The Concealed Perspective: A Qualitative Study of How Having a Sibling with Autism Influences Family Dynamics and Life Course Decisions

Isabel Michniak

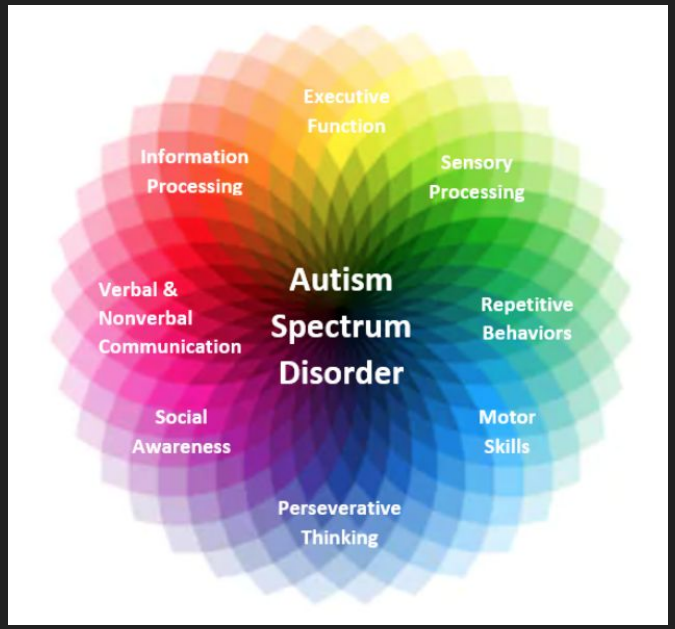
THE CONCEALED PERSPECTIVE

Research Question

How does having a sibling with autism influence family dynamics and life course decisions?

WHAT CURRENT LITERATURE SAYS

Autism Spectrum Disorder and Emotion Work



"By 'emotion work' I refer to the **act of trying to change in degree or quality an emotion or feeling**. To 'work on' an emotion or feeling is, for our purposes, **the same as 'to manage' an emotion** or to do 'deep acting'" (Hochschild 1979: 561).

Family Dynamics and the Life Course

- Positionality in the family
- Difference in treatment growing up (Jensen et al 2013; Siennick 2013)
- Families influence negative behaviors, GPA, and college expectations (Cooksey, Menaghan and Jekielek 1997; Heard 2007)

Conducting the Research

- Why interviews?
- Recruitment - Qualifications
- Interview Questions
- Confidentiality

FINDINGS

Family Dynamics: Responsibilities, Unequal Attention, Emotion Work

"I think the biggest challenge for me was always, and as much as I enjoyed it, like, I was always like the **built in babysitter,** that's what I like to call myself." - Jade*

He was spoiled more, um, I didn't quite, I know I wanted to do gymnastics as a kid. But we didn't have the money because we needed to invest more money into like Ethan's care. So I didn't get to do that. But I did, like get to do other stuff**. It's just that's like what I really wanted to do. And I never got the chance to**" - Lisa

"One of the issues that I've had is...maybe you can attribute this to my sister as well, is like blocking in some of my own thoughts and feelings because, um, my parents already have enough emotional stuff going on with my sister. And some, maybe sometimes part of that, um, Like locking them in like, like my whole mind, thought like, okay, **maybe if I don't speak as much about what's, what I'm going through, they won't be as worried.**" - Dave

*All names are pseudyonyms.

The Life Course

"Like, there's so many options. And now I'm kind of thinking like animals and autism, like kind of connecting that somehow .... **I do love the autism piece, but I'm afraid I'm going to get burnt out on it.** Because, I mean, we live with it. And it gets frustrating." - Marissa

"Yeah, I think we've gotten closer now, as she's become ... I think she had this rebellious teenage phase. **I didn't have that because I wasn't able to have that.**" - Donna

Future Expectations and Goals

"I want of course, I want her to be happy. and It's, I want her to ....one of my biggest concerns is that as we're trying to, like, figure out her future, **could we potentially be holding her back because we don't know what she's capable of**" - Donna

"I'd like him to, like, have a **career maybe, or maybe even just, like, move out and live by himself a little bit**, not like, you know, a full apartment by himself, but kind of just, you know, to be really independent, because I think he can, he's very capable of doing that. He's not, he's, um, yeah, he's a very capable person." - Lisa

"So I would hope that, you know, for the most part, I want noah to be happy. **Just living just a good life.** That's That's the goal. I obviously I don't see him going to, you know, college or anything." - Matt

Conclusion

Siblings with autism often feel overlooked and grew up performing emotion work through their additional roles and responsibilities. Their family experiences played a strong role in their decision-making for future endeavors, including college and work.

"And, of course, there's like, the situations where, like, I think, like, Okay, what if she didn't? What if she didn't have autism? how would this, how would this situation have played out? how, how, could something be different? Then I retract back and say, ***how would I be different?***" - Dave

"I'm very happy with, that my childhood was like that. Yes, I had more responsibility than the average kid. And I was definitely more of a parent. But I think it's definitely made me a better person. I think it makes us better people. **Because we learn that empathy, we learn to take care of people**" - Donna