

The Sibling-in-Law:

Understanding an Unknown Member of the Disability Community

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### **Abstract**

Little attention has focused on siblings-in-law, the spouses of siblings of individuals with disabilities. Using an online survey, 102 siblings-in-law provided information concerning themselves, their spouses, in-law family, and experiences. Overall experiences were rated as positive (51.0%), mixed (34.3%), or negative (14.7%). Compared to respondents with negative outcomes, respondents with positive and mixed outcomes felt being a sibling-in-law more positively impacted their marriage, relationship with in-laws, parenting, desire to advocate, and career. Before marriage, these two groups better understood sibling-in-law responsibilities and reported less worry about marrying into a family with a member with disabilities or having children with disabilities. In open-ended reflections, 1/3 of respondents discussed family dynamics; improving disability knowledge; future planning; and marriage considerations. Practice and research implications are discussed.

## **The Sibling-in-Law:**

### **Understanding an Unknown Member of the Disability Community**

Although important for all of us throughout the lifespan, families are crucial for individuals with disabilities. As most adults with intellectual and developmental disabilities (IDD) live at home with their families, parents are a major source of support, love, and basic needs throughout their lives (Seltzer, Floyd, Song, Greenberg, & Hong, 2011). In addition, families play an essential role in navigating the service delivery system, advocating, and creating opportunities in the community for the individual with a disability (Grossman & Magaña, 2016). Given the increasing lifespans of individuals with IDD in conjunction with parental aging or death, attention has recently been directed toward adult siblings assuming more caregiving responsibilities once their parents can no longer do so (Bigby, Webber, & Bowers, 2014; Burke, Taylor, Urbano, & Hodapp, 2012; Orsmond & Fulford, 2018).

While adult siblings of individuals with IDD have started to be examined in research (Hodapp et al., 2017), little attention has yet been focused on another important family member, the sibling-in-law—the spouse of an adult sibling who has a brother or sister with IDD. Although siblings-in-law have been mentioned briefly in a few studies (e.g., Bigby, 2000; Burke, Fish, & Lawton, 2015; Kuo, 2015), only Vanhoutteghem, Van Hove, D'haene, and Soyez (2013) has focused exclusively on this group. Their narrative study was, however, limited to 14 siblings-in-law, all of whom shared residential arrangements with their brother/sister-in-law with disabilities. Although many siblings-in-law spoke of their experience after their spouses assumed unexpected full-time care of the adult with IDD in their home (usually after crises), co-residence of individuals with IDD and their siblings represents the experience of relatively few siblings (approximately 10-20%) (Freedman et al., 1997; Woodman et al., 2014).

To understand siblings-in-law of individuals with IDD, it is important to first understand the more general in-law relationship. Recent studies focus on the ways in which the relationship is involuntary, characterized by having a linchpin, and is triangular. In-law relationships are involuntary because, although adults choose to marry their spouses, they generally have little choice in negotiating in-law relationships (Serewicz, 2006). The son or daughter serves as a linchpin, in that the sibling-in-law only knows the in-laws through the spouse (Serewicz, 2008). Lastly, this in-law relationship is often viewed as a three-way, triangular relationship, having three “sides” of differing emotional strength. The two spouses have a close bond, as does the son-daughter with his/her parents, yet the son/daughter-in-law has a weaker bond with the in-laws. This weaker connection has been thought to sometimes cause a sense of imbalance and envy (Yoshimura, 2010).

Although difficult for all families to navigate, in-law relationships become more complicated when a family member has IDD. Beyond including an extra person in what is traditionally a three-way relationship, the role of each individual becomes more complicated. The spousal relationship becomes more complex because one spouse is also the sibling to a brother/sister with disabilities. In most cases, such relationships are fairly close, with most siblings spending time and feeling emotionally connected to their brother/sister with disabilities (Hodapp & Urbano, 2007; Orsmond & Fulford, 2018). In terms of caregiving, siblings are more likely to anticipate and assume caregiving roles when the adult sibling is female and/or the “lone sibling” to the brother/sister with disabilities (i.e., the family’s offspring include only the sibling and the brother/sister with disabilities; Burke et al., 2012).

