



# Supporting Black Autistic Girls

in the Transition to Adult Health Care



**Health care transition** is the process of moving from a pediatric to an adult model of health care. For Black autistic girls, health care transition can be a critical time to address disparities and build skills to promote health across the life span.

## Why?

Girls are less likely than boys to receive a timely diagnosis of autism.



Black children are more likely to experience misdiagnosis and extremely delayed autism diagnosis.

**Black autistic girls, at the intersection of these disparities, experience the impact of both.**

*Constantino, 2020; Maenner et al., 2021; Lovelace et al., 2018; Purlway & Johnson, 2005*

## The Impact of Disparities

The challenges of getting a diagnosis can exist through late adolescence and young adulthood, often leading to negative educational, medical, and employment outcomes, high anxiety, low self-esteem, and suicidal ideation.

Even with the knowledge of emotional and physical risk faced by Black autistic girls and women, the literature is disturbingly silent on their experiences and needs.



Cultural responsiveness



Health equity



Autism acceptance

The **Supporting Autistic Black Girls in the Transition to Adult Health Care** toolkits were developed by Black autistic girls and women, and their families, to help health care providers and families better understand the health care and health care transition (HCT) needs of Black autistic adolescent girls and young women.

The toolkits include tools for autistic Black girls and women and their families, alongside tools to help providers understand how to best support them as they move to adult health care.



# Supporting Black Autistic Girls

in the Transition to Adult Health Care



## Preparing for a Health Care Visit

*For self-advocates and families*

Preparing for a health appointment can be challenging for autistic individuals.

Black autistic girls and young women often enter the health care space expecting to be misunderstood. The data Black women's health care experiences tells us we often aren't listened to, and our neurodivergence can be misunderstood. Feeling prepared for health care visits can help.

### Before the Health Care Visit



**Write questions ahead of time** to ask during your health care visit. Prepare a script and practice it if that is helpful to you.



Ask important questions before the appointment, through your **patient portal**, by email or by calling your health care provider.



Make a **list of symptoms** you are having and do some research in advance on what those symptoms might mean so you can discuss them with your health care provider.



**Plan what you want to wear** to feel comfortable and feel that you are dressed appropriately for the health care visit.

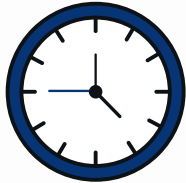


**Prepare to have a clear discussion about your needs.** If your health care provider does not understand your perspective or experience, plan for how you will make your ideas clear.

Participating and **feeling engaged during a health appointment** can be challenging for autistic individuals.

Black autistic girls and young women shared their best advice on how to get the most out of a medical visit.

## During the Health Care Visit



**Prepare for delays and uncertainty.** Bring something to do. If there is a delay, ask what time you can expect to see your health care provider.



**Start by sharing any concerns you have** with your health care provider and any ideas you have about planning your care.



Take paper and a pen or pencil to **write notes** during your visit or use your phone to take notes.



**Listen** carefully and **ask** questions.



**Take a care partner** with you as a second set of ears who can help you listen, advocate for yourself, and understand what the health care provider is saying.

**Following up after a health care visit** is an important step in managing your care.

Black autistic girls and young women shared their best advice on how to stay informed after a health care visit.

## After the Health Care Visit



**Review appointment notes** to make sure they reflect your conversation with the provider. You have the right to request that your medical record be corrected if you find an error.



Share any **questions or thoughts** you had after the visit through your patient portal, by email or by calling your health care provider.

## Resources to Help You Prepare for Health Care Visits

- [For Autistic Adults: Preparing for a Visit](#) | Academic Autistic Spectrum Partnership in Research and Education
- [The Right to Make Choices](#) | Autistic Self Advocacy Network (ASAN)
- [Making Appointments](#) (3-minute video) | Waisman Center
- [Healthy Living](#) | LifeCourse Nexus
- [Healthcare 101: Medical Terminology for Beginners](#) | AIHT Education



**Share this document**



## Supporting Black Autistic Girls

in the Transition to Adult Health Care

FAMILY VOICES<sup>®</sup>

For self-advocates and families

# Finding the Right Fit with Your Health Care Provider

As you move to adult health care, you will need to find adult health care providers instead of providers who work only with pediatric patients. We asked Black autistic girls and young women about what was important to them when they search for a new provider. Here's what they said.

**Do your homework.** It can take some time and effort to find the right medical or mental health care provider.



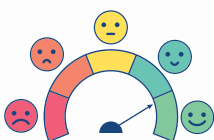
- **Talk to your current health care providers** about who might be a good fit for your adult health care. Ask them to connect you with adult providers. They can even meet with you as a team to help transition your care.
- **Ask other young adults and families** who they see for health care services. Find out which providers have experience with autistic patients in your area.
- **Read the online bio** of a potential provider and look at online reviews of real patient experiences.

**Watch and listen.** When you are with your health care provider, pay attention to how they interact.



- Do they **talk to you directly** instead of your care partner?
- Do they **listen to you** and respect the ways you communicate?
- Do they try to **get to know you**?
- Do they **give you time** to talk about what matters to you?
- Do they **believe what you say** about your health and your needs?

