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Reciprocity and Social Capital in Sibling Relationships of People with Disabilities

John Kramer, *University of Massachusetts Boston*

Allison Hall

Tamar Heller, *University of Illinois at Chicago*



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RUNNING HEAD: SIBLINGS AND SOCIAL CAPITAL

**Title:
Reciprocity and Social Capital in
Sibling Relationships of People with Disabilities**

**John Kramer, Ph.D.
Institute for Community Inclusion,
University of Massachusetts Boston**

**Allison Hall, Ph.D.
Institute for Community Inclusion,
University of Massachusetts Boston**

**Tamar Heller, Ph.D.
Institute on Disability and Human Development,
University of Illinois at Chicago**

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Abstract

Sibling relationships are some of the longest-lasting relationships people experience, providing ample opportunities to build connections across the lifespan. For siblings and people with intellectual and developmental disabilities (I/DD), these connections take on an increased significance as their families age and parents can no longer provide care. This paper presents findings from a qualitative study that addresses the question, “How do siblings support each other after parents no longer can provide care to the person with I/DD?” Findings in this study suggest that siblings with and without disabilities experience reciprocity as a transitive exchange, which occurs through the creation of social capital in their families and community, and that nondisabled siblings mobilize their social capital to provide support to their sibling after parents pass away. Implications for future research as well as policy and practice will be discussed.

Introduction

Sibling relationships are some of the longest-lasting relationships humans experience (Cicerelli, 1995; Goetting, 1986), offering extended relationship experiences over the life course. A key aspect of sibling relationships is the dynamic ways siblings use their resources to support each other at different points in each other's lives. This paper examines support reciprocity as a transitive exchange, meaning that feelings of support and of being supported are not perceived as equal across two people in a relationship, but might be across multiple people. This also may provide opportunities for building social capital in sibling relationships when one of the siblings has an intellectual and developmental disability (I/DD) at the point after their parents are no longer primary caregiver to the person with I/DD.

Aging presents a set of important issues unique to families of people with disabilities. Researchers concerned with the support needs of families of people aging with intellectual and developmental disabilities have recently expanded their interest in adult sibling relationships (Dykens, 2005; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Greenberg, 1993; Heller & Kramer, 2006; Seltzer et al., 2005; Stoneman, 2005). Siblings often play an expanded role in the provision of support for aging people with I/DD as parents become unable to provide care or pass away. In recent years, an increasing number of adult sibling authors, researchers, and other leaders have begun speaking publicly about their experiences and relationships with their adult siblings with disabilities, as well as calling for increased support in their new role as caregiver (Meyer, 2009; The Sibling Leadership Network, 2008).

This expanding interest in adult sibling relationships may be related to increased lifespans of people with I/DD. These longer lifespans require an extension of support, much of which

remains informal and family-provided (Heller & Factor, 1991, 1993; Heller & Kaiser, 2007; Heller & Kramer, 2006; Heller, Miller, Hsieh, & Sterns, 2000). Parents often expect their adult children without disabilities to step in when they relinquish their caregiving responsibilities (Freedman, Krauss, & Seltzer, 1997), and, as they grow older, often identify their other children to be primary caregivers (Heller & Factor, 1991, 1993; Heller & Kaiser, 2007; Heller & Kramer, 2006; Heller et al., 2000).

One of the key issues in sibling research is the concept of reciprocity. Typical sibling relationships are diverse, but overall characterized as being “reciprocal” across the life span (Cicirelli, 1995). Reciprocity is the “notion that if you receive something from others, you are expected to give something in return” (Bubolz, 2001). Among siblings of a brother or sister with I/DD, these relationships tend to be more “asymmetric” in reciprocity, with nondisabled siblings providing more support to siblings with I/DD than they receive from those siblings (Stoneman & Berman, 1993). Reciprocity in the context of adult sibling relationships where one sibling has a disability has been conceptualized by the inequality of emotional, physical/practical, and financial resources shared (Stoneman & Berman, 1993). Implicit in much of this work is that functional sibling relationships should, all in all, be roughly equivalent in the amount of support given and received between both members of a sibling pair. When the relationship does not measure up to this, it is thought to place a burden on the net support giver.

Some evidence exists that such sibling relationships in adults are similar in reciprocity to typical sibling relationships of adulthood (Doody, Hastings, O'Neill, & Grey, 2010). Hall (2005) found evidence that relationships of individuals with I/DD were reciprocal among siblings, parents, and adult children, but did not assess whether the reciprocity was equal. Others found

little evidence of symmetric reciprocity between people with I/DD and their family members (Lunsky & Benson, 1999).

These inconsistencies may suggest a gap in our understanding of how siblings experience and expect reciprocity. We do not know whether siblings of people with disabilities have expectations that their brother or sister with disabilities will provide them with support commensurate with what they gave them, or whether others in their network provide support to the person with disabilities. Little research exists on the extent to which reciprocity occurs across a network of family and friends, sometimes called a “transitive” exchange (Louch, 2000), or the extent to which transitive reciprocity may produce social capital for the sibling with a disability. Using this idea, social capital could be created through transitive exchanges within networks of support, rather than a one-on-one reciprocal exchange between a person with a disability and his or her sibling.

Social capital consists of “shared norms or values that promote social cooperation, instantiated in actual social relationships” (Kiernan & Mank, 2011). Social capital creation can be used as a way to conceptualize reciprocity, especially in social support, which an individual builds and mobilizes within the family and community over time (Furstenberg, 2005). Additionally, social capital can be used to accomplish complex tasks or achieve goals that would be unattainable on one’s own (Devlin, 2011) through “bridging” and “bonding.” Bonding social capital exists between members of a group who “see themselves as equal” and as having some sort of uniting characteristic. Participation in specific groups such as neighborhood associations or advocacy organizations promotes an effective bond between individuals within this group. According to Putnam, these bonds form the “superglue” that enables community solidarity.

