likely outcome if I do nothing?"
- "How will I know if the treatment has worked?"
- "Is this treatment meant to cure my condition or manage it- are we trying to make symptoms go away, or make them easier to tolerate?"

Follow-up & Next Steps

- "What symptoms should I watch for that mean I should call you or go to the emergency department?"
- "How soon should I schedule my next appointment?"
- "Who do I contact if I have questions between visits?"
- "Should I see a specialist? If so, can you recommend someone or offer a referral?"

Communication & Support

- "Can you explain that in simpler words or in a simpler way?"
- "Do you have written instructions or resources I can take home?"
- "I need written instructions or information that is written simpler."
- "Is there someone (nurse, care coordinator, patient portal) I can reach out to if I don't understand the instructions or need help?"

DESCRIBING YOUR SYMPTOMS

A FILLABLE GUIDE

This worksheet helps you tell the doctor or nurse about your symptoms. Symptoms are feelings or changes in your body that show you might be sick or unwell, like a headache or fever. **You do not have to answer every question.**

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SYMPTOMS

What are your main symptoms? *"I feel..."*

Do you get other symptoms at the same time?

"I also have..." *Examples: cough, pain, fever, rash, etc.*

LOCATION

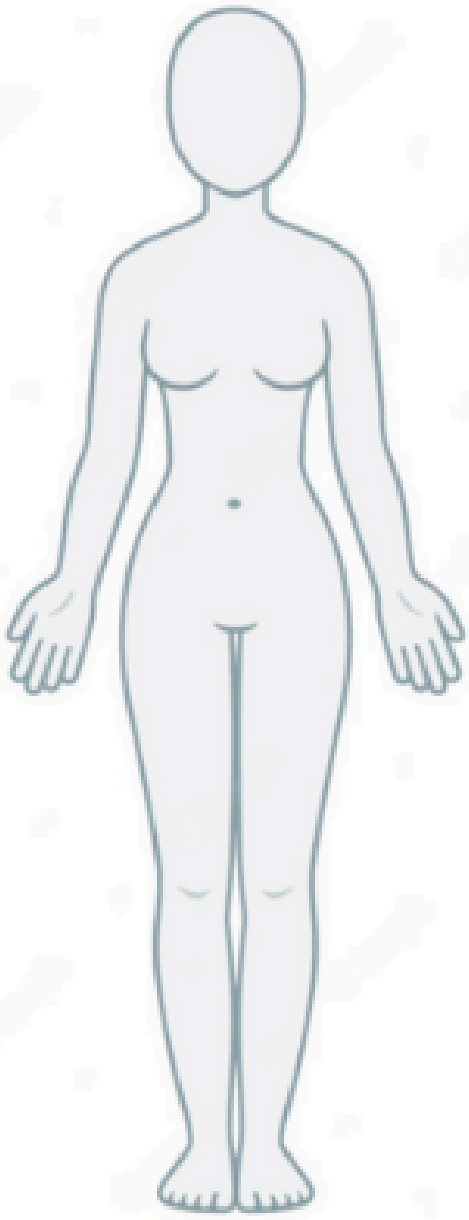
Where on your body is this symptom?

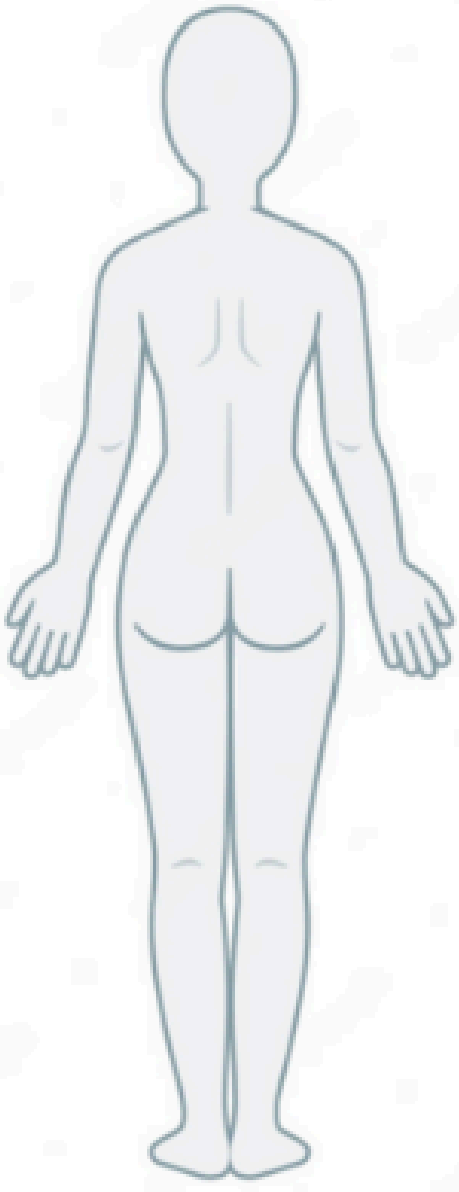
"The pain is in my..."