The dynamic with parents—the in-laws—also becomes more complicated. Compared to most adults who do not have disabilities, offspring with disabilities more often live at home with

their parents far into their adult years (Fujiura, 2014; Stancliffe, et al., 2012). The sibling-in-law is thus impacted by how their in-laws parented their children, one of whom they married (the spouse) and the other whom they may eventually assume care for (the offspring with disabilities). Siblings-in-law who have a sense of obligation to the in-laws and a clear understanding of their role within the spouse's family may possess improved "solidarity and connectedness," resulting in an overall positive relationship for all involved (Serewicz, 2006). Conversely, unhappy in-law relationships may be characterized by divergent expectations of parents and of their son/daughter-in-law (Serewicz, 2006).

Complications also concern the offspring with a disability, especially relating to the individual's functional abilities and behavior problems. For example, closer sibling relationships have been reported when the person with autism spectrum disorder had greater levels of functional independence (Orsmond & Seltzer, 2007). In addition, when adults with disabilities demonstrate higher levels of behavior problems, parents experience more stress and sibling relationships worsen (Blacher & Baker 2017; Hayes & Watson, 2013; Hodapp & Urbano, 2007; Orsmond, Kuo, & Seltzer, 2009; Orsmond & Seltzer, 2007).

In-law relationships may also become more complex due to the sibling-in-law's knowledge of disabilities. Whereas the in-law family has known about disabilities for years, most siblings-in-law do not share this experience, furthering a sense of being an outsider. Beyond knowing less about disabilities, the sibling-in-law may not anticipate that their spouse may adopt advocacy roles (Burke, Arnold, & Owen, 2015), roles related to the individual with a disability ("case" advocacy) or to the cause of disabilities more generally (Burke et al., 2015).

Finally, one must consider the voices of the siblings-in-law themselves. At this point, research shows only the reactions of siblings-in-law when their brother/sister-in-law with

disabilities unexpectedly moves into their household. During these crises, many siblings-in-law felt their voices and opinions were unappreciated or even unheard (Vanhoutteghem et al., 2013). Yet few studies have examined the voices of siblings-in-law in other, less dire circumstances. It is unknown, for example, whether respondents consider being a sibling-in-law a positive or negative experience, how siblings-in-law describe their circumstances, who they comment on, and the main topics or themes they describe.

In exploring the sibling-in-law relationship, then, this study asked the following research questions. First, how do the respondents rate their experience as a sibling-in-law overall (positive-mixed-negative) and how does this rating relate to other life areas? Second, how does the quality of the relationship correlate with early information-expectations of the role itself, characteristics of the brother/sister-in-law with disabilities, or other potential correlates? Finally, to gain a more nuanced understanding of their experiences, how do siblings-in-law characterize this relationship when provided open-ended questions? Collectively, this study provides the first in-depth understanding of the complex in-law relationship when one is married to an adult sibling of a brother/sister with a disability.

## **Method**

### **Participants**

Respondents included 102 siblings-in-law—spouses of siblings who had a brother or sister with IDD. Specifically, 62 were male and 40 were female, with a mean age of 38.81 years (ranging from 22-71). Of this sample, 57.8% had their own children. As shown in Table 1, most respondents were White and well-educated. All respondents were married to a spouse who was the sibling to one or more offspring with IDD. If their spouse had more than one sibling with IDD, respondents were asked to complete the survey in regards to the oldest brother/sister-in-law

with disabilities. All respondents answered through a web-based survey, with qualifying participants all 18 years or older and married to an adult who has a brother/sister with IDD.

Spouses of respondents included 64 females and 38 males, with a mean age of 38.25 years (ranging from 22-71). Most spouses were also White and well-educated. Among mothers-in-law who were still living (75.5%), the average age was 62.79 years (ranging from 43-90). The mean age of fathers-in-law was 64.39 years (ranging from 45-89); 72.5% of fathers-in-law were alive.

