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Devon R. Casey

University of New Hampshire - Main Campus, drp36@wildcats.unh.edu

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Between Wind and Water: Experiences of Mothers of Adolescents with Autism During the Post-High School Transition

Devon R. Casey, OTS & Susan Cook Merrill, PhD, OTR/L, FAOTA  University of New Hampshire

Research Question
How do mothers of adolescents with autism experience and prepare for their child's post-high school transition?

There are now a substantial number of families with adolescents who have autism. Little is known about how mothers of late-adolescents with autism experience their child’s post-high school transition.

Methods
- Qualitative Description
- Two-part interview series
- Creswell’s Qualitative Analysis
- Lifestyle Balance Model

Participants (n=3)
- Primary, care-providing mothers of adolescents with autism aged 18-19 years, enrolled in a full-time education program
- All participants were between 45 and 50 years old

Themes

Staying Afloat: Navigating the Transition
- Constantly adapting: “You think you have it all down pat...and then ‘wham!’ out of the blue, one of them completely changes.”
- Looking ahead: “It’s scary to think about what will happen to him when I’m not here.”
- Navigating an unknown system: “It’s so hard when you don’t know what you’re doing, it really is. You just don’t know where to go or what to do or who to ask.”
- Finding programs that offer balance: “I’m going to get him what he needs. He can never be cured, but he needs to be that best that he can be.”

Uncharted Waters: A Lack of Information
- Turning to Peers: “Other mothers are your best forms of information because they’ve been there, done that, or they’ll go through it with you.”
- Lack of Professional Support: “It would be nice if the medical people knew more.”

Conclusion
Mothers of adolescents with autism feel they are in uncharted waters, without a map. Mothers expressed deep concern about finding post-high school environments in which their children could:
- create a personal identity
- feel safe
- be appreciated as unique
- be engaged and challenged

Mothers also feel the strain of being the first wave of families who are making these decisions.

Occupational Therapy Intervention Implications
- Use the Lifestyle Balance Model to help parents identify programs that will support their adolescents’ occupational performance and participation.
- Consult with programs to facilitate adolescents’ transition.
- Facilitate ongoing communication between families and post-high school programs.

References

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