Title: Disabilities within Families

Authors: Myles Maxey, Kathy Piercy, Troy Beckert

Introduction: Having a child with a disability impacts all family members; both parents and siblings have to adjust and adapt (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008). Some parents and siblings are able to adapt positively (Graff et al., 2012; Mitchell & Hauser-Cram, 2010) while others tend to struggle in adjusting (Breitkreuza, Wunderli, Savage, & McConnell, 2014). Additionally, there are both internal (Peralta & Arellano, 2010) and external (Breitkreuza, et al., 2014) factors that contribute to the ability to successfully adapt. The purpose of this study was to understand differences in family perceptions when a family member has a disability and to evaluate differences in parental and sibling perceptions within these families. Three research questions guided this study: (1) What areas are most important to Family Quality of Life?; (2) What impact does disability have on family satisfaction levels within these areas?; and (3) From the perspective of family members, what perceived influence does an individual with disabilities have on familial and other relationships?

Method: We collected data in two phases. First, 36 primary caregivers in families with at least one family member with a disability ($M_{age}$ of family member with a disability= 18.2 years ($SD= 10.51$ years)) completed The Family Quality of Life Survey (Brown et al., 2006), a measure of perceived family quality of life to the primary caregiver of the individual with disabilities. Type of disability varied across families, including, but not limited to, intellectual, autism spectrum, down syndrome, and cerebral palsy. Second, at the conclusion of the survey, primary caregivers were asked about their willingness to participate in an interview about their experiences with another family member. Of the families who agreed to be interviewed, five dyads, both a parent and a sibling (over the age of 18), were selected to be interviewed separately about their experiences based on their unique experiences, both positive and negative. The interviews took place over video conferencing software (i.e. Skype or Facetime) and lasted approximately 45 minutes. Interviews were recorded and transcribed verbatim in preparation for analysis.

Results: Phase One. The Family Quality of Life Survey assesses, using a Likert scale ranging from 1 (hardly important at all; very dissatisfied) to 5 (very important; very satisfied), primary caregivers’ perceptions of their family quality of life and aspects that contribute to it, including family health, family relationships, support from others, support from providers, values, recreation and leisure activities, community interaction, and financial well-being. Our first research question sought to find out which of these areas were most important to the respondents. Primary caregivers identified family relationships ($M= 4.75, SD= 0.55$), financial ($M= 4.52, SD= 0.68$), family health ($M= 4.31, SD= 0.62$), support providers ($M= 4.21, SD= 0.99$), and values ($M= 4.18, SD= 1.26$) as the most important areas to their family quality of life. Our second research question sought to understand levels of satisfaction within these same areas. Values ($M= 3.91, SD= 1.07$) and family relationships ($M= 3.83, SD= 1.11$) had the highest levels of satisfaction, while participants reported that recreation and leisure activities ($M= 2.90, SD= 0.98$) and financial ($M= 2.87, SD= 1.31$) were the least satisfying. Phase Two. The analysis for the qualitative data followed a concept-driven approach (Gibbs, 2008). Informed by the literature, the concept-driven codes were separated into internal and external factors (Gardiner & Iarocci, 2012). Additional codes were identified that related to the research questions, but did not fit into the established codes. The recognition that it is not about you anymore and finding shared interest activities to maintain family relationships emerged as two key internal factors. Religion and spiritually were internal factors that played an important role in individual and familial ability to cope and adapt. Additionally, family members deemed setting aside quality time for other family members important. While parents were self-critical for their perceived lack of time with their other children, the sibling respondents did not share these same feelings. Sibling respondents acknowledged spending less time with parents, but they never felt less loved. Supportive providers, those who offered opportunities for all to have new experiences and enhanced social opportunities were identified as key external factors. However, the lack of available services and worry about the level and type of care received resulted in apprehensions. Both parents and siblings felt that having a family member with disabilities enhanced mutual understanding, increased patience, and contributed to more compassion.
Discussion: Expanding on previous research, these results suggest that a combination of family relationships, outside support providers, and family values and beliefs help increase the perceived overall family quality of life and satisfaction in families with disabilities. Further, there appears to be a bidirectional influence, where the family impacts the individual with a disability while also being impacted by their child/sibling with a disability. Findings have implications for supports and resources that should be offered to parents and siblings. The positive aspects of having a family member with a disability along with successful adaptation practices are important to share with families of newly-diagnosed children.

References/Citations: