Symposium Title: Qualitative Approaches to Understanding Family Experiences

Chair: Gael I. Orsmond

Discussant: Julie Lounds Taylor

Overview: Recent editorials have espoused enthusiasm for and discussed the merits of rigorous qualitative research to help better understand the experiences associated with intellectual/developmental disabilities (IDD) and autism spectrum disorder (ASD) (Bolte, 2014; O’Reilly, Lester, & Muskett, 2016). Such qualitative studies can better inform the development and refinement of interventions for this population or supports for family members. In this symposium, we highlight the utility of three different qualitative approaches to understanding family experiences, especially during the adolescent and adult years. In the first presentation, Wong and colleagues describe a case analysis of video data from an adolescent sibling and her brother. Coding of naturalistic sibling interactions, incorporated with analysis of the sibling’s reflection on her roles, yielded insights about her dual roles as a sibling and a caregiver. In the second presentation, Burke and colleagues describe an analysis of how sibling dyads (adults with IDD and a sibling) make decisions regarding independent living, employment, and self-determination. The siblings had different expectations for how decisions would be made. The findings suggest the need for interventions or supports to enable individuals with IDD to engage in decision-making and to enable siblings to support their brothers and sisters with IDD. In the last presentation, Shivers and Lee analyzed open-ended responses on a survey completed by family caregivers of individuals with ASD. Although not prompted, family caregivers expressed concern about the future, suggesting that many family members still lack support, particularly as the child with ASD ages out of child and adolescent services. The symposium will conclude with a discussion by Julie Lounds Taylor on how qualitative approaches contribute to understanding family experiences and may be useful in the development or refinement of supports and services, especially as the populations of individuals with IDD/ASD age and the service landscape continues to change.

Paper 1 of 3

Paper Title: “Sometimes I Wish I Could Cut Into Half”: A Case Analysis of Social Roles and Behaviors of an Adolescent Sibling and Her Brother with ASD

Authors: Jasin Wong, Gael I. Orsmond, Ellen S. Cohn

Introduction: Siblings are socializing agents; within the relationship siblings can learn and practice socially appropriate behaviors. Typically-developing siblings have a large impact on social engagement for youth with autism spectrum disorder (ASD). Previous studies have shown the preliminary effectiveness of including typically-developing siblings in the social interaction interventions for young children with ASD (Ferraioli, Hansford, & Harris, 2012; Oppenheim-Leaf, Leaf, Dozier, Sheldon, & Sherman, 2012). However, no prior research has investigated (1) the strategies siblings naturally use to guide, teach and modify the behavior of their brother or sister with ASD to behave in a socially accepted manner, (2) sibling’s perceptions of being the social facilitator of their brother or sister with ASD, and (3) how youth of ASD respond when their sibling guides their behavior in daily social interactions. Therefore, our aim in this case analysis were to (1) explore the strategies an adolescent female sibling used to shape the behavior of her older brother with ASD and assist her brother to act appropriately in public social contexts; (2) investigate the sibling’s perception or her roles and behavior in the sibling relationship; and (3) examine the responses of the brother with ASD when he was taught, guided and directed by his sister.

Method: We conducted a qualitative case analysis using video data from a sibling dyad. The data were collected as part of a larger prior study, in which typically-developing adolescent siblings were asked to make video-recordings of their daily family life,
sibling interactions, and shared activities with their brother or sister with ASD for 4 hours over 1-2 weeks. Participants were also instructed to create a reflective monologue about their sibling relationship in the video using prompts to describe their experiences. We selected this sibling dyad for analysis based on the range and variability of social interactions in the video content including smooth between-sibling interactions, varied shared activities, the presence of sibling quarrels and a detailed personal narrative provided by the sibling during her monologue. A content analysis was conducted using the concept of physical and linguistic manipulation as described by Solomon (2011). We selected video segments which represented the sibling’s attempts to tailor her brother’s behavior, identified the strategies she used, and analyzed the responses of the youth with ASD to her sister’s attempts. Finally, we examined the sibling’s monologue to investigate how the sibling viewed her roles in the sibling relationship within the family.