Among brothers/sisters-in-law with IDD, 57 were males and 44 were females (1 not reported). The mean age was 36.50 years (ranging from 1-75). The daily work or activities of the individual with a disability varied greatly. Most individuals either worked for pay in the community (35.3%; of these, 19.6% in competitive employment; 10.8% with assistance; 4.9% with modifications) or were involved in an activity/day program (31.4%). Others worked in a supervised workshop (10.8%), performed volunteer work (6.9%), or were in school or training for future jobs (3.9%). An additional 12.7% did not work or had no activity setting. Living arrangements of the brother/sister-in-law also ranged widely, including living with parents (47.1%), group homes (20.6%), respondent's homes with their sibling and sibling-in-law (10.8%), supervised apartments (6.9%), on their own (6.9%), or other (7.7%; with roommates, spouses/significant others, nursing homes, or supported living arrangements).

## **Procedure**

To examine the characteristics and perspectives of sibling-in-law respondents, we first created an anonymous web-based survey. After receiving feedback from four siblings-in-law, adult siblings, and professionals within the disability community, additional questions were created to allow siblings-in-law to share their individual experiences. The survey was then

piloted with four siblings-in-law, as well as three professionals. After revisions were made, the study was submitted to the University Institutional Review Board (IRB). Once approved by the IRB, the survey was transferred to REDCap, a data collection platform (Harris et al., 2009).

Recruitment efforts utilized flyers, social media posts, and email to target adult siblings and siblings-in-law. Through email, contacts were made to the Sibling Leadership Network, SibNet, SibNet20, Siblings Australia Inc., and The Arc (both at national and local levels). Many of these disability organizations shared the survey link and flyer on their social media platforms (including Facebook and Twitter), or on their personal websites. Wrightslaw's Yellow Pages for Kids (<http://www.yellowpagesforkids.com>) was also used to contact additional organizations that involved families and siblings (to reach their spouses). Flyers and sign-up sheets were distributed at The Arc's 2018 National Convention and we also contacted multiple University Centers for Excellence in Developmental Disabilities (UCEDD's).

The online survey went live in mid-September 2018 and closed in mid-January 2019. All surveys were completed electronically and anonymously. The survey consisted of 166 questions, which took respondents approximately 30-45 minutes to complete. All survey responses were stored in REDCap, before being transferred and exported to IBM's Statistical Package for the Social Science (SPSS). Analyses of open-ended questions were conducted by exporting the responses of the final four open-ended questions from REDCap to Microsoft Excel.

## **Survey**

The survey was comprised of the following five sections:

**Respondent and spouse information.** In section one, the respondent answered demographic questions about him/herself, their spouse, and their family. Questions included: age, gender, ethnicity, education, where they lived, employment, income, overall health, if they

had a family member with a disability, and personal involvement in the disability community. In regards to their spouse's information, additional questions were asked about their marriage and the couple, if they had children, who lived in their household, how far away they lived from the individual with disabilities, how many siblings their spouse had, and what "number" their spouse was (e.g., 1=oldest offspring, 2=second oldest, etc.).

This section also included questions regarding when the respondent was first told about their spouse's brother or sister with IDD, and how he or she felt this situation would impact their relationship, marriage, knowledge about disabilities, and other future considerations. The siblings-in-law also rated how much thought, before marriage, they had given to the effects of marrying into a family in which at least one person has a disability, if they worried about having a child with a disability, and to what extent they felt the need to talk about issues of disability with their spouse. Respondents were asked to what extent they felt their brother/sister-in-law would change their life in regards to 12 life aspects (i.e., where they would live, their career, ways they would relate to their spouse's family, help their spouse advocate, etc.).

**Information about the in-laws and the individual with a disability.** This section asked demographic questions regarding the mother-in-law (and father-in-law) such as highest education level, overall health (if alive), and their ability to care for their offspring with disabilities. Next, respondents were asked about their brother/sister-in-law with disabilities, including gender, age, disability category, state in which they resided, current and predicted future living situations, daily activities/work, and overall health. As the second section gathered specific information about their spouse's family, respondents were instructed, "If necessary, you may consult with your spouse on this section to obtain more information."