Bridging, on the other hand, serves as the “sociological lubricant,” in which professional affiliation, rather than personal characteristics, drives the connection. Bridging social capital allows individuals to be connected to resources and information that would be otherwise unavailable through bonding social capital.

Social capital changes over the course of one’s life. In childhood, family members serve as role models for how to engage in reciprocal and meaningful relationships with others. One’s personal and family networks lay the foundation (Belcher, Peckuonis, & Deforge, 2011; Gotto, Calkins, Jackson, Walker, & Beckmann, 2010) for social capital formation that constitutes the “aggregate” of family resources (Belcher, et al., 2011; Gotto, et al., 2010; Mueller, Houser, & Riddle, 2009) that facilitate the successful transition of children to adult life. Most individuals’ social networks transition from family-centered to peer and friendship-centered networks as the individuals get older and leave their family of origin (Gray, 2009). However, for people with I/DD, this pattern differs, as they often remain closer to their familial networks as they age (Knox & Bigby, 2007). This could have important implications for connecting to resources and supports throughout ones’ life.

Social capital also arises from “the exchange of resources or supports or services between people” that “is not based on the immediate return requirement...but rather the notion that people...have a general expectation that *someone* (emphasis added) will return the favor at some time in the future” (Chenoweth, 2004). In other words, social capital is not created through *quid pro quo* in individual relationships. Under this concept, reciprocity is assessed on a general level as an aggregate of all one’s giving and receiving of support. Family members would include extra-familial resources in their assessments of reciprocity. So while it may be that reciprocity is

asymmetric between two people, it might be functional and adaptive if one includes a third person or more.

Families draw on social capital to accomplish complex life tasks. For example, social capital within families links members to one another and creates a network that helps parents raise their children to become community members (Kiernan, Hoff, Freeze, & Mank, 2011). Since much of the support that families provide people with I/DD remains informal, families rely on social capital, often their personal networks and individual resources, to supplement what government services cannot provide. This “family capital” provides the “resources for family members that affect their current and future functioning” (Belcher, 2011). Where social capital provides the “glue” that bonds communities together, family capital—more specifically, the security it can provide—allows family members to participate in the world and broaden their social connections with others (Belcher, 2011).

Families of people with I/DD encounter considerable obstacles when it comes to forming family capital with their children. Numerous studies have reported the negative economic and social impact of parenting a child with I/DD (Parish, Seltzer, Greenberg, & Floyd, 2004). Raising a child with a disability may also hinder a family from forming social capital. For example, when a parent has to advocate for an extended period of time for support for the child with a disability, it may come at the expense of time devoted to other activities that lead to networking and social capital creation (Widmer, 2008).

One factor determining the amount of social capital available to children is number of siblings, more brothers and sisters representing “in this interpretation, a dilution of adult attention to the child” (Coleman 1988). Coleman posited that families with multiple children

would mean less social capital invested by the parents in each individual child (Coleman, 1988). Under this conception, siblings are seen as antagonistic to each other in regards to competing for parental resources. However, Seaman & Sweeting (2004) found them to be sources of knowledge about “extra-domestic arenas.” Their findings, in this particular study, suggest that siblings may widen and broaden the networks of younger children within the family. In this case, siblings are a strong influence on social capital building, with parents acting as a moderator between children.

Researchers suggest that, as people with I/DD age into middle adulthood they substitute professionals and other connections in the place of peers, spouses, and children (Widmer, 2008). With sibling relationships being more likely to last lifelong, looking at these relationships may provide a different and unique lens for examining the use of family capital across the lifespan. In childhood, researchers, professionals, and siblings themselves have long posited that the time a parent must devote to a child with disabilities posits a unique stress on the family at the expense of nondisabled children (Stoneman & Berman, 1993). However, the evidence for this effect has been inconclusive (Doody, et al., 2010). One issue that has not been looked at is the social networks and social capital of siblings where one of the siblings has I/DD.

Siblings of people with disabilities generally have a different life course trajectory from their brothers and sisters. Siblings may have, as a result of these differences, a qualitatively different kind of access to social capital than parents and people with disabilities do. For example, it is likely that parent experience around disability has deeply affected parent access to social network—particularly bridging networks—that lead to growth and connections for themselves and their children. The present study explores how siblings mobilize their social

capital to influence outcomes for their sibling with disabilities. More specifically, the present study looks at 1) the role of reciprocity in sibling relationships in social capital creation, 2) how family capital is created through sibling relationships, and 3) how siblings use their social capital to support brothers and sisters with I/DD.

Method

Participants

The sample for this study (Table 1) included eight adult sibling pairs in which one sibling had an intellectual disability, and who lived around two major metropolitan areas in the United States. The small sampling size enabled the researcher to focus in more depth within each sibling pair.

Sibling pairs were recruited in one of two ways: 1) siblings with I/DD were recruited through a local self-advocacy organization, or 2) nondisabled siblings were recruited through sibling advocacy organizations in the community. The sample of participants consisted of selected siblings of self-advocates whom the researcher had worked with previously and whose parents were no longer providing primary support. All participants were adults who could communicate verbally. It also targeted a diverse sample that included an African American and a Latino family.

The sibling demographic data, including the siblings with disabilities' impairment, was self-reported by the nondisabled sibling. Both siblings completed a consent process and agreed to participate in research that was approved by the Office for the Protection of Research Subjects at

the researcher's university. All data was digital and kept on a secure, password-protected computer. Six of the eight siblings of people with disabilities identified as being primarily responsible for the support needs of the sibling with a disability. Two of the eight responded that other siblings in the family had shared/divided responsibility. In addition to the listed impairment, two of the siblings with disabilities were identified by their siblings as having mental illness.