**Findings:** The brother with ASD engaged in several behaviors that his sibling attempted to redirect or stop, such as initiating an interaction with meaningless sounds, exaggerated expressions, or mimicking TV show characters. The sister used two different behavioral strategies when responding to her brother’s socially inappropriate behaviors. One strategy was to try to understand her brother’s desire for interaction, naturally following her brother’s lead, adjusting the conversation topic to align with her brother’s interest, and assisting her brother to continue the interaction by extending the topic or contributing to the conversation so that it would continue. This type of response often resulted in harmonious and positive engagement within the sibling interaction. The second strategy included attempts to change her brother’s behaviors with commands and corrections, often without an explanation of why the behavior bothered her. In this behavioral response, the sibling established herself in a position of authority. The brother with ASD responded with frustration, as indicated by his tone of voice and brief comments, or did not respond at all. The mutually negative responses resulted in discordant interactions. In the siblings’ monologue, she identified and described two sibling roles that paralleled these strategies. She described that “sometimes I wish...like I [could] cut into half” in the relationship: a role she describe as being a “normal sibling” and another role being that of a “caregiver.” As a “normal sibling”, she was able to interact with her brother in an egalitarian manner, including mutual teasing, arguing on equal grounds, and stating her honest opinion. However, as a caregiver, she was obliged to make compromises, comfort her brother, use strategies to manage her brother’s emotions, make accommodations and teach her brother how to interact in socially acceptable ways.

**Discussion:** Typically developing siblings are often expected to fulfill a caregiver role for their brother or sister with ASD. Previous studies also reported benefits of sibling-mediated social intervention for individuals with ASD (Tsao & Odom, 2006). In this case analysis, the sibling was observed to engage with her brother both as a caregiver (teacher, director) and as a sibling. She identified conflict between these two roles for herself. Future studies could further investigate the impact of these multiple roles within the sibling and family relationships.

**References/Citations:**
Paper Title: Understanding the Perspectives of Individuals with Intellectual and Developmental Disabilities (IDD) and their Siblings Regarding Independent Living, Employment, and Self-Determination

Authors: Meghan M. Burke³, Chung eun Lee³, Sarah Hall⁴, & Zachary Rossetti³

Introduction: As the lifespan of individuals with IDD grows, the population of individuals with IDD outliving their parents increases. While waiting for adult services, parents may transition their caregiving roles to their adult children without IDD. Many siblings look forward to pursuing caregiving roles for their brothers and sisters (Orsmond & Seltzer, 2007). However, we know very little about how individuals with IDD and their siblings make decisions about independent living, employment, and self-determination for individuals with IDD. Further, most research only examines the perspectives of the siblings of individuals with IDD (Taylor, Burke, Smith, & Hartley, in press). The purpose of this study was to understand how sibling dyads (i.e., the individual with IDD and their sibling) make decisions regarding independent living, employment, and self-determination.

Method: Participants included 9 adult sibling dyads (i.e., the individual with IDD and the sibling without IDD). Sibling (i.e., the participant without IDD) participants were predominantly female and White. Although average ages were in the mid-30s, respondent ages ranged from 18 through 75 years. Individuals with IDD (i.e., the brothers and sisters of participants) were primarily male. Participants completed dyadic interviews (i.e., the sibling was interviewed alone; the individual with IDD was interviewed alone; and then the sibling and the individual with IDD were interviewed together). The research team developed a semi-structured interview protocol by reviewing the sibling literature. All interviews were recorded and transcribed verbatim. We analyzed the data using constant comparative analysis (Glaser & Strauss, 1967). Using a line-by-line approach, the research team members independently coded each piece of text. Individually, we compared each piece of data to the previously coded data to determine whether the data represents a novel idea (Creswell, 2003). After all of the data were coded, we met to discuss the codes. Using the agreed upon codes, we independently reviewed the data again. We met to compare the codes, organized the codes into categories, and grouped the categories into themes. Then, we conducted cross-case analysis (within and between the dyads).