Examples: lower back, hip, foot, chest, throat, etc.

BODY CHART

Optional: Using a pdf mark up tool, put an X or shade in the areas of your body where the symptoms are.





SYMPTOM INTENSITY

How bad is it? Does it bother you a little bit or a lot?

"It is very..." Examples: bad, small, limiting, mild, etc.

"It bothers me..." Examples: a lot, a little, sometimes, when I...

If the symptom is pain, what is the pain like?

"The pain feels like..."

Examples: dull, achy, sharp, burning, heavy, tingly, etc.

PAIN SCALE

Optional: You may want to use a pain scale to describe how bad your pain is. If you are having pain, your provider may ask you to use a pain scale, so it may help to think about it before your appointment.

No Pain	Uncomfortable	Upsetting	Intense	Awful	Unthinkable
0	2	4	6	8	10
I feel comfortable and can do everything I normally do I don't feel any pain at all right now.	I notice mild pain, but I can manage it easily. It's there, but it doesn't stop me from doing things I normally do.	The pain bothers me and makes some things harder. I may not be able to do everything I usually do.	The pain is strong and stops me from doing many things I normally do. It makes talking, moving, and other regular things difficult.	The pain is severe and hard to ignore, I need help managing it. It stops me from doing most things I normally do.	The pain is unbearable and all I can think about. It is the worst or near the worst pain I can imagine.

Your pain matters! If something is hurting you or uncomfortable, you deserve to be heard and supported to make things easier/better.

FREQUENCY & DURATION

How long has it been going on? When did you first notice the symptom?

"It started..." "I noticed the symptoms..."

Examples: slowly, all at once, yesterday, last month, etc.

Does the symptom come and go or is it there all the time? Does anything cause it?

"Most of the time it feels..." "But sometimes it feels..."

FREQUENCY & DURATION

What makes the symptoms feel better? What makes them worse?

"It gets better when I..." "It gets worse when I..."

SYMPTOM HISTORY & PATTERNS

What is normal for you? How is this symptom different from how you usually feel?

"Usually I feel..." "It's different because..." "It's similar to..."

Have you ever experienced something like this in the past? What has worked for you in those times?

"The last time I felt this way was..."

"Something that helped was..."

TREATMENTS

What have you tried doing to treat or support your symptoms so far? Has it helped?

What lifestyle changes have you tried?

Examples: drinking more water, food & nutrition, supplements & herbs, movement & exercise, assistive devices or supports, etc.

"I've tried..." *"It has/has not helped..."*

TREATMENTS

What medications, supplements, or natural remedies have you tried? How did they help or not?

"Home remedies or holistic supports I've tried are..."

"It has/has not helped..."

IMPACT ON LIFE

How have the symptoms affected your life? Do they keep you from doing things you normally do?

Do other people around you, like family and friends, have the same symptoms?

YOUR THOUGHTS & INPUT

What do you think is causing the problem? Are you worried about something in particular?

"It might be related to..." *"I'm worried about..."*

YOUR THOUGHTS & INPUT

Is there a solution or support you already have in mind or something you would like to try?

What do you think you might need after the symptom lessens?”

OTHER DETAILS

Is there anything else that you think may help your provider understand what is going on?

Are there other conditions or symptoms you'd like to discuss?

PROVIDER RESPONSES & NOTES

IS MY PROVIDER A GOOD FIT?

