

Anton's Story

Anton is a 20-year-old African American young adult who lives with his parents, Jonelle and Gerald, and two younger siblings. They live in a mid-sized town. Anton's father is a teacher, and his mother works as a lab assistant. Although the family knew he was not developing like other preschoolers, they were surprised when a diagnosis of pervasive developmental disorder with a cognitive disability was made. Since that time they have watched him make progress both at home and school. Although he continues to learn new skills, they know he lacks the skills to be independent, and they are worried about what will happen when he turns 21 and is no longer enrolled in school. Recognizing that Anton would not be able to manage his affairs as an adult, his parents applied for and received guardianship before he turned 18 years old.

At this time, Anton's school program has focused on learning life skills. His individualized education program (IEP) team has been focused on transition to adulthood since he was 14 years old. A staff person from the Division of Vocational Rehabilitation (DVR) has attended Anton's IEP meetings since he was 18 years old. His most recent cognitive assessment placed Anton in the low moderate range of intellectual functioning. Along with other special education students in his high school, he spends time learning skills to increase his independent cooking skills (for example, preparation of a snack but not meal preparation), cleaning, table-setting, bed-making, laundry, personal hygiene including shaving, and household safety. In addition, the students are exposed to a variety of work tasks, including office tasks such as paper-shredding. The students also run a bakery once a week, preparing and selling baked goods to teachers and students. Anton finds it difficult to participate in the kitchen activities, because the loud noise in that environment is overwhelming for him. He does well when he accompanies a staff person to a small grocery store to pick up supplies. With supervision, he cleans the counters at the end of the sale. Anton is learning to ride a bus to the grocery store with an adult, but he often takes off when he exits the bus. The city bus environment seems to agitate Anton, as he makes loud vocalizations and slaps his head. He also has been known to run to calm himself, but when he sees something of interest he will often run off to investigate and not return on his own. Resistive inputs (e.g., running on the playground and pushing a weighted cart) have both been helpful calming strategies at school. Anton's educational assistant has been able to establish a relationship with Anton, but his interactions with peers and other adults at school are very limited.

At home Anton's family includes him in some household activities. Anton is learning to use the microwave to warm up food and make popcorn. Anton's parents never leave him without adult supervision at home, as he has no awareness of unsafe situations or the ability to call for help if he has a problem. Bathing, dressing, and toileting are completed independently with step-by-step cueing. The family has added locks to all doors at home in order to prevent Anton from wandering off. He has younger siblings who come and go from the house, and they are not able to prevent him from darting out the door. He is reported to have difficulty tolerating loud noises at home and doesn't like being touched by others unless he initiates it. When he is on his own, he makes loud vocalizations incessantly, which disturb his siblings and often disrupt their activities. Anton likes to sleep with his back up against a wall and hums to get himself to sleep.

Jonelle has been talking to other parents. She has heard that opportunities for living in the community are limited in their county and that there is a waiting list. Jonelle and Gerald are concerned that a trust fund being contemplated by the children's grandparents may make Anton ineligible for services.

Summary

Anton's parents are concerned about the upcoming transition when he turns 21. They are uncertain what options there will be for him to fill his days and they wonder if he will always live with them or his siblings. Additionally, they are concerned that their home is not secure enough to prevent him from running off. Although the school has been able to keep Anton safe, his parents are concerned that he may run away from new people who are unfamiliar to him at a job site or in the community. Jonelle and Gerald need to continue to work to financially support the family and worry that one of them may have to quit their job to care for Anton.

Anton is functioning in the low-moderate range of intellectual disability and also has a diagnosis on the autism spectrum. Sensory processing challenges have an impact on his participation in school activities and his learning of daily living and prevocational skills. His propensity to run to explore and to escape situations that are uncomfortable for him raise significant concerns for his safety and need for supervision and monitoring. His diagnosis on the autism spectrum limits his social opportunities and relationships.

Follow-Up Suggestions and Recommendations

- 1. School staff to collaborate with county resources to identify possible employment settings which Anton could successfully enter, as well as supports needed.*
- 2. Family to receive information from a lawyer specializing in disability law regarding financial planning and, specifically, information regarding trusts.*
- 3. Transition team should address Anton's sensory processing challenges in work and community environments in order for him to make a successful transition.*
- 4. Discuss with family to consider changing his medical care from a pediatric to an adult practice specializing in adults with neurodevelopmental disabilities.*