



Supporting Black Autistic Girls

in the Transition to Adult Health Care

FAMILY VOICES[®]

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. | 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)
- [A2G in Your State](#) | Center on Youth Voice, Youth Choice (youth-voice.org)



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