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UNDERSTANDING THE EXPERIENCES OF TYPICALLY
DEVELOPING SIBLINGS OF PEOPLE WITH AUTISM

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Understanding the Experiences of Typically Developing Siblings of People with Autism

While research into the experiences of people with autism and their families is flourishing, there remains relatively little research on the experiences of typically developing siblings, particularly those on the brink of adulthood. Ms Caitlin Calio, Masters of Teaching, and Professor Ann Higgins-D'Alessandro at Fordham University in the USA, are dedicated to overcoming this important knowledge gap to help inform both theory and the development of appropriate practical support.

The research literature on people with autism continues to expand in many helpful ways, including consideration of the impact on families. Previous research on the experiences of typically developing siblings of people with autism has primarily focused on experiences in childhood and adolescence. However, emerging adulthood – the age span from around 18 to 30 years old – is a critical period of development for American youth before entering the stable roles of adulthood work and love. During this time, the development of identity takes a prominent role, characterised by changes in how they think about autonomy and community or belonging, and the drive to achieve a balance between these differing and potentially conflicting aspects of life.

Given the lack of literature on this important developmental period, Ms Caitlin Calio and Professor Ann Higgins-D'Alessandro at Fordham University in the USA initiated a support group for emerging adults at college with siblings with autism. They wanted to create a forum in which individuals could share their experiences, and they also wanted to determine whether the participants found the group meaningful and useful. Additionally, the researchers wanted to better understand how the participants'

sibling relationships shaped their sense of identity and relationships, and obtain detailed insights into the participants' views of their family's functioning.

The support group, known as Sibling Allies, met five times in 2017 and each meeting lasted between 35 and 65 minutes. All the participants provided their consent for the meetings to be recorded and transcribed. This allowed Ms Calio and Professor Higgins-D'Alessandro to undertake a qualitative analysis of the discussions.

More specifically, the researchers adopted an approach known as Multi Grounded Theory. This structured analytic process consists of four steps: 1. Inductive Coding and Classification, 2. Conceptual Refinement, 3. Pattern Coding, and 4. Theory Condensation. The first three steps facilitate the development of key themes and categories, while the final step allows the development of action-paradigm models to organise themes into units of (a) Conditions, (b) Actions that occurred, and (c) Consequences.

In their analysis, Ms Calio and Professor Higgins-D'Alessandro identified ten thematically derived action-paradigm models to illustrate researchable relationships



among the conditions, actions, and consequences of participants' lived experiences. These models were organised into three main categories, named Individual Experiences, Family Life in Private, and Family Functioning in Public. The researchers argue that the importance of the models within these three categories is that they capture the experiences of typically developing siblings of people with autism.

Within the category of Individual Experiences, models focused on social isolation resulting from negative reactions when trying to share about their sibling with autism, participants' sense of responsibility, and concerns for their sibling's future. This sense of responsibility led to decisions to stay near home for college, come home unasked and seek advocacy positions. During college, participants recognised that it's important for them to balance their responsibility with their own autonomy and future planning.

For Family Life in Private, one model includes the family's emotional experiences, especially shaping family life

around the needs of the sibling with autism. A second model focuses on the dual nature of the participants' relationships with their siblings. They described both a typical sibling relationship, as well as a parentified caretaking role. What came through in discussions of family life was that all participants cherished and took pride in their siblings.

For Family Functioning in Public, models include the effects of stigma and reactions of the extended family. The challenges of taking the whole family out in public, to a restaurant, religious services, shopping, and especially to extended family events were the focus of the participants' most sad and poignant discussions. Participants encountered people, even extended family members, who lacked knowledge, would criticise, or reject the sibling with autism and expect the family to apologise for his behaviour.

The researchers were keen to place their findings into the context of the existing literature. A key issue that participants brought up, and had been previously



identified, was the rarity of opportunities to share their sibling experiences in a non-judgmental setting. Encouragingly, participants also reported that this was something the support group provided, leading to a sense of comfort for them. For example, the participants recognised that they shared many of the same struggles and complex emotions, with one participant describing the meetings as ‘really good therapy sessions’. The sense of shared experience also led to the development of unique group humour, with the participants developing over time, their own language of jokes and humour.

This provides a useful example of one of the three action-paradigm models identified by the researchers in terms of the meaningfulness and usefulness of the group for participants. Here, we see how the condition of rarity of opportunity to share sibling experiences led to the action of the shared experience of sadness within the group, which led to the friendship and bond underpinning the consequence of the participants’ gladness to be part of the group.

These, along with the researchers’ other observations, provide support for the utility of the Multi Grounded Theory approach in the context of understanding the experiences of typically developing siblings of people with autism, and provide a firm basis for further modelling of these complex phenomena in future research.

Overall, it is clear that the participants valued the Sibling Allies group, reflected not least in their reports that they were keen to maintain contact following the end of formal group sessions and had already discussed meeting together in the future. They also felt the group would be a great resource for other individuals in their position, supporting the researchers’ conclusion that such provision would be meaningful and useful to other college participants.

“It’s really unexplainable, but everyone here got it:” Analysis of an ASD sibling support group for emerging adults published in *Research in Autism Spectrum Disorders*. DOI: <https://doi.org/10.1016/j.rasd.2021.101857>.