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

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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.¹ Little is known about how mothers of late-adolescents with autism experience their child's post-high school transition.



Methods

- ❖ Qualitative Description²
- ❖ Two-part interview series
- ❖ Creswell's Qualitative Analysis³
- ❖ Lifestyle Balance Model⁴

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.”

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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 Model⁴ 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.