To assess the functioning level of the brother/sister-in-law with IDD, the Activities of Daily Living (ADL) scale was used to identify the individual's level of independence (Lawton, Moss, Fulcomer, & Kleban, 1982). The ADL scale included 17 daily living activities (e.g., toileting, completing household tasks, grooming, etc.); respondents rated the individual on a scale of: (1) "Does not do at all;" (2) "Does with help;" or, (3) "Does on own or independently." The mean score was 35.41 (range from 17-49; alpha = .93). Respondents also rated the brother/sister-in-law's behavior problems within the past six months. Using the Scales of Independent Behavior-Revised (SIB-R), respondents answered an eight-item measure that provides Externalizing, Internalizing and Asocial Domain subscales, as well as an overall General Maladaptive Index (GMI; Bruininks, Woodcock, Watherman, & Hill, 1996; alpha = .76). When the respondents answered "Yes" to one of the eight measures, they were asked to specify the frequency (< once a month to 1+ per day) and severity (Not at all to Extremely) of the behavior. If the respondents answered "No," they did not see the frequency or severity questions. The ADL and SIB-R measures have been used in previous studies of adult siblings of brothers-sisters with disabilities (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2019).

**Support types, advocacy, and caregiving.** The third section involved questions regarding the levels and types of support (tangible, emotional, or informational) that the respondent provides to the brother/sister-in-law with disabilities. Additional questions investigated both the respondent and their spouse's involvement in the disability community and if they assumed any advocacy roles.

This section also inquired about the respondent's and the spouse's caregiving roles and if the spouse is currently the adult with disability's legal guardian or conservator. Respondents rated spouse's caregiving of their brother-sister with disabilities in each of the five domains,

residential, financial, legal, interacting with the service system, and providing companionship (Burke et al., 2012); their spouse could be the (2) “Primary Caregiver” to (0) “No Caregiving” for each domain. Also, using a 5-point scale from (1) “No/NA” to (5) “Always,” the respondent shared how much time he or she assisted the spouse in various caregiving and support roles.

**Future consideration and input on being a sibling-in-law.** Respondents were then asked to think about the future, reflect on their experience, as well as the impact of being a sibling-in-law. In addition to identifying who would assume responsibility of caring for their spouse’s brother or sister with disabilities when the parents are no longer able, additional questions asked the respondent to reflect on how being a sibling-in-law had impacted his or her positive internal characteristics (e.g., empathy, compassion, etc.; Cronbach’s alpha equaled .85), as well as the current influence this role has had on their career, parenting, relationships, and involvement in the disability community (i.e., the same 12 aspects as discussed in Section 1).

We also focused on the sibling-in-law’s overall experiences as positive, mixed, or negative. We asked: “Considering everything from the present moment, how do you consider having a sibling-in-law with a disability?” The response options included: 1- very bad; 2- somewhat bad; 3- mixed, neither good nor bad; 4- somewhat good; and 5- very good. We then created overall experience categories of “negative” (1 & 2); “mixed” (3); and “positive” (4 & 5).

**Open-ended questions.** We ended the survey by asking 4 open-ended questions: “Describe the overall effect of being married to a sibling of a person with disabilities;” “What has been the most surprising and unexpected part of having a brother/sister-in-law with disabilities?;” “What advice would you share with other siblings-in-law or what could have helped you prepare for this role?;” and “Is there anything else you would like to tell us about the

experience as a sibling-in-law?" These open-ended questions did not have a character limit, which allowed the respondent to provide extra details and information.

### **Analyses**

Analyses followed the three main goals of this study. First, we determined the percentage of respondents who reported having a positive, mixed, or negative overall experience as a sibling-in-law. In addition, we investigated whether having a positive, mixed, or negative overall experience related to other individual life aspects such as their career, marriage, relationship with in-laws, and involvement with disabilities. Second, we examined how the respondents with negative-mixed-positive experiences differed in regard to pre-marriage considerations (i.e., prior knowledge about disabilities, fears, discussion with spouse, and expectations), as well as to characteristics about themselves, their spouse, in-laws, and the brother/sister-in-law with disabilities. For these analyses, we compared different variables across the three outcome groups through one-way ANOVA's (for continuous outcome variables) and chi-squares (for categorical variables). To control for multiple hypothesis testing, we used a Benjamini-Hochberg correction procedure (BH correction; Benjamini & Hochberg, 1996).