Results: We have preliminary methodological and research findings. Regarding our method, we found that not only the communicative ability of the individual with IDD but also the ability and interest to discuss decision-making was necessary to participate in this project. To include as many individuals with IDD as possible, we incorporated pictures, rapport building, and a prescribed interview sequence to ensure the participation and accurate responses of the individuals with IDD. Beyond the methodological findings, we also found that individuals with IDD (compared to their siblings) had different expectations for their future living and employment decisions. The joint interview between the sibling and the individual with IDD revealed decision-making “in action” as the sibling pair discussed decisions and related steps.

Discussion: Given the dyadic nature of siblings, it is critical to include the individual with IDD and the sibling in research. Various strategies are needed to ensure the inclusion of individuals with IDD in research. Further, interventions may be needed to enable individuals with IDD to engage in decision-making and to enable siblings support their brothers and sisters with IDD.

References/Citations:

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Title: Concerns of Family Caregivers of Individuals with Autism Spectrum Disorder across the Lifespan

Authors: Carolyn M. Shivers\textsuperscript{5}, Gloria K. Lee\textsuperscript{6}

Introduction: Autism spectrum disorder (ASD) affects approximately 1 in 68 individuals in the United States (Centers for Disease Control, 2015). Family members, particularly parents, often manage a wide range of caregiving responsibilities for these individuals. Such caregiving can be demanding, stressful, and have a great impact on the family system. Numerous studies have shown that caring for individuals with ASD can create physical, financial, and mental burdens for family members (e.g. Phelps, Hodgson, McCammon, & Lamson, 2009). However, the specific perceptions of stressors are not always captured by existing, quantitative measures. It is important to allow family members to share their own experiences to better understand the factors that impact well-being for caregivers.

Method: Participant responses were gathered from a larger survey study examining physical and mental health among family caregivers of individuals with ASD. In addition to completing measures of demographic information, service system utilization, coping strategies, and physical and mental health outcomes, respondents had the opportunity to provide answers to open-ended questions describing what life is like caring for an individual with ASD. Nearly one-third of survey respondents (31.4%, n=61) provided answers to these open-ended questions. The current sample was largely female (93.4%) and consisted of mostly parents of the individual with ASD (95.1%). The individuals with ASD (i.e. the recipient of caregiving) were mostly male (80.3%, n=49), with an average age of 17.88 years, though the age range extended from 4 to 80 years old. Nearly half of the individuals with ASD from the current sample (47.5%) were over the age of 18, a higher proportion than in the full survey sample. Participant responses were analyzed with line-by-line coding to establish categories of responses, which were entered into NVivo 10 (QSR International 2012) to establish uniformity across the results.

Results: The most common theme discussed by caregivers was worry about the future. Caregivers mentioned concerns about how the family member with ASD would cope in adulthood, with limitations including the lack of services for adults with ASD, the individuals’ own reluctance to practice functional skills, and the local restrictions on independence (e.g. lack of public transportation, limited job opportunities). The financial strain, particularly the cost of services and lack of government funding, was another common theme. Many parents also expressed general concerns of who would assume caregiving responsibility when the parents are no longer able to do so. Additionally, respondents discussed personal challenges, such as lack of alone time and isolation from peers and extended family. A small number of caregivers reported positive outcomes, such as feeling blessed and learning life lessons from the individual with ASD. Of these positive responses, most caregivers explained that their family member with ASD was high-functioning, thus framing the reported blessings in relation to the perceived struggles of family members of individuals with more severe ASD symptoms.

Discussion: It is important to note that the open-ended questions did not specifically ask for stressors or difficulties, yet the vast majority of responses described struggles and challenges in caring for an individual with ASD. The number of “negative” responses, along with the higher proportion of caregivers of adults with ASD providing responses, suggests that many family members still lack support, particularly as the child with ASD ages out of child and adolescent services.

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References/Citations:

- NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2012.