People with Disabilities and their Siblings: Building concepts of support, and transitions (SUMMARY)

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SUMMARY

Sibling relationships are one of the longest lasting relationships that humans experience, allowing for a longer time of accumulated shared experiences. Sibling relationships play an important role for people with Intellectual and Developmental Disabilities (I/DD) who are living longer. Researchers, policymakers, and advocates are increasingly noticing the important role that siblings play in the provision of support for aging persons with I/DD. However, the majority of sibling literature investigates the sibling relationship through the lens of psychological adjustment, stress, and burden and does not include the perspectives of people with I/DD. Researchers have critiqued this body of research and set out guidelines for future sibling disability research. This study uses a Disability Studies approach and Life Course theory to respond to the guidelines. The present study examines the perspectives of siblings with and without I/DD as they both age and experience the support transition from parent to nondisabled sibling. The purpose of this study is to examine the nature of the sibling relationship, the meaning of support, and the effect of social context on siblings with and without disabilities after support transition.

Purposeful sampling was used to recruit adult sibling pairs that represented diverse backgrounds. Sibling pairs were recruited through self advocacy organizations or sibling advocacy organizations. A total of 8 sibling pairs were recruited from the Chicago, Illinois and Columbus, Ohio. The sample for this study ranged from 25-53 yrs. of age for siblings with I/DD and 32-59 yrs. of age for nondisabled siblings. Six of the 8 siblings of people with disabilities identified as being primarily responsible for the support needs of the sibling with a disability. Two of the 8 responded that other siblings in the family had shared/divided responsibility. Seven of the 8 nondisabled siblings were female; 6 of the sibling dyads were nondisabled sisters of brothers with I/DD, there was one all male sibling dyad, and one all female sibling dyad.

This study used an Informal Conversational Interview (ICI) method to obtain an in-depth understanding of the perspectives of siblings with and without I/DD about the sibling relationship. The ICI is an open-ended interview that is more likely to be equally directed by the interviewer and interviewee. Several strategies were used to ensure that the interview process was accessible to siblings with I/DD, including; rapport, the use of short, simple questions, rephrasing questions, allowing extra response time, choosing a support person, and the use of an accessible interview guide. A series of 3 interviews was conducted with each sibling pair; one individual interview with each sibling and one joint interview with both siblings. Siblings decided the location and order of the series of interviews. Consent was an ongoing process and obtained prior to each interview. All interviews were audio and video taped and transcribed verbatim. All transcripts were coded using Atlas-ti v.5 software. A constant comparative method was used to first, derive grounded codes, and second, axial codes. The axial codes were further developed into themes and subthemes.

Three primary themes emerged from the data, “Development of Sibling Support Style,” “Diverging and Converging Trajectories,” and “Development of Supportive Connections and Social Capital.”

The theme “Development of Sibling Support Style” consists of 4 subthemes. The sibling support style was developed via “reflections of past support” and in response to the increased responsibilities associated with the “support transition.” Siblings describe the “nature ” of the
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support style as overseeing affairs, supplanting parent roles, and advocating. The “logistics” of sibling support were delivered via a team of other nondisabled siblings or a single nondisabled sibling; however, in both instances siblings-in-law and nieces and nephews played a role in the supported sibling relationship.

The theme “Diverging and Converging Trajectories” consists of two subthemes that reflect the life course of the supported sibling relationship. Sibling trajectories diverged as siblings grew up realized difference “Sibling Realizing Difference” reflects the moment in which siblings noticed their trajectories diverging. However, sibling trajectories began to converge when “aging and anticipating futures.”

“Development of Supportive Connections and Social Capital” occurred within two locations represented by the subthemes “in the family” and “in the community.” Within the family, siblings with I/DD valued various family roles and the support they provided to their nondisabled siblings, but also valued their own space. Development of social capital and supportive connections in the community were enacted via activities and leisure shared by siblings, participation in faith communities, and the employment of siblings with I/DD.

The relationships between the themes in this study describe a supported sibling relationship between two siblings in which one has I/DD and the other is a primary supporter. In addition, past history and personal demographics underlie all the themes in this study. The interaction of these themes enables the researcher to describe the supported sibling relationship and the factors that influence that relationship. Five postulates describe the supported sibling relationship: 1) Supported sibling relationships are more egalitarian than parental relationships, 2) Sibling relationships are emotionally close, 3) Sibling relationships are not symmetrical, but they are reciprocal, 4) support to siblings with I/DD occurs across a network of supportive connections, and 5) the supported sibling relationship provides opportunities for autonomy in community participation for siblings with I/DD. Additionally, three factors impact the supported sibling relationship: 1) age and life course contexts, 2) gender, and 3) policies and services that enhance social capital. The dissertation ends with a discussion of implications for Disability Studies, services and supports, and policy and advocacy. Recommendations will be made for how siblings can be included as allies in furthering advocacy efforts of people with I/DD and their families.