The third goal involved qualitative analyses using those respondents who answered at least one of the four open-ended questions. The first author coded all responses using phenomenological qualitative analyses; this approach allows the coder to categorize and assign a descriptive code to individual responses (Creswell, 2013). Codes were organized into 7 major themes (with 14 related sub-themes or categories). After defining each theme, we considered non-examples to refine and strengthen theme definitions. To assess coding reliability, a graduate student then served as a second coder, independently coding all respondents' answers. Kappas were used to check reliability between coders for all 7 major themes. The median reliability

coefficient value was .67 (range from .50 to .79). Cicchetti (1994) defined “acceptable” and “good” reliability coefficients as values that range from .40 to .59 and from .60 to .74, respectfully. When disagreements occurred, the coders discussed each case individually, before assigning each to its appropriate theme.

## Results

### Nature of the Overall Experience

Of the 102 respondents, 14.7% ( $n = 15$ ) were represented in the *negative outcome* group (3= very bad; 12= somewhat bad), 34.3% ( $n = 35$ ) in the *mixed outcome* group, and 51.0% ( $n = 52$ ) in the *positive outcome* group (22= somewhat good; 30= very good).

Overall experiences were related to 12 life outcomes. We used an adjusted rating scale of “worse,” “same,” and “better.” As shown by Table 2’s ANOVAS, five items were worse in the negative outcome group compared to the mixed and positive outcome groups. Those who considered the sibling-in-law experience to be negative overall more often reported this experience had adversely affected their: marriage, desire to advocate for others, relationship with in-laws, parenting, and career (for all significant ANOVAs,  $p's < .015$ ).

### Correlates of Overall Experience

Three main correlates emerged of those respondents who considered the overall experience of being a sibling-in-law as positive, mixed, or negative.

**Early views.** A first group of correlates concerned the perceptions, concerns, disability knowledge, and preconceived notions held by respondents before marriage. Although prior disability knowledge was similar across the three groups, as shown by the ANOVAs in Table 3, respondents from the negative outcome group (versus the mixed or positive outcome groups) had given less thought to whether the sibling-in-law experience would be positive or negative, if they

would provide caregiving for the brother/sister-in-law with disabilities, or provide support for their spouse to care for their brother/sister with IDD (all  $p$ 's < .032). This group also did not expect to participate or support their spouse in advocating for: the individual with a disability or disability rights. Also compared to the other two groups, the negative outcome group was (even before marriage) more worried. They were more anxious about marrying into a family with a member who has disabilities and about having children with disabilities.

**Characteristics of the brother/sister-in-law with disabilities.** Compared to those in the other two groups, the brothers/sisters-in-law with disabilities in the negative outcome group had higher levels of maladaptive behaviors. Although overall SIB-R General Maladaptive Scores did not differ by group, the Externalizing domain scores markedly differed in the negative outcome group ( $X = 36.73$ ) as compared to the mixed (66.24) or positive (72.88) groups (lower scores reflect higher levels of maladaptive behavior),  $F(2, 99) = 5.47, p < .01$ . Such scores were also reflected in higher percentages within the negative outcome group of behaviors relating to hurting others, hurting property, and disruptive behavior. To give one example, “Destructive-Hurtful to others” was noted in 40% of the negative outcome group, as compared to 12.1% and 13.7% of the mixed and positive outcome groups, respectively,  $X^2(2, N = 102) = 6.64, p < .05$ .

**Positive internal growth.** Reflecting on the effects of being a sibling-in-law, the mixed and positive outcome groups—versus the negative outcome group—reported significantly more growth in compassion, empathy, being open to learning opportunities, and in understanding differences (all  $p$ 's < .005). See Figure 1.

### **Voices of the respondents**

Across all four questions, 78.4% ( $n = 80$ ) of respondents answered one or more of the open-ended questions. We identified seven overarching themes (see Table 4).