TIPS TO HELP YOU DECIDE

It is important to find a provider who treats you with respect and care. This document contains tips that might help you decide if your provider is a good fit for you.

Introduction

Finding a provider who understands disability, and how disability affects your experiences with race, culture, and gender, can be hard. It's not just about getting into the building — **your provider should also treat you with respect.**

If a provider talks down to you, assumes things about you because of your disability, race, or gender, or makes you feel uncomfortable, **it's okay to ask for a different provider.** You can talk to other disabled people, do some research, and ask questions before your visit to help find a provider who's a good match for you.

Below are some tips about ways people act and things to look for that might help you decide if your provider is a good fit for your needs.

Green Flags

Respectful and Supportive Behaviors

- [ ] Answers your questions clearly.
- [ ] Patient and not rushed if you need repeats or explanations.
- [ ] Listens and adjusts treatment if something isn't working.
- [ ] Suggests affordable options if medication is expensive.
- [ ] Will research and follow up if unsure.
- [ ] Is sympathetic and responsive to your frustration, disappointment, or anger.
- [ ] Treats you as an equal partner in your care.
- [ ] Everyone on the team gives good care.
- [ ] Considers your personal priorities in treatment.
- [ ] Sits down to talk to you. Makes eye contact.
- [ ] Asks if you have questions and pauses for your response.
- [ ] Support staff are respectful and kind.
- [ ] Team communicates well about scheduling, costs, and care plans.
- [ ] You leave appointments fully understanding your care plan.

Red Flags

Disrespectful and Unsupportive Behaviors

- [ ] Uses shaming or blaming language.
- [ ] Ignores concerns about pain, symptoms, or costs.
- [ ] Talks over you or doesn't leave time for questions.
- [ ] Dismisses or is defensive to your feelings of frustration, disappointment, or anger.
- [ ] Stands while talking, looks at computer screen and does not make eye contact.
- [ ] Does not explain or give rationale for any orders or procedures.
- [ ] Talks only to caregivers instead of you.
- [ ] Doesn't work well with other providers for complex needs.
- [ ] Doesn't consider your mental, emotional, or spiritual health.
- [ ] Does not give you an opportunity to ask questions.
- [ ] You leave appointments without understanding your plan of care.

KNOW YOUR HEALTHCARE RIGHTS

It's important to make decisions with your healthcare provider and know your rights to receive the best healthcare you can. This tool is meant to support you in advocating (speaking up) for support and explain what do if you're not getting the care you deserve.

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What are Your Rights?

You have the right to ask your provider or facility for a written list of your full patient rights. These should include the right to:

- Be **informed** about the care you receive
- Get information in a way that meets your needs (for example if you have vision, hearing, speech, learning difference, or your preferred language)
- **Make decisions** about your care — or **refuse care** if you choose
- Know the **names and roles** of the people treating you
- Receive **safe, respectful, and fair care**
- Have your **pain and concerns taken seriously**
- Be **treated with courtesy** and **listened to**
- **Bring a support person or advocate** with you during care (professional, family, or friend)
- **Know if** something goes wrong in your care
- Get a **list of all your current medicines, treatments, and procedures**
- Receive respectful care free from discrimination, no matter your:
  - Age, Race or ethnicity, Religion or culture, Language, Disability, Gender identity or sexual orientation, Income or background
- You have the right to be **listened to AND BELIEVED!**

What is Your Role?

You are an important part of your care team and making decisions about your health. You should:

- **Take an active role** in your care and decisions

  "I need (or would like to) _____."

- **Ask questions** until you understand your treatment and choices

  "What does that mean for my care?"

- **Follow instructions** from your caregivers when possible

  "When do I take this medication?" "How do I prevent infection?"

- **Share information** about your health, such as:

  "The medications and vitamins I take are _____."
  "I'm allergic or have reactions to_____."
  "My experience before with this was _____."
  "I'd be more comfortable (or prefer) if_____."

- **Advocate (speak up!) for yourself** with providers and your support network

  "I would like to see a specialist."
  "I would like to change providers."
  "I don't understand. Please explain what you mean."
  "I understand what you said. I have a concern about _____."

What is the Role of Your Advocate?