<INSERT TABLE I ABOUT HERE>

Design and Procedure

The present study consisted of an open-ended qualitative design. Each sibling pair case participated in a series of three open-ended interviews with the first author: 1) a single interview only with the sibling with an I/DD, 2) a single interview only with the sibling who did not have a disability, and 3) a joint interview with both siblings.

The original purpose of this study was to explore the nature of how siblings support each other after their parents are no longer providing primary support to the individual with a disability. To accomplish this, we used open-ended interviews, as they are more likely to be equally directed by the interviewer and interviewee (Taylor & Bogdan, 1998). Since research on sibling relationships has generally not included the perspectives of people with disabilities, the interviewer took steps to avoid assumptions about the nature of the relationship of the participants. This led to fewer disability-specific questions, with the advantage of being able to focus the open-ended questions on the relationship itself, rather than on impairment and

disability. To ensure accessibility for siblings with I/DD, the basic interview questions focused on concrete aspects of the sibling relationship. The question pool can be found in Table III.

<INSERT TABLE III ABOUT HERE>

Several strategies were used to ensure that the interview process was accessible to siblings with I/DD, including establishing rapport, using short and simple questions, rephrasing questions, allowing extra response time, allowing the sibling to choose a support person, and using an accessible interview guide when requested (Mactavish, Lutfiyya, & Mahon, 2000). The accessible interview guide was a brief outline of the interview questions using plain language with accompanying pictures/illustrations. Furthermore, the information collected in the earlier interviews guided and informed the follow-up questions in later interviews, also helping the interviewer to choose more concrete follow-up questions. For example, in an early joint interview, one nondisabled sister brought up the employment status of her brother with a disability. The interviewer then addressed this issue in a subsequent interview and was able to refer to concrete ways his sister supported him in working.

Qualitative research is strengthened by providing an authentic interpretation of the data. Part of this requires qualitative researchers to “own up to their perspectives” (Taylor & Bogdan, 1998). The primary researcher has two brothers with disabilities. He also had known several of the individuals through a local provider organization’s chapter of People First, a self-advocacy organization from which several of the interview subjects came. The researcher’s personal experience with the People First members allowed the researcher to create an immediate rapport with these individuals, contributing to a comfortable starting place for these individual interviews.

Analyses

This study used thematic analysis and constant comparative coding (Taylor & Bogdan, 1998). The analysis process for this study was as follows. First, the researcher read through the transcripts, sorting data line by line into coding categories using ATLAS.ti (Atlas-Ti v.6, 2010). The codes consisted of meaningful chunks of data and were varying sizes that communicated one idea. Then, during the coding process, the researcher looked for emerging themes and solicited/unsolicited statements (Taylor & Bogdan, 1998). Themes consisted of similar or related answers to the interview questions. Solicited statements were direct responses to the question. Unsolicited statements consisted of novel or especially illuminative passages of transcripts that communicated an idea the researcher was not looking for.

For each interview pair, the researcher first coded the individual interviews, then joint interviews. When coding, the researcher affixed a prefix to each code to indicate if the code came from an individual interview from a sibling with a disability, nondisabled sibling, or from a joint interview.

When the coding was completed, the coding structure was collapsed into major themes. If codes did not fit into themes, they were recoded for improved thematic consistency where applicable. As the researcher developed the coding structure and themes, he compared and refined categories for clarity and authenticity. Finally, the researcher analyzed the pairs within and cross-case (Patton, 2002). This was done so that the researcher could analyze similarities and differences between members of a sibling pair, between sibling pairs, and between siblings based on disability status.

Finally, the researcher provided randomly selected participants a written summary of the themes from the interviews as a form of member checking to ensure authenticity of the representation of the data. The member-checking portion of this study did not produce any changes to the findings. A few siblings, while not offering specific commentary on the themes in the present findings, suggested that future research should include all siblings within a family and also siblings of people with mental illness.

Results

Results from this study describe how siblings build reciprocity and how family capital is created through sibling relationships. The overarching themes emerging from this study are that a) sibling relationships build reciprocity through enacting family roles; b) family capital is created through reciprocity of support and through shared experiences and; c) reciprocity is built through co-participation in activities and leisure experiences. Subthemes that emerged are presented below. Table 2 presents the themes and subthemes that emerged from the analysis.

<Insert table 2 about here>

Theme 1: Sibling relationships build reciprocity through enacting family roles.

In the present study, siblings with and without I/DD reported actively exchanging favors and support within their relationship to build family capital. Three subthemes describe the avenues by which social capital is generated within the adult sibling relationship: enacting family roles creates social capital in sibling relationships, reciprocity strengthens sibling relationships, and reciprocity is built through co-participation in activities and leisure experiences.

1a. Enacting family roles creates social capital in sibling relationships.

In the present study, enacting family roles created more opportunities for family capital. For example, one of the roles commonly associated with sibling relationships, being an aunt or uncle, fostered opportunities for family capital creation. In this study, siblings with I/DD spoke often about enacting roles within their families. For instance, in this passage Miguel described his role while his sister was away on a trip, “My sister is out of the country right now, so I will be taking care of my nieces and nephews.” For Miguel, he was filling in for the role of his sister while she was away. While it is likely Miguel was not solely in charge of his nieces and nephews, it is likely they felt comforted by his being there with them while their mother was away.

