



Supporting Black Autistic Girls

in the Transition to Adult Health Care



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.

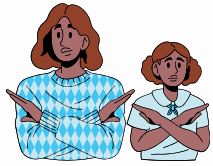
African American and Black families are part of a collectivist culture. This means there is less focus on individualism and more focus on interdependence. This can show up in the health care experience. Family members are often integral to care planning and there may not be an emphasis on young adults 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