**Look inward.** Consider how you feel when you are with your provider.



- Do you feel heard and **respected**?
- Do you feel like the provider **cares** about you?
- Do you feel like your provider shows **ableism** or discriminates against you or your care partner?
- Is the provider's care setting **accessible** and comfortable for you?
- Does the provider **include** your care partner in the ways you prefer?

**Learn more.** Moving to adult health care is a process. Here are some tools to get started.



- [Getting Ready for HCT - Moving to Adult Health Care](#) | Center for Transition to Adult Health Care for Youth with Disabilities
- [Switching to an Adult Doctor](#) | Family Voices
- [Finding Providers](#) | AASPIRE Healthcare Toolkit for Patients and Supporters
- [Roadmap to Transition A Handbook for Autistic Youth Transitioning to Adulthood](#) | Autistic Self Advocate Network



**Share this  
document**



## Supporting Black Autistic Girls

in the Transition to Adult Health Care

FAMILY VOICES<sup>®</sup>

# Working with a Care Partner as You Move toward Adult Health Care

For self-advocates

As you transition to adult health care, you may find your role shifting. Earlier in your life, your parent or caregiver might have been the one to speak up for you and serve as your advocate.

As the adult years approach, it is important to start taking a step forward so you can be a leader in your health care decisions. You may still want to have your parent or caregiver step in as a care partner to help you think about your care and make health care decisions.

**Get ready to take the lead.** Being a leader in your care starts with understanding your own needs.



- **Get a good understanding about autism** and any other medical or mental health conditions you have.
- **Know your health history.** Your parent or care partner can help you look at and understand your online medical records.
- Understand what **treatments and medications** are available to you, and which ones have worked for you in the past.

**Start speaking up for yourself.** Your voice matters.



- **Practice talking about your health** and what you need to be your best self.
- **Speak up** if your care is not working well for you.

**Focus on relationships and communication.** Get to know your team and help them get to know you.



- **Be thoughtful about how autism affects you and shows up in your life.** Share that information with your care partner and health care team so they can provide the supports you need to participate in your care.
- **Develop a relationship with your health care team.** Get used to talking to them and communicating through email, your patient portal, or by phone.
- **If you choose to have a parent as your care partner, make sure you are willing to collaborate with them about your care.** Your relationship and ability to communicate without a lot of conflict will support your health care decision making.

**Learn more.** Here are some tools to help you get ready to transition to adult health care.

- Take a [\*quiz\*](#) from Got Transition to see if you are ready to transition to adult health care.
- Watch this video about moving to adult health care from Got Transition in [English](#) or [Spanish](#).
- Learn about transitioning to adult health care through this [infographic](#).
- Read about [Moving Into Adult Health Care: What Do Young Adults with and without Disabilities Need to Know?](#) from the Connecticut State Department of Health.



**Share this  
document**





## Supporting Black Autistic Girls

in the Transition to Adult Health Care

FAMILY VOICES<sup>®</sup>

# Stepping in as a Care Partner

For families and caregivers

As your child transitions to adult health care, you may find your role shifting. Earlier in their life, you might have been your child's voice, speaking up for them and serving as their advocate. As the adult years approach, it is important to start taking a step back and allowing your child to be a leader in their health care decision making.

**Get into a supportive mindset.** Being a care partner is about supporting their needs and preferences.



- Parents and/or advocates should **get consent** from young adults about advocating on their behalf.
- **Be a champion** for your child/young adult by understanding their needs, ways of communicating, and preferences.
- Make sure you're not putting pressure on your child/young adult to make decisions; **let them lead.**
- **Have patience** with the process your child is going through. Growing up is tough and learning to make decisions on your own takes support.
- Introduce your child to their online medical record and patient portal so they can start to **understand their own health information.**

**Create a learning plan for yourself.** Transition to adulthood is a whole new experience, and there is a lot to learn.



- **Learn about autism** and keep up with current research so you know how to best support your child through this transition.
- Consider **how autism impacts your child's capacity** to communicate and make decisions. Be ready to support them in the ways that are meaningful to them.
- Learn about **supportive decision making**, person-centered planning, and alternatives to guardianship.

## Create a learning plan for your child. The process can start early.



- **Provide opportunities** for your child to participate in their health care. This can start with helping them understand what their providers do, ask their own questions, and think about their health care needs.
- Encourage **new responsibilities** at different stages. Have your child check in at their appointments or order their own medications from the pharmacy, and increase their responsibility over time.

## Develop strong relationships. Your team is more important now than ever.



- Talk to your child's health care team about transitioning to adult care and building relationships with adult providers in your community.
- If your child needs you to step in and advocate for them, do it in a way that builds positive relationships with the health care team.

## Learn more. Here are some tools to help you support your child's transition to adult health care.

- Visit [www.movingtoadulthealthcare.org](http://www.movingtoadulthealthcare.org). | Center for Transition to Adult Health Care for Youth with Disabilities
- [Parents & Caregivers](#) | Got Transition
- [Moving Into Adult Health Care: What Do Parents Need to Know?](#) | Connecticut State Department of Health
- [Supported Decision-Making](#) | National Resource Center
- [From Justice for Jenny to Justice for All: EVERYONE Has the Right to Make Choices](#) | National Resource Center ([supporteddecisionmaking.org](http://supporteddecisionmaking.org))
- [A2G in Your State](#) | Center on Youth Voice, Youth Choice ([youth-voice.org](http://youth-voice.org))



**Share this  
document**