Other siblings expanded on this enacted aunt/uncle role, showing it to be an emotional connection. Jim said, “I love being an uncle.” He continued, “Tammy’s got eight. That’s a lot of kids, and so does my brother.” As he continued talking about being a great-uncle, his facial expression brightened and his responses detailed what he and his other nieces and nephews do together. This suggests that Jim highly valued his role as an uncle, which he actively engaged in. Jim looked forward to becoming an uncle again, saying, “My niece, Shelly—that is Tammy’s daughter...That’s who is having another baby. She’s gonna have another girl. A little baby. [She now has] two boys, and two girls...[It makes me feel] pretty great...I feel very happy.” Jim’s narrative suggests anticipation of his new unclehood role.

1b. Family capital is created through reciprocity of support and through shared experiences.

Siblings in this study showed that their relationships consisted of reciprocal interactions. Siblings with I/DD described how they felt supported by their nondisabled sibling, and also how they provided support to their nondisabled siblings. This illustrates how social capital is used and co-created through a give-and-take process. Siblings with I/DD described their perceptions of how they give and receive support. For instance, George recalled, "...My brother worried about me all the time." He continued, "When stuff happens, he make[s] sure I'm doing okay...and my brother worried about me. About two three years ago I got surgery on my hip bump...so they operate me that's all...my brother he went moved by me so he worry about me." George's recollection illustrates his awareness that his brother cares about him, and his appreciation of his brother's support.

Showing appreciation for this support helps to maintain social capital. George also talked about a key moment where he gave support back to Matt: "My brother went to a hospital one time...he had a problem with his stomach. His appendix in here...I worry about him so much...but he's fine. He's all better...I [did] worry about him." By acknowledging how much George worried when Matt was in the hospital, he contributed back by showing the same concern and care for his brother.

Another important way siblings with I/DD provided support was to help with chores. For instance, George relayed that he always clips coupons for Matt: "I like that...he wants to cut coupons. Save on food and stuff." George's example suggests that he has a broad understanding of support because he did "little" things to make his brother happy. Other respondents talked

about these types of activities, which often included cleaning or decorating. Michelle, another respondent, mentioned: “I like being a sister because I like helping with my sister out around the house, I like to decorate the house. I help set the table, things like that.”

Finally, Gloria spoke about how, since her mother was diagnosed with Alzheimer’s, Martin has provided cognitive support: “Martin...has stepped up, [saying] ‘Where are you going?’...he puts away the milk. He has stepped up without being told.” By providing cognitive support to their mother in the form of reminding her about basic household tasks, Martin is fulfilling a key role in his family and building social capital by providing direct support to his mother, and indirectly, to his sister by participating in his mother’s care.

1c. Reciprocity is built through co-participation in activities and leisure experiences

Siblings co-create social capital in their relationship by engaging in shared activities and leisure pursuits. All of the siblings in this study described engaging in shared leisure activities with each other in the community and being connected to different communities. Shared activities were an important element in building supportive connections and social capital. Mutual activities discussed in the interviews centered on leisure activities, vacations, and family traditions.

One example of a leisure activity happened when Michelle and Kim went to get a manicure. Michelle, when asked about what she likes to do with Kim, stated, “[We]...go out shopping. We put some makeup on and put nail polish on...” Matt and George talked about participating in a literacy group for people with disabilities together. In another example, George relayed how he much enjoyed participating in a book club with his brother: “...And then [we] go

to...book clubs too. I like...[going to TCBY] and afternoon I did and in night I read Harry Potter.” By engaging in shared leisure activities, siblings with I/DD and nondisabled siblings create more opportunities to make connections in the community and, in turn, build social capital.

Other examples of shared activities consisted of John going to the museum with his brother-in-law Clark, Tammy and Jim double dating, and Gloria and Martin eating at the restaurant another brother owns every week. These shared activities create spaces for siblings to enjoy each other’s company while also creating opportunities to form mutual connections in the broader community and to build social capital.

Shared vacation experiences also created space for siblings to have fun and build shared memories. Siblings recalled vacations and trips they had taken together in the past. Siblings reminisced about the fun times they had visiting family in other countries, taking their first plane ride to Florida, and going on trips to Las Vegas. George brought up his trip to Vegas with his brother and cousin in the following passage: “...I want to go to ...Las Vegas...I been there. It was awesome,” he continues. “...Me and my cousin...so we went to Vegas, played games, went to concerts...and I saw a showgirls...is awesome. I set him up one time. My cousin was embarrassed...(laughs)...I went, I went out [for] one girl. I went for him, take pictures. She kiss[ed] me. I like[d] it.” George’s experience suggests that he shares activities with his male family members that, in contemporary American culture are considered “bonding” opportunities for adults. The shared activities and leisure examples suggest that siblings have relationships that extend beyond the provision of support.

Theme 2: Nondisabled siblings employ bonding and bridging functions on behalf of their siblings with disabilities.

While siblings with and without I/DD had elements of reciprocity and provided fertile ground for social capital, the implementation of social capital came mainly from the nondisabled siblings. In this study, nondisabled siblings mobilized social capital to accomplish many goals in respect to their relationships. Three goals in particular stood out in the present study. They were: 2a) Bonding: nondisabled siblings assist in daily support of people with I/DD; 2b) Bridging: Nondisabled siblings mobilize social capital to improve employment prospects; and 2c) Bridging: Siblings mobilized social capital to advocate for disability rights.

2a. Bonding: nondisabled siblings assist in daily support of people with I/DD.

Nondisabled siblings in this study mobilized social capital from within their own families and communities to provide support to their brother or sister with I/DD. For example, some nondisabled siblings described a team approach to support where guardianship and daily support responsibilities were shared with other family members, usually other nondisabled sibling(s). For example, Luisa was “relieved” when, after years of advocacy, she got a placement for Miguel into a community organization support program during the day. Gloria provided day-to-day support to Martin while her other nondisabled brother and mother shared guardianship for him.