The first major theme involved *In-Law Family Dynamics*, with 65% ( $n = 52$  of 80) of the respondents discussing dynamics within the spouse's family. Siblings-in-law discussed communicating with the in-laws regarding future caregiving (i.e., successful or breakdowns), agreements and appreciation of the in-laws, disagreements and challenges with the in-laws, and respondents reflecting about their brother/sister-in-law with disabilities (i.e., recalling specific interactions, expectations, and abilities).

*Improving Disability Knowledge* was the second major theme, noted by 51.1% of respondents who answered the open-ended questions. Defined as respondents expressing a growth in their understandings of disabilities, this theme touched on issues specific to the brother/sister-in-law and to disabilities in general. Not only did this theme focus on gaining education or awareness of disabilities, it also included siblings-in-law who discussed the need for support groups (i.e., local or national disability organizations, Facebook groups), advocacy for disability rights/better services, and the lack of support from governmental agencies. Compared to respondents with less disability knowledge, those (10) individuals who had prior involvement with disabilities (i.e., siblings, parents, teachers) provided more sophisticated and specific advice (e.g., "With your spouse, read one of Dr. Gottman's books or, even better, go on one of their retreats. Apply what you learn.").

Considerations regarding the respondents' nuclear family were grouped into a third theme, *Family/Future Planning* (40%). This category included mentions of finances, children, and caregiving for the sibling-in-law (i.e., altering living arrangements, future considerations). Some respondents (8), especially those who anticipated future caregiving, discussed the impact their brother/sister-in-law had on whether or not to have their own children. As one respondent

noted, “I am also surprised with the fact that I decided not to have children of my own so I can focus on my brother-in-law's care.”

The fourth theme, *Marriage Considerations* (35% of respondents) referred to their spouse and/or the impact having a sibling-in-law with IDD has had on their marriage. Respondents typically discussed the need for communication with their spouse or being supportive of the spouse. Positive remarks included: “If our marriage wasn't rock solid, we'd be lost” and “my wife is a star.” Negative statements included: “Be prepared to not be the primary partner in a relationship” and “It impacts a marriage because there is no time for us.”

Three other, less-often mentioned themes were also noted. *Positive Internal Growth* (22.5%), involved respondents mentioning their own change regarding characteristics such as empathy, compassion, or being a better person as a result of being a sibling-in-law. In addition, some siblings-in-law shared their experiences more generally as *Positive* (22.5%) or as *Negative* (13.75%). See Table 6 for quotations representing each theme.

### **Discussion**

This study begins the process of understanding the experiences of those individuals who have married a spouse who has a brother/sister with IDD. Although a few studies have focused on selected aspects of these siblings-in-law (e.g., Vanhoutteghem et al., 2013), our study is the first to examine such a large cohort, or to have tapped into such a wide range of issues. In this study, we asked siblings-in-law to reflect from before marriage to the present about their roles and relationships, as well as to rate the overall outcome of being a sibling-in-law. This study has three major findings.

Our first finding concerned how respondents felt about the overall sibling-in-law experience. Most respondents considered their sibling-in-law experience to be fairly positive,

with about half rating the overall experience as positive, and another one-third as mixed. There was, however, also a sub-group that considered the sibling-in-law experience as negative overall, with this group representing roughly 15% of all participants. This negative outcome group (versus the other two groups) also showed more adverse outcomes concerning their marriages, their relationships with their in-laws, their parenting, their careers, and their desire to be (or to assist their spouse as) an advocate. Like findings from adult sibling studies, this study also found impacts on career choice, having children, personal relationships, and overall feelings regarding people with disabilities (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). The negative outcomes group also was less inclined to assist their spouse as an advocate for their brother/sister-in-law with IDD and/or more services.