You can choose a professional advocate, family member, or friend to support you as you navigate your healthcare and your decision making. You may need to fill out a form to name your advocate. Your advocate can make decisions for you if they are your legal guardian or have health care power of attorney.

Your Advocate CAN...	Your Advocate CANNOT...
Be with you during care for **comfort and support**	**Make decisions for you**, unless they are your legal guardian or have health care power of attorney
Ask questions or get information when you cannot	
Remind you about instructions or help with decisions	**Make you see a provider** who makes you feel uncomfortable or is disrespectful
Speak up for you if you are not getting the care you need	

What is Informed Consent?

Your health information is private. Providers must keep it confidential unless you give written permission to share it. You have the right to informed consent about your health information.

- **Informed consent** means your caregivers explain treatment options, risks, and what might happen if you choose not to be treated, in ways you can understand like plain language.
- You must give informed consent before **any experimental treatment.**
- Photos or recordings may be taken for your care, but the facility must **ask permission** before using them for anything else.
- Sometimes, people will have unfair judgements about others based on disability, race, or gender that will make them more likely to not value your consent. This kind of treatment is not okay and you deserve to be listened to.

How to Advocate for Your Rights

If you're not getting the care you need or there's a problem, you have the right to:

- Get an **honest explanation** and **apology** as soon as possible
- Have a **second opinion** and/or change your provider
- Ask for someone to help or **for an advocate** to support you
- Have your feelings heard and **your choices respected**

How to Report a Concern or Issue

1. Contact the **state agency** that licenses or certifies the facility.
2. Call the **facility directly** to give feedback or request changes.
3. File a complaint with **The Joint Commission** here.
4. File a complaint with the Centers for Medicare & Medicare (CMS) in addition to the the Joint complaint here.

How Do I Prepare?

It can be helpful to prepare for your visit, so you know what to expect. **You can use the questions below to plan** and discuss with your provider ahead of time to prepare for your care and/or use a Making an Appointment Tool to support.

- How will you support my communication?
  - For example: *"Is an **interpreter** available in my preferred language?" "Do you have information in plain language?" "Are you familiar with AAC devices?"*
- Can a family member or friend stay with me for support?
- Can I name an advocate, and do I need to fill out a form?
- Who can I talk to if I have a **problem or complaint**?
- How do I **get my test results or a copy of my medical records**?
- Does this facility provide the treatments or services I need? If not, where will I need to go

A GUIDE TO

CONNECTING WITH OTHER SELF-ADVOCATES

This guide is meant to help you find others to connect with. Connecting with other disabled self-advocates can be very helpful to share experiences, support each other, and learn ways to deal with ableism in healthcare and everyday life.

INTRODUCTION

This guide is meant to help you find others to connect with. Connecting with other disabled self-advocates can be very helpful to share experiences, support each other, and learn ways to deal with ableism in healthcare and everyday life.

It can be especially helpful to connect with other people who share your experiences with race, gender, and more, as there may be specific experiences you have as a disabled Woman of Color that are different than other disabled people due to racism and sexism. Being part of a group can also help you take action together to challenge unfair systems and push for change.

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Why connect with other self-advocates?

Connecting with other disabled self-advocates can be powerful and supportive. You can share your stories, learn from others, and get emotional support. Advocacy groups can help you learn tips for dealing with ableism and other kinds of discrimination in healthcare and daily life and work together to make changes while building friendships and pride in your identity.

Connecting Online

Social Media and Online Spaces

Online spaces can help you connect even if you can't attend in-person events. Follow hashtags like #DisabilityJustice, #BlackDisabledLives, #DisabledAndProud, #DisabledAndBlack, #DisabledWomen, and #NeurodiversityOfColor to find real-time conversations and support networks.

You can find communities on:

- **Facebook**
- **Instagram**
- **Reddit**
- **TikTok**
- **Discord and Slack** - Example: SF Disability Cultural Center has a Discord and runs almost all of its programs in hybrid or online formats.