However, even the nondisabled siblings who played a central role relied on spouses, children, and/or service agencies. For example, while Matt and George’s other nondisabled siblings were not involved in George’s support, Matt did rely on his spouse. For example, Matt said he “didn’t get it quite right the first time around” when it came to his marriage, citing his first wife’s lack of acceptance of his brother as a factor in his divorce. He remarried to someone

who “accepted George as much a part of her life as” Matt did. Matt also made reference to connections he made with service agencies for George’s daily support. He said he had to go to “really high levels on occasion” to advocate for his brother because he felt the staff were “putting George in harm’s way.” In other words, Matt used social capital in the form of key network connections to change the support situation for George, which he felt was detrimental.

One family in particular illustrates the complex nature of how bonding social capital can be mobilized within families to provide support to siblings with I/DD. John, Michael, Nicole, and Shirley were all siblings from the same family, with John and Michael both having disabilities. While in the past Nicole felt solely responsible for her brothers’ support, her role as primary supporter has shifted somewhat and is now shared with Shirley. John and Michael also receive support from the spouses of Nicole and Shirley and, in turn, John provides support to both Michael and his other sibling with I/DD. John recalled,

So Nicole arranged to come to my apartment the next Wednesday to have Christmas and Joe...and...I w[ere] getting along quite good with Joe and he asked me...can I come to your apartment?

Through John’s story, it is revealed that John mobilized social capital within his family by relying on his sister Nicole to provide transportation to Joe. By doing so, Nicole facilitated the support between two of her brothers, giving them an opportunity to strengthen their relationship. John continues to explain how both Nicole and her husband provided an opportunity to deepen that connection:

Allen was giving me a ride back [after the appointment]...I had money with me—I was going to offer to pay for Joe too...on the train, and I remember Joe wouldn't let me pay and I remember at that point I was I was making a six per hour a day. So I was going to help him and get a taxi...I wanted to kind of make up for bad times [with Joe].

John's story reveals that he was conscious of the lack of capital he had built with his brother earlier in his life, and now wanted to try to contribute something back to him. He worked in collaboration with his nondisabled sister to build social capital with his brother with I/DD. In turn, his role in supporting his brother with I/DD helped to support his sisters' role as primary caregiver, and enabled him to contribute social capital to the relationship.

2b. Bridging: Nondisabled siblings mobilize social capital to improve employment prospects.

Some nondisabled siblings recognized the importance of employment, mobilizing their own capital and connections to create employment opportunities for their siblings with I/DD. Kim recalled her nondisabled brother's connection with the community in getting their sister Michelle a job:

So my [nondisabled] brother says, "I'll work on the job side of it." He hits the pavement. He knows a few people in town [be]cause he's lived there for six or seven years by now... We don't even know that there's agencies available. I start making calls about housing kinds of things. My brother starts pounding the street of local merchants. He actually gets a bite from the local grocery store that's willing to give [Michelle] a try.

While her nondisabled brother used existing connections to create the opportunity, Kim had to find a way to sustain the opportunity. She found out about a policy that would enable her to be paid for providing support to Michelle:

I had called [a local rehabilitation agency] to find out how the whole job coach thing worked and found out that you could get a job coach or you could get the wage subsidy for “x” amount of hours. Like, “Okay, I’ll be willing to be her job coach if we get the wage subsidy,” ‘cause that gives a little sugar cube to the employer, take a chance. It’s not really gonna cost you anything for “x” number of months. The T family in Western Springs really have open hearts and that’s all I can say. They were willing to give a chance in a job that probably is more advanced than what she even has today. [When she was] working in the bakery, I went in and job coached with her. She’s still with the T-Family Grocery Stores since 1993.

This passage suggests that three factors led to Michelle’s successful community employment. One was her brother’s ability to use his capital to create an opportunity for employment. Second was the support Kim was willing to provide. Third, there was a policy that gave Kim the framework to implement that support; the funding for Michelle’s job coach was determined through state policy.

Many siblings with I/DD did not have these three factors of support. John, for example, did not have employment opportunities in the community when he lived with his mother. John recalled, “...I never really worked for anybody...I never really knew what it was like to have somebody telling me what to do...” According to John, he did not know how to talk to bosses or

potential employers because his early opportunities to build experience and employment connections were limited when he lived with his mother. According to John, this may have impacted his opportunities to build connections in the community through the workplace.

This situation changed when John's mother passed away. He revealed in his story how, after his mother died, his sisters used their connections to secure an employment opportunity that he could be successful in. John said, in reference to Nicole, "Because when I lived [with her]...she found me odd jobs and I made some cash." According to John, Nicole used her social capital within her community to get her brother connected to employment.

2c. Bridging: Siblings mobilized social capital to advocate for disability rights.

Siblings also mobilized social capital, usually professional connections they have made in the community, to advocate for better services. For example, Matt initially chose to get involved with statewide legislative advocacy to help get services and supports for people with IDD. Doing so, while helping to expand the rights of people with disabilities in general, also helped him to understand how the systems in his state worked and provided more opportunities to procure services for his own brother:

I was able...to talk to the right people, to be able to deduce that...this is the best process to use to be able to effectively advocate for my brother. My training as an advocate kind of...afforded me some valuable contacts on the state level so that I could be even more educated and have other types of contacts that could assist if needed...I did have to really go to very high levels on occasion to advocate on [George's] behalf and in my view,

protect him from the staff that the provider had and that I thought was infringing upon his rights and putting him in harm's way.