This pattern of “mostly good, some bad” mirrors findings from over a decade of studies on adult siblings. In considering the relationships of adults with their brothers/sisters with disabilities, most siblings report a warm and close relationship, and spend fair amounts of time together (Doody, Hastings, O’Neill, & Grey, 2010; Hodapp & Urbano, 2007, Hodapp, Urbano, & Burke, 2010; Orsmond & Seltzer, 2007; Orsmond, et al., 2009). At the same time, most studies also note a sub-set of adult siblings who did not report good—or even fairly good—relationships with their brother/sister with disabilities. Parallel findings were derived from this study’s sibling-in-law respondents.

Second, this study tied the overall sibling-in-law experience to premarital expectations and anxieties, to characteristics of the brother/sister-in-law with a disability, and to the degree of personal growth. In contrast to the groups reporting mixed or positive experiences, those respondents reporting a more negative overall experience noted differences even before marriage. The negative outcome group anticipated that being a sibling-in-law would involve

fewer responsibilities in caring for their brother/sister-in-law with disabilities, supporting their spouse in caregiving, or in disability advocacy. At the same time, this group (again compared to the other two outcome groups) was more worried and anxious about marrying into a family with a member with disabilities and about having their own child with a disability. Such uncertainty, lack of information, and anxiety have been reported by adult siblings, especially by those who were anticipating caregiving responsibilities for their brother/sister with disabilities but who were not included in their parents' future planning (Burke et al., 2015). Without clear guidelines and expectations—especially concerning future caregiving and navigating support systems—these siblings-in-law may also experience increased challenges.

Overall outcome groups also related to characteristics of the individual with IDD. Compared to those reporting mixed or positive overall experiences, respondents who rated their experience as negative reported their brother/sister-in-law as having higher levels of externalizing behaviors. Such connections between externalizing behavior problems and adverse impacts on others have been found repeatedly in the parent stress literature (Blacher & Baker, 2017; Hodapp, Dykens, & Masino, 1997). Similarly, when their brother/sister with disabilities displayed lesser levels of maladaptive behavior, adult siblings report relationships that are closer and more positive (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007) and (in ASD) they are more willing to engage with their brother/sister (Orsmond et al., 2009). Such findings closely align with findings from these sibling-in-law respondents, who also reported a worse overall experience when their brother/sister-in-law exhibited higher levels of maladaptive behavior.

A final set of correlates connected to changes in internal growth, an increasing focus of disability research (e.g., Dykens, 2006; Taunt & Hastings, 2002). Compared to sibling-in-law respondents reporting a negative overall experience, those in the mixed or positive groups

reported that having a brother/sister-in-law with disabilities has resulted in increased positive internal growth. Siblings who report positive relationships with their brother/sister who has a disability also develop greater degrees of compassion, responsibility, and understanding of others' differences (Hodapp et al., 2010). Having a brother/sister with disabilities has also increased levels of siblings' empathy (Meyer & Holl, 2014), the greatest overall area of internal growth for these sibling-in-law respondents.

Third, this study provided preliminary understandings of the perspectives of these siblings-in-law. Through qualitative analyses of the four open-ended questions, siblings-in-law produced responses along the seven major themes. In considering these open-ended responses, we return to the intricacies of the in-law experience, and how that experience may change when marrying into a family that has a member with disabilities. In typical in-law relationships, a "triangle" exists, with parents, offspring (the spouse), and son/daughter-in-law constituting the three sides of the triangle (Serewicz, 2008).

In disability families, however, this triangle evolves into a square, as one must also consider the brother/sister with disabilities. New issues also arise, such as how the in-laws are currently parenting their offspring with IDD as well as how the sibling-in-law is typically an outsider to the world of disabilities. From both quantitative ratings and the open-ended questions, the importance of clear expectations becomes paramount. Specifically, those respondents who reported a more positive (versus negative) overall experience had clearer expectations early on (i.e., before marriage) and were less apprehensive. Additionally, the parenting behaviors of the in-laws were often mentioned (both positively and negatively), as were the connections between parenting behaviors and (externalizing) behavior problems of the individual with IDD. These

complications—unique to persons marrying into a family in which at least one person has a disability—were noted by these sibling-in-law respondents.

