



Supporting Black Autistic Girls

in the Transition to Adult Health Care

Health Care Provider's Guide

- Introduction
- Understanding Black Family Relationships
- Engaging and Supporting Black Autistic Girls and Their Care Partners in the Health Care Setting
- Preparing for a Health Care Visit

Download tools for Black autistic girls and their families at familyvoices.org/healthcaretransition/resources. These tools include:

- Preparing for a Health Care Visit
- Finding the Right Fit with Your Health Care Provider
- Working with a Care Partner as You Move toward Adult Health Care
- Stepping in as a Care Partner





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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; Purtleway & 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.



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Understanding Black Family Relationships

We heard from Black autistic women and caregivers of Black autistic girls about their health care experiences. One concern they mentioned consistently was about how their providers lacked understanding of their culture and family relationships. While no cultural group is a monolith, they offered some ways to understand Black culture that can inform how providers begin to interact with and engage patients and families.



Recognize the differences between individualism and collectivism.

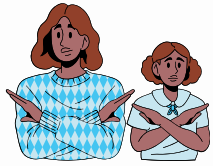
African American and Black families are part of a collectivist culture. This means there is less focus on individualism and more focus on interdependence. This can show up in the health care experience. Family members are often integral to care planning and there may not be an emphasis on young adults being “on their own.” Adult patients may bring a parent or relative as a care partner who helps them make decisions. It is important to respect the family relationships patients value and ask how to include family in the plan of care.



Understand the barriers Black patients experience. Black autistic girls face multiple barriers in their lives and in their health care, from access to outcomes. As a provider, you may encounter patients who suspect they are autistic but who have not had access to diagnostic services. Black autistic girls are frequently misdiagnosed with mental health conditions. Their autistic traits may look different, and their “stims” may be internalized or hard to notice.



Take a trauma-informed approach. The Black autistic young women we spoke with told us their providers often don't understand the social pressures and community issues they experience. Community violence, police violence against Black bodies, intergenerational trauma, and even being neurodivergent were highlighted as experiences of trauma. There is often stigma about mental health and a lack of knowledge about neurodivergence in their families and communities. They want their health care providers to take time to learn from and about them.



Be attentive to the impacts of bias and stigma. We heard about the pressures Black girls and women face in the health care setting in particular. There was a focus on presenting in certain ways in order to avoid discrimination, including speaking and dressing in ways that help Black girls and women “be taken seriously.” We also heard about this impact of cultural mismatches between patients and providers and how it affected Black autistic girls and women. They felt that they often had to mentally prepare for their providers to “push back” on what they said, which made them feel unheard in their health care visits. Establishing trust with patients from minoritized groups may take extra effort in light on the ongoing inequities in health care.

For Further Reading

- [Examining the Process and Impact of Parent Affiliate Stigma on Raising a Child with ASD in African American Families](#) – Dr. Allysa Ware
- [Improving Health Care Transitions for Children and Youth with Special Health Care Needs](#) – Science Direct
- [Building Patient-Provider Trust to Help Patients Navigate a Biased System](#) – Center for Health Care Strategies
- [Family Voices United to End Racism Against CYSHCN and their Families \(FamU\) - Family Voices](#)
- [The National Center for Cultural Competence \(NCCC\)](#)
- [Cultural Competence: Essential Ingredient for Successful Transitions of Care | the National Transitions of Care Coalition](#)
- [Medical Gaslighting](#) – National Disability Rights Network



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FAMILY VOICES[®]

Engaging and Supporting Black Autistic Girls and Their Care Partners in the Health Care Setting

As Black autistic girls move to adult health care, they need to find adult health care providers. 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.

I observe the health care provider to see if they're right for me.



- I expect my health care provider to **talk to me directly** instead of my care partner.
- I expect my health care provider to listen to me and **respect the ways I communicate**.
- I expect my health care provider to try to **get to know me**.
- I expect my health care provider to **give me time** to talk about what matters to me.
- I expect my health care provider to **believe what I say** about my health and my needs.

I check in on my feelings about my health care provider.



- I want to feel **heard** and **respected**.
- I want to feel like my health care provider and their staff **care about me**.
- I want to **avoid ableism** or feeling discriminated against.
- I want my health care provider's care setting to be **accessible** and **comfortable**.
- I want my health care provider to **include my care partner** in the ways I prefer.



I make sure my provider can support my needs in the health care setting.

- I want my provider to ask **closed-ended questions** when possible. Open-ended questions can be hard to answer.
- I want my provider to acknowledge and **address my questions**.
- I want my provider to talk to me directly but understand that my family is **part of my team**.
- I want my provider to recognize that I may need support sometimes but not at other times. **My capacity can be different** from day to day.
- I want my provider to **be inclusive** of alternative ways of communicating.
- I want my provider to give me **information and resources** to support my health. Help me prepare for appointments by giving me information **in advance**.
- I want my provider to explain things to me in **plain language**.
- I want my provider to **help me manage the anxiety** that comes with health care visits. Make me aware of delays and help me feel at ease.
- I want my provider to provide resources for **transportation**.

Health Care Transition Resources for Health Care Providers

- [Six Core Elements of Health Care Transition™](#) | Got Transition®
- [Transition Planning Tips for Linguistically and Culturally Diverse Youth with Disabilities](#) | The Pacer Center
- [Incorporating Pediatric-To-Adult Transition into NCQA Patient-Centered Medical Home Recognition: 2019 Update](#) | Got Transition®
- [Integrating Young Adults with Autism Spectrum Disorder into Your Practice: Tips for Adult Health Care Clinicians](#) | Got Transition®
- [Pediatric to Adult Care Transitions Initiative](#) - The American College of Physicians
- [Moving Into Adult Health Care: What Do Primary Health Care Providers Need to Know?](#) | Connecticut Kids as Self Advocates



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Preparing for a Health Care Visit

For health care providers

Preparing for a health appointment can be challenging for autistic individuals. For those with intersectional identities, the preparation can be complex.

Black autistic girls and young women often enter the health care space expecting to be misunderstood. The data on the impact of bias on Black women's health care experiences, combined with misconceptions about neurodivergence and how it presents in Black women, can lead to miscommunication. Providers can build trust and set the stage for a successful health care visit.

Before the Health Care Visit

- Communicate with the patient and **encourage them to write questions ahead of time** to ask during the health care visit.
- **Send any paperwork** that will need to be completed by mail or through your patient portal in advance, since the task of completing forms might feel overwhelming to the patient on the day of the visit.
- **Prompt the patient** to share about symptoms they are having and be open to discussion about what they may have researched in advance about their symptoms.
- **Prepare** for how to approach a conversation in which the patient does not feel understood.

During the Health Care Visit

- Prepare office staff to **communicate about delays**.
- **Provide time** for the patient to take notes during the appointment.
- If a patient brings a care partner, **acknowledge the care partner** and ask the patient how you should engage with the care partner during the visit.

After the Health Care Visit

- Share information and educational materials with the patient through the **patient portal**.
- Encourage **two-way communication** between visits.

Resources to Help Providers Prepare for Health Care Visits with Autistic Individuals

- [AASPIRE Healthcare Toolkit: Patient-Centered Care Tools for Autistic Adults](#)
- [Supported Decision Making video, UCSF School of Medicine \(5:35\)](#)
- [Healthy Living | LifeCourse Nexus](#)
- Share the tools for self-advocates and families with your patients.