For Matt, using his connections to directly advocate on his brother's behalf was possible through the mobilization of his social capital. Similarly, Shirley revealed a story about how she used her personal connections to advocate on her brothers' behalf:

[My husband] Clark worked with...our [state] representative[']s spouse. So that made it a little bit easier to get in the door...I had done a little bit of public testifying...One of the...tricks that I used...I ran around with this laminated poster of [my brothers] and I would shove it in people's faces...[as a way to get]...a little bit more attention that way.

Shirley made advocacy for supports and services a central part of her role in providing support to her brothers with I/DD. While Matt began his advocacy with a more advanced understanding of disability systems in his state, Shirley's understanding was more limited. Shirley was starting with little knowledge about disability, saying, "I realized that to get him any Social Security benefits, he had to have a diagnosis." She describes having to investigate the steps to receive that diagnosis. However, in both of these examples, advocacy was a primary aspect of their support role.

Discussion

Reciprocity is a precondition for social capital

In the present study, reciprocity is built through shared activities and experiences between siblings, which in turn can create opportunities to build social capital. Under a social

capital framework, people with I/DD have an active role in “producing reciprocity” (Luecking, 2011). Hence in the present study, people with I/DD focused more on reciprocity within their families through enacting family roles and actively participating in shared activities. Nondisabled siblings, in turn, mobilized their social capital in the community on behalf of their siblings.

The way siblings spoke about their relationship is consistent with Chenoweth’s description that reciprocity can produce an expectation of exchange in the future (2004). Additionally, reciprocity is also consistent with “bonding,” while nondisabled siblings facilitated “bridging” roles in social capital creation (Carter, Austin, & Trainor, 2011; Walker, 2011). In this study, reciprocity seemed to consist of siblings with disabilities enacting their family roles (e.g., unclehood or aunthood) in exchange for nondisabled siblings bridging them to resources in the community they themselves might have a more difficult time accessing.

Reciprocity and bonding social capital

Siblings with I/DD tended to perform “bonding” activities in that they focused on their families of origin, doing things with family, and fulfilling new family roles such as aunthood and unclehood. Examples of this can be seen in George cutting coupons and expressing emotional support with Matt, or John supporting his other brothers with disabilities in socializing and connections. Under this conception, bonding and bridging functions of social capital are asymmetric; they are not equal to each other and occur with different frequency and intensity. For example, George’s clipping coupons might be something small he does consistently over time, whereas Matthew’s advocacy may be more intense, but a shorter duration.

In another example, Martin built bonding social capital in his family by providing support to his mother who was diagnosed with Alzheimer’s. Martin had a chance to, in a presumably

time-limited way, enact bonding functions of social capital by enacting his family role in taking care of his mom. This in turn gave his nondisabled sister time to find a placement for their mother, something that George would not likely have been able to do on his own.

Other examples included people with disabilities providing support to other siblings or other family members, such as providing care for nieces and nephews. Miguel's watching his nieces and nephews was likely a low-key, consistent way he could support his sister in "stepping out" momentarily to run errands etc., including trying to find a day program for him.

Bridging social capital was usually done by nondisabled siblings

The bridging function employed by nondisabled siblings was perhaps most sharply defined through the area of employment. They used their social capital as a "bridging" function to assist in obtaining jobs in the community for their sibling with a disability and advocating for community services and supports. For example, Kim and her brother both employed bridging functions of social capital to achieve employment for their sister. Previous studies have underscored the importance of people with I/DD benefitting from new ways to get involved in their communities across different networks (Rogan & Rinne, 2011).

Using a social capital framework, in particular, transitivity, for looking at sibling relationships might also help uncover the complexities of relationships than occur within a sibling dyad. People may rely not on one-on-one exchanges of support, but rather networks of asynchronous or unequal exchange to produce reciprocity. Under this concept, reciprocity is experienced more globally than a quid-pro-quo exchange. For example, in the present study transitivity occurred with spouses of the nondisabled sibling. Shirley used her husband's political connections to get connected to support. It is doubtful that she expected a directly reciprocal

action from her brother in return. Additionally, while siblings with disabilities reported helping out through enacting unclehood roles as an important aspect of their relationship, nondisabled siblings did not. It might be that nondisabled siblings' children felt supported in a unique way from their uncle or aunt that nondisabled siblings did not report.

Future research should include information about family capital, networks, and underlying transitive connections of support for siblings, heeding previous calls to situate sibling relationships within broader community, environmental, and policy factors (Heller & Arnold, 2010; Heller et al., 2008; Heller & Kaiser, 2007; Heller & Kramer, 2009). The greater extent to which people with I/DD and their siblings increase their capacity to mobilize social capital in bonding and bridging, the better the community outcomes of people with disabilities and their families are likely to be.

Race and sibling relationships

Though issues related to social capital and race did not directly arise out of this research, it is plausible that there were differences in expectations around siblinghood that could impact social capital. African American and Latinos might have different levels of bridging and bonding social capital, especially when socio-economic status is considered (Denner, Kirby, Coyle, & Brindis, 2001; Litwin & Shiovitz-Ezra, 2011; Swartz, 2008). Cicirelli (1994) notes that sibling relationships are more “fundamental” in determining family functioning in non-Caucasian families where siblings have greater expectations of helping to raise their brothers' and sisters' children (Cicirelli, 1994), which is consistent, perhaps, with Miguel and Jim's example. There could be some differences between racial/ethnic groups in the present study, but with so few

participants, differences were hard to determine. Future research could perhaps find stronger relationships by interviewing more families from various racial and/or ethnic backgrounds.

