

Title: The Role of Siblings: Qualitative Perspective of Adolescents with Autism Spectrum Disorder or Intellectual Disability and their Caregivers

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Introduction: Sibling relationships are shaped by shared social environments and connections within the family unit (Cicirelli, 1994; Sage & Jegatheesan, 2010). In families of children with disabilities, research has characterized the sibling relationship as both uniquely negative and positive. For example, typically developing (TD) siblings may be exposed to adverse behaviors from their siblings with disabilities and feel burdened by caregiving responsibilities (Ross & Cuskelly, 2006). However, there is also evidence to suggest that less sibling rivalry exists when one child has a disability (Kaminsky & Dewey, 2002). The majority of sibling research has been conducted from the perspective of the TD sibling, but less is known about perceptions of the sibling with a disability. In this qualitative study, we describe how adolescents with autism spectrum disorder (ASD) or intellectual disability (ID) and their caregivers perceive the role of their siblings.

Method: Data were drawn from the Collaborative Family Study, a longitudinal study of family adjustment of youth. Our sample included 31 target adolescents with ASD, 17 adolescents with ID, and 68 TD adolescents and their caregivers. Semi-structured interviews were completed with the target adolescent and their caregiver for each diagnostic group; questions regarding the adolescent's school environment, social and romantic relationships, and relationship between siblings were asked. For the current study, questions regarding the sibling relationship were further examined, specifically regarding the perceived role of the sibling of ASD, ID, and TD adolescents. There were seven possible sibling roles: teacher, student, caretaker, warden (being taken care of), friend, rival, and source of annoyance.

Results: Only codes of sibling role rated above 10% are reported here. Target adolescents and caregivers across all three groups most frequently described siblings as performing the role of friend (Adolescent participants: TD = 45.6%, ASD = 54.8%, ID = 35.3%; Caregiver participants: TD = 31.9%, ASD = 41.4%, ID = 50.0%). Following the role of friend, caregivers across all three groups described the sibling relationship as fitting a teacher role (TD = 20.3%, ASD = 31.0%, ID = 25.0%). Adolescents with ASD described their siblings as being more annoying than both TD and ID adolescents (TD = 8.8%, ASD = 29.0%, ID = 0.0%). Additionally, adolescents with ID (11.8%) and their caregivers (10.0%) were the only group that described siblings as being in a caretaker role.

Discussion: Both adolescents and caregivers in all three groups frequently described the siblings' role as a friend, indicating agreement between the respondents and suggesting the existence of a positive relationship between siblings in the family despite different diagnostic status. Caregivers also perceived siblings to have teacher-like roles, which may be indicative of the fact that siblings act as peer models within the home. Interestingly, adolescents with ASD describe their siblings to be annoying more frequently, compared to adolescents with ID or TD. Given the core social communication deficits associated with ASD, these adolescents may need to exert greater efforts to maintain a sibling relationship or they may simply misunderstand their siblings' behaviors. Adolescents with ID and their caregivers were the only group to primarily describe the siblings as caretakers. The siblings of adolescents with ID may provide more explicit caretaking acts than siblings of ASD adolescents, due to ID siblings greater cognitive and adaptive impairments. Overall, this study underscores the importance of recording perspectives of adolescents with disabilities, particularly in ways other than "positive" or "negative." Employing qualitative methodology to detail the views of individuals with disabilities expands current research on sibling relationships and also helps to contextualize disability within the family unit.

References:

Cicirelli, V. G. (1994). Sibling Relationships in Cross-Cultural Perspective. *Journal of Marriage and the Family*, 56(1), 7. doi: 10.2307/352697

Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43(2), 225–232. doi: 10.1111/1469-7610.00015

Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability*, 31(2), 77–86. doi: 10.1080/13668250600710864

Sage, K. D., & Jegatheesan, B. (2010). Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell. *Journal of Intellectual & Developmental Disability*, 35(2), 92–103. doi: 10.3109/13668251003712788

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