Navigating the Emotional Journey

Walking a Tightrope: Parenting Older Adolescents with ASD



Parenting an older adolescent with ASD sometimes feels like walking a tightrope extending through thick clouds to unseen horizons. Parents must find a workable balance between being appropriately protective

of that older adolescent, while also letting go to promote as much independence as possible. All of this occurs without the benefit of a roadmap to, or the fast-forward capability to foresee, your child's future. But there are definite skills to aid us on our parenting journey: proactive planning; accepting what we can't control; listening to our kids; and believing in possibilities.

Proactive Planning

Adolescents with ASD need many supports in place to secure a smooth and successful future. While high school presents lots of challenges, many supports and accommodations are in place that do not continue beyond high school. For example, there are usually long waitlists for services and less opportunity for social interaction after K-12. And appropriate jobs are often difficult to find. As a result, parents must intentionally create opportunities for individualized support in many forms, including visual systems, community supports, mentorship, and one-to-one providers.

Who Is in Control?

Parents must also decide whether to seek legal guardianship in order to remain involved in making crucial decisions for their growing children. Although sometimes necessary, guardianship has the potential of negatively impacting an adolescent's sense of control over his own life. Besides, it perpetuates a stigma that people with ASD are not able to manage their own affairs.

Our son recently turned 18. Together we decided that it made most sense for him to give

us power of attorney to collaborate with him on medical and financial decisions. It is a complex issue that each family must address in their own way.

Even when proactive steps are taken, we must still learn to live with an underlying fear of things happening outside our control. Carol Osborn, in *The Art of Resilience* ©1997, comments: "Of course you should do what you can, but remember there are forces beyond your control ... things we cannot know. There is mystery... Sometimes it is helpful to have a graphic reminder that this world is quite simply not your show. One way to really get this message is to go to the nearest ocean and try to stop the waves from rolling in" (p.159).

We want to do everything possible to help our adolescents grow in positive ways, but at the same time we must transition to a different stage in our own development as parents. Mary, a psychotherapist whose 34-year-old daughter has a developmental disability, told me, "At some point, I came to realize that my daughter is going to be who she is. I finally was able to drop

the expectation that she be other than she is. My own growth as a human being comes from learning to accept the reality of my life, as it is."



Listen to Our Adolescents

As we come to more clearly see who our children are as individuals, we can begin to better recognize their capabilities. We must encourage our adolescents to help us know who they are and what they need from us, if we are to fully grasp their strengths and abilities. Be honest with them and let them know that you don't have all the answers and that this is new territory to you, too.

My son, Jordan, shared some things he needs from me as an 18-year-old. He said, "Allow me more opportunities for independence. Listen to me while I process circumstances that come up, especially ones that feel uncomfortable and confusing. Let me try to figure it out first;

give me feedback if I need it. Push me to take risks that feel uncomfortable; for example, encourage me to speak up if someone says something that makes me feel hurt."

Believe in Possibilities

Individuals with ASD repeatedly say they want people in their lives (including parents) to hold higher expectations



for them to allow more opportunities for growth as they rise to the level of greater challenges.

Our job is to believe in possibilities. I heard a story once about a young man with cystic fibrosis who wanted to run track and play the saxophone. Although his parents feared the effect on his lungs, the family doctor advised them to let him try. When questioned about the wisdom of that decision, the young man said, "to try and to fail, that's okay, but not to try—that's not living." There's significant wisdom here that we need to heed however difficult it can be to "let go."

When parenting adolescents with ASD, we may feel shaky in walking that tightrope. But if we engage in proactive planning, accept what we can't control, listen to our kids, and believe in possibilities, we are more likely to find our balance and make it to the other side.

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Adreon's Advice on ASD

Transition to Adulthood

Planning the transition to adulthood requires a great amount of planning. The following are a few suggestions to consider when developing and implementing a transition plan.

- Become familiar with the differences between IDEA and ADA.
- If the student will be transitioning to a traditional community college or university, consider fading supports that will not be available in the next environment.
- Emphasize work/study skills such as keeping track of assignments, breaking down projects into smaller components, and establishing time frames.
- While the student is in high school, have him/her become increasingly responsible for explaining his/her challenges and needed accommodations to school personnel and others.
- Arrange for work experience activities while the student is still in high school.

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