Limitations and future research

While member checking in this study confirmed the credibility and authenticity of the results, some important limitations need to be addressed. The main limitation of this study is that it relied on exemplar cases of siblings who have positive relationships. Not all adult sibling caregiving relationships may be marked by this level of emotional or physical closeness. The findings of this study would probably look very different, for example, in sibling relationships that were distant or antagonistic. These siblings might feel some sort of honor or duty to their family, but might be much more reluctant or ambivalent about being involved. The self-selected nature of the exemplar sibling relationships in the present paper may have screened out siblings who do not have the range and depth of social capital across the family and community.

Additionally, the functional level of siblings with I/DD does not represent all experiences. Most of the siblings with I/DD in this study were able to tell stories about their relationships in their family and reflect on their experiences. Social capital may work differently in sibling relationships in which the person with I/DD is not able to communicate and reflect upon their relationships. Finally, though not thought of as a key variable in this open-ended exploratory study, socio-economic status was not measured well. Other research has documented at length how social capital is related to socio-economic status (Carter, et al., 2011).

The topic of siblings with I/DD mobilizing social capital requires further investigation. In particular, it would be interesting to explore siblings with I/DD who are employed and connected to the community. It is possible, for example, that people with I/DD who are employed longer

and are more economically self-sufficient rely less on their nondisabled siblings for support. Future research in this area may want to consider interviewing self-advocacy leaders or individuals with I/DD who have a long work history. It is likely that these individuals have more connections to their communities, raising the possibility that they could more easily mobilize social capital and rely less on the social capital of their siblings and other family members.

Additionally, while the open-ended interview protocol was designed to mitigate negative and positive dichotomies in sibling research, it was a limitation in terms of the depth of the knowledge gained about social capital and reciprocity. The findings in this study emerged from questions not particular to these concepts, but were coded using these concepts. A future study might better capture these concepts if the research questions focused on them in an in-depth and specific fashion, particularly around network mapping and mobilizing.

Finally, it should be noted that this research study might be biased in ways unknown to the author. While it is believed that being a sibling of a person with a disability provides key “insider” knowledge in this context, it might have led the respondents to respond more positively or more negatively about their relationship than they might otherwise do.

Future research could also explore ways to build social capital for nondisabled siblings, to maximize support of people with disabilities. This type of research could meaningfully address the support provided by siblings with I/DD that extends beyond sibling dyads. Also, future research on sibling relationships might be strengthened by including some measure of social capital in survey and/or qualitative interview protocols (e.g., (Walker, 2011).

Implications.

It is likely that siblings will continue or perhaps expand the support roles they play in each other's lives. Results from this study underscore the impact of siblings' social capital on employment outcomes for people with I/DD, and the importance of employment on the social capital of people with disabilities. People with I/DD who are employed for a longer period of time have more opportunities to build connections as well as their own economic self-sufficiency. For siblings in later life, this could mean nondisabled siblings having to provide less support while people with I/DD experience greater economic empowerment.

Conclusion

Siblings in this study co-created social capital in the support relationship. Nondisabled siblings mobilized their social capital to create a network of support and maximize employment and community participation outcomes for their brothers and sisters with I/DD. This study illustrates that social capital can be a useful framework in understanding support in sibling relationships expanded constructs of reciprocity and burden. Future research on sibling support is encouraged to use theories of social capital to examine how supporting all family members can lead to positive outcomes. h

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Works Cited

- ATLAS-Ti v.6. (2010). Atlas-Ti v.6 Qualitative Data Analysis: Scientific Software Development GmbH.
- Belcher, J. R., Peckuonis, E. V., & Deforge, B. R. (2011). Family Capital: Implications for Interventions with Families. *Journal of Family Social Work, 14*(1), 68-85.
- Carter, E. W., Austin, D., & Trainor, A. A. (2011). Factors Associated With the Early Work Experiences of Adolescents With Severe Disabilities. *Intellectual and Developmental Disabilities, 49*(4), 233-247. doi: 10.1352/1934-9556-49.4.233
- Cicirelli, V. G. (1995). *Sibling Relationships across the Life Span*. New York: Plenum Press.
- Denner, J., Kirby, D., Coyle, K., & Brindis, C. (2001). The Protective Role of Social Capital and Cultural Norms in Latino Communities: A Study of Adolescent Births. [Article]. *Hispanic Journal of Behavioral Sciences, 23*(1), 3.
- Doody, M. A., Hastings, R. P., O'Neill, S., & Grey, I. M. (2010). Sibling relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities, 31*(1), 224-231.
- Dykens, E. (2005). Happiness, Well-Being, and Character Strengths: Outcomes for Families and Siblings of Persons With Mental Retardation. *Mental Retardation, 43*(5), 360-364.
- Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation, 35*(2), 114-123.
- Goetting, A. (1986). The Developmental Tasks of Siblingship over the Life Cycle. *Journal of Marriage and the Family, 48*, 703-714.
- Gotto, G. S., Calkins, C. F., Jackson, L., Walker, H., & Beckmann, C. (2010). *Accessing Social Capital: Implications for Persons with Disabilities*. Kansas City, MO: A National Gateway to Self-Determination Project, University of Missouri - Kansas City.
- Gray, A. (2009). Social capital of older people. [Journal Article]. *Ageing and Society, 29*(1), 5-31.