Peer and Support Groups

Many organizations host virtual support meetings and community check-ins for people with I/DD. Some examples include:

- **Autistic Self Advocacy Network (ASAN)** – autisticadvocacy.org
  Peer-led advocacy for autistic people, including affiliates and state-based groups.
- **Autistic Women & Nonbinary Network (AWN)** – awnnetwork.org
  Centering autistic women, girls, and nonbinary people through peer support and leadership.

Connecting Based on Disability and Identity

For Women of Color

- **Divas With Disabilities Project (DWD)** – divaswithdisabilities.org
  An organization and digital community for Black and Brown women with disabilities who are challenging stereotypes through visibility and empowerment
    - DWD's PrideAbility program specifically supports disabled Black & Brown LGBTQIA+ people

- **National Black Disability Coalition (NBDC)** – blackdisability.org
  A national network centering Black disabled people in health, education, and advocacy

- **The Color of Autism Foundation** – thecolorofautism.org
  Supports African American autistic individuals and families with culturally competent education and advocacy

- **Chicagoland Disabled People of Color Coalition (DPOCC)** – chicagolanddpocc.wordpress.com
  A collective for disabled people of color in the Chicago region focused on racial and disability justice

Connecting Based on Disability and Identity

For Disability Justice and Reproductive Health

- **Black Reproductive Justice Agenda** – blackrj.org/blackrjpolicyagenda
  Advocacy for reproductive health, rights, and justice centering Black people.

- **Center for Racial and Disability Justice (CRD Justice)** – crdjustice.org/repro
  Focuses on reproductive rights and disability justice, supporting self-advocates and policy change

For People in the South

- **New Disabled South** – newdisabledsouth.org
  A regional network for disabled people across the southern United States. Offers advocacy training, leadership development, and policy work

Connecting with Local Resources

Disability Information and Access Line (DIAL)

DIAL is a free national hotline that helps people with disabilities learn about:

- Rights and benefits
- How to find local services
- COVID-19 and emergency information

Phone, text, or videophone: 888-677-1199
Email: DIAL@usaginganddisability.org
Website: dial.acl.gov

Centers for Independent Living (CILs):

Centers for Independent Living (CILs) are community-based groups run by and for people with disabilities. They can help you learn independent living skills, get information about housing, employment, and transportation, and/or connect with local advocacy and peer groups

To find your local CIL: Visit www.ilru.org/projects/cil-net/cil-center-and-association-directory

Connecting with Local Resources

Local Advocacy Networks

Local chapters of national groups like **The Arc** and **Easterseals** can connect you with self-advocacy groups, peer mentors, family and community support programs

Find your local Arc: thearc.org/find-a-chapter

Find your local Easterseals: https://www.easterseals.com/find-your-easterseals

Tips for Getting Started

1. **Use social media in ways that work for you.** Choose accounts that feel affirming and protect your privacy. Follow hashtags to help find the spaces you're looking for.

2. **Join online events.** Many groups have online hangouts, "lunch and learns," or chat spaces that are free.

3. **Start local.** Call your local disability rights group to ask if they know of any peer advocacy groups for people of color.

Quick Resource List

Type of Support	Organization	Website
National Advocacy	The Arc	thearc.org
Autistic Support	Autistic Self-Advocacy Network	Autisticadvocacy.org
Autistic Support	AWN Network	awnnetwork.org
Reproductice Justice for Black Folks	Black Reproductive Justice Agenda	blackrj.org/blackrjpolicyagenda
Disability + Reproductive Justice	Center for Racial and Disability Justice - Reproductive Justice	crdjustice.org/repro
Independent Living	Centers for Independent Living	ilru.org
Regional (Midwest)	Chicagoland DPOCC	chicagolanddpocc.wordpress.com
Autistic People of Color Support	The Color of Autism Foundation	https://www.thecolorofautism.org/
General Disability Info	Disability Information and Access Line (DIAL)	dial.acl.gov

Quick Resource List

Type of Support	Organization	Website
Visibility and Representation	Divas With Disabilities	divaswithdisabilities.org
Disability Services	Easterseals	https://www.easterseals.com/find-your-easterseals
Black Disability Justice	National Black Disability Coalition (NBDC)	https://blackdisability.org
Regional (South)	New Disabled South	newdisabledsouth.org
LGBTQ+ People of Color	PrideAbility	https://divaswithdisabilities.org/prideability/