

Family Relationships and Support for Autistic University Students in the UK



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1. Background

- Autistic students have mentioned that family support is helpful, but the role that family plays in autistic students' university journeys is not well understood [1].
- Existing research also lacks representation from family members, especially non-parental ones (e.g., siblings).
- Autism community members agree that this topic is a priority for research (see Methods).

2. Aims/Research Questions

- 1. Understand autistic university students' family relationships and dynamics
- 2. Understand how family members support autistic university students and vice versa
- 3. Understand if and how family demographics might impact the support relationship between autistic students and their family members

4. Key Findings

Theme 1: Impact of Mental Health and Other Co-Occurring Conditions

- Students' physical and mental health difficulties impacted their university experiences and family support
- Being supported was helpful in students returning to or reattempting university

Theme 2: Family Relationships and Family Involvement are Heavily Intertwined

Theme 3: The Role

of Siblings

- Most family relationships positive; some neutral or strained
- Positive relationships often corresponded to positive descriptions of support, e.g.:
- Parents provided immediate help during crises
- Students helped siblings with academic work
- Negative relationships due to:
- Family member not accepting of autism
- Students had to heavily support their family members
- Other determinants of and barriers to support included family members' available resources and students' independence

 Siblings with recent university experience may help mitigate barriers to support

- Often have more up-to-date knowledge than parents
- May be able to suggest relevant/targeted support options if autistic students/parents are not aware of them
- Helpful to feel understood by and have the option of support from siblings with similar experiences

Impact on family support:

"[Daughter] went through a period of depression, which made it difficult to support the autism, as her mental health problems took priority." [Dawn B, parent]

Factors affecting support:

"We're really lucky because we have the family capacity to get involved and do what we can to help." [Harriet, parent]

"I was really self-sufficient... I didn't want any help." [Zoe, student]

Information may be received differently when coming from a sibling compared to a parent: "It's coming from the position of, like, 'Oh, I just heard about this thing that might be useful."

[Ruby, sibling]

3. Methods

Community Involvement

- A steering group voted on the research topic and helped refine study design and materials
- Group members were 4 autistic university students/graduates, 2 autism mentors, and 3 family members of autistic students

Participants

- 26 autistic students (ages 19-55; 12 female, 4 male, 5 non-binary, 5 other description)
- 8 parents, 3 siblings of autistic students (ages 19-69; 10 female, 1 male)

<u>Measures</u>

- Individual semi-structured interview (Zoom, email exchange, inperson, and webchat)
- Questions about university experiences and family involvement

<u>Analysis</u>

 Common ideas ("themes") were identified from participants' responses through Reflexive Thematic Analysis [e.g., 2]

5. Discussion, Implications & Conclusion

- Family members, especially parents, often remain involved in autistic students' university journeys [3].
- While many students benefit from family support, they also often provide support to their family members.
- Both student (e.g., desire for independence; co-occurring conditions) and family (e.g., financial situation; whether family members have been to university) factors impact the amount and direction of family support.
- Future research should investigate if and how family support impacts outcomes such as university completion and future employment.

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[3] Dallas, B., Ramisch, J., & Ashmore, A. (2018). How Involved Should They Be? Students with ASD in Postsecondary Settings and Their Family Members. The qualitative report, 23(5), 1208-1222.