- Greenberg, J., Seltzer, M., Orsmond, G., & Krauss, M. (1999). Siblings of Adults With Mental Illness of Mental Retardation: Current Involvement and Expectation of Future Caregiving. *Psychiatric Services, 50*(9), 1214-1219.
- Greenberg, J. S. (1993). Aging Parents of Adults With Disabilities: The Gratifications and Frustrations of Later-Life Caregiving. *Gerontologist, 33*(4), 542-550.
- Heller, T., & Arnold, C. (2010). Siblings of Adults With Developmental Disabilities: Psychosocial Outcomes, Relationships, and Future Planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 16-25.
- Heller, T., & Factor, A. (1991). Permanency Planning for Adults with Mental Retardation Living with Family Caregivers. *American Journal on Mental Retardation, 96*(2), 163-176.
- Heller, T., & Factor, A. (1993). Aging Family Caregivers: Support Resources and Changes in Burden and Placement Desire. *American Journal on Mental Retardation, 98*(3), 417-426.
- Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., & Dufresne, D. (2008). The Sibling Leadership Network: Recommendations for Research, Advocacy, and Supports Relating to Siblings of People with Developmental Disabilities (pp. 25). Chicago, IL: Sibling Leadership Network.
- Heller, T., & Kaiser, A. P. (2007). *Opening Remarks/ Conference Program*. Paper presented at the The Sibling Leadership Network Conference, Washington, D.C.
- Heller, T., & Kramer, J. (2006). Involvement of Siblings of Adults with Developmental Disabilities in Future Planning *Research Brief* (pp. 2). Chicago: Rehabilitation Research and Training Center on Aging with Developmental Disabilities.
- Heller, T., & Kramer, J. (2009). Involvement of Adult Siblings of Persons With Developmental Disabilities in Future Planning. *Intellectual and Developmental Disabilities, 47*(3), 208-219.
- Heller, T., Miller, A. B., Hsieh, K., & Sterns, H. (2000). Later-Life Planning: Promoting Knowledge of Options and Choice-Making. *Mental Retardation, 38*(5), 395-406.
- Knox, M., & Bigby, C. (2007). Moving towards Midlife Care as Negotiated Family Business: Accounts of people with intellectual disabilities and their families "Just getting along with their lives together". [Article]. *International Journal of Disability, Development & Education, 54*(3), 287-304. doi: 10.1080/10349120701488749

- Litwin, H., & Shiovitz-Ezra, S. (2011). The Association of Background and Network Type Among Older Americans: Is "Who You Are" Related to "Who You Are With"? [Article]. *Research on Aging, 33*(6), 735-759. doi: 10.1177/0164027511409441
- Louch, H. (2000). Personal network integration: transitivity and homophily in strong-tie relations. *Social networks, 22*(1), 45-64.
- Luecking, R. G. (2011). Connecting Employers With People Who Have Intellectual Disability. *Intellectual and Developmental Disabilities, 49*(4), 261-273. doi: 10.1352/1934-9556-49.4.261
- Lunsky, Y., & Benson, B. A. (1999). Social circles of adults with mental retardation as viewed by their caregivers. *Journal of Developmental and Physical Disabilities, 11*(2), 115-129.
- Mactavish, J., Lutfiyya, Z., & Mahon, M. (2000). "I can speak for myself": involving individuals with intellectual disabilities as research participants. *Mental Retardation, 38*(3).
- Meyer, D. (Ed.). (2009). *Thicker than Water/Essays by Adult Siblings of People with Disabilities*: Woodbine House.
- Mueller, P., Houser, J., & Riddle, M. (2009). How Attitudes Towards the Disabled Affect the Generational Transfer of Social Capital in Families. [Article]. *Conference Papers -- American Sociological Association*.
- Parish, S. L., Seltzer, M. M., Greenberg, J. S., & Floyd, F. (2004). Economic Implications of Caregiving at Midlife: Comparing Parents with and without Children Who Have Developmental Disabilities. *Mental Retardation: A Journal of Practices, Policy and Perspectives, 42*(6), 413-426.
- Patton, M. (2002). *Qualitative Research and Evaluation Methods* (Third ed.). Newbury Park, CA: SAGE Publications, Inc.
- Rogan, P., & Rinne, S. (2011). National Call for Organizational Change From Sheltered to Integrated Employment. *Intellectual and Developmental Disabilities, 49*(4), 248-260. doi: 10.1352/1934-9556-49.4.248
- Seaman, P., & Sweeting, H. (2004). Assisting young people's access to social capital in contemporary families: a qualitative study. [Article]. *Journal of Youth Studies, 7*(2), 173-190. doi: 10.1080/1367626042000238703
- Seltzer, M. M., Floyd, F., Greenberg, J., Lounds, J., Lindstrom, M., & Hong, J. (2005). Life course impacts of mild intellectual deficits. *American Journal on Mental Retardation, 110*(6), 451-468.

- Stoneman, Z. (2005). Siblings of Children With Disabilities: Research Themes. *Mental Retardation*, 43(5), 339-350.
- Stoneman, Z., & Berman, P. W. (1993). *The Effects of mental retardation, disability, and illness on sibling relationships: research issues and challenges*: Baltimore : Paul H. Brookes Pub. Co.
- Swartz, T. T. (2008). Family capital and the invisible transfer of privilege: Intergenerational support and social class in early adulthood. [Article]. *New Directions for Child & Adolescent Development*, 2008(119), 11-24. doi: 10.1002/cd.206
- Taylor, S., & Bogdan, R. (1998). *Introduction to Qualitative Research Methods*. New York: John Wiley & Sons, Inc.
- The Sibling Leadership Network. (2008). The Sibling Leadership Network: Recommendations for Research, Advocacy, and Supports Relating to Siblings of People with Developmental Disabilities. 25. Retrieved from http://www.rrtcadd.org/assets/SLN_White_Paper.pdf
- Walker, A. (2011). CHECKMATE! A Self-Advocate's Journey Through the World of Employment. *Intellectual and Developmental Disabilities*, 49(4), 310-312. doi: 10.1352/1934-9556-49.4.310