### **Implications for Practice**

Taken together, these findings lead to several practical suggestions. Although most siblings-in-law are doing fine, we must still recognize the small sub-group who judge their overall experience as negative. We need to target this group, possibly at various stages across the sibling-in-law years. Noting the expressed need for open and honest communication, we might create toolkits or communication guides for adult siblings that incorporate the comments and concerns of siblings-in-law. Such resources could serve as starting points in discussing what their spouse expects of them as a sibling-in-law. Presented before marriage, discussions surrounding these resources might ease the anxieties and clarify expectations about what it means to become a sibling-in-law.

Second, many participants reported having little experience or knowledge regarding disabilities. Especially for those who reported having a brother/sister-in-law with more externalizing behaviors, it might be important to provide access to some type of disability education. By learning more about what disabilities are, as well as existing service systems and groups, these respondents might feel more prepared and comfortable around their brother/sister-in-law. Currently, most material and training focuses on parents, teachers, and (sometimes) adult siblings; such training might be extended to interested siblings-in-law. For example, various resources exist to help in ameliorating difficult, often externalizing, maladaptive behaviors (McIntyre, 2013). Increasingly, online courses or modules are available; consider the recent advances in distance learning and training, often focused on parents of children with autism (Casale, et al., 2017; Juárez et al., 2018). Extended to siblings-in-law, such resources might

allow these individuals to acquire information to better understand their brother/sister-in-law or disabilities in general.

Third, regardless of the nature of their overall experience, many siblings-in-law felt like outsiders to the world of disabilities. Especially in their open-ended comments, many advised new siblings-in-law to find a network or support group to alleviate the caregiving responsibilities, share information, and connect with others. Current support groups have been successful in connecting individuals with similar roles (i.e., siblings) by providing education and resources, creating a network of support, and advocating for the disability cause in general (Bray, Carter, Sanders, Blake, & Keegan, 2017; Solomon, Pistrang, & Barker, 2001). As support groups are often difficult to find or geared toward immediate family members, online support groups specifically for siblings-in-law might allow these individuals to network with one another, as well as to be recognized and valued.

In considering future research in this area, we also acknowledge this study's limitations. One direction, then, might be to include multiple perspectives in sibling-in-law studies. Such perspectives might include how the spouse sees the sibling-in-law's concerns and in-law relationships, as well as perspectives of the adult with disabilities and of the in-law parents. An additional limitation involved receiving all of our information from these sibling-in-law respondents, including information about the functioning level and behavior problems of the adult with disabilities. We noted as well that, oftentimes, siblings-in-law may have needed greater information from their spouses about their brother/sister-in-law with disabilities or even about other in-law family members.

In addition, future studies might pursue different, possibly more expansive channels of recruitment. As few organizations directly involve siblings-in-law, we used adult sibling groups

as our main recruitment venue. By utilizing this strategy, however, we likely had sibling-in-law respondents whose spouses are more involved with their brother/sister with disabilities and are more committed to the disability cause. Such respondents may have different experiences than less connected siblings-in-law or spouses. Additional directions for research result from using an English and web-based survey, as our sample was predominantly White, educated, and middle/upper-class. Future research should target a more generalizable sample. Finally, we acknowledge that our study was cross-sectional and, at times, respondents had to recall, retrospectively, what they knew or how they felt in the years before marriage, which for many was decades in the past. Studies that are more contemporaneous and/or longitudinal, using a wider, more diverse sample of siblings-in-law, would improve our understanding of this group.

Nonetheless, this study begins the process of understanding the experiences of siblings-in-law. While most siblings-in-law consider their experiences as either positive or mixed, some reported their experience as negative overall, and this negative overall experience related to anticipating lesser effects, but having increased anxiety before marriage, as well as worse outcomes regarding their marriages, relationships with in-laws, and careers. Additionally, those respondents reporting a negative overall experience also had brothers/sisters-in-law who showed higher levels of maladaptive behavior. Siblings-in-law who had a mixed or positive overall experience (vs. those with negative overall experiences) also reported greater amounts of positive internal growth. If we want to improve the experiences of siblings-in-law to individuals with disabilities, we must understand and support these unknown members of the disability community.

### References

- Benjamini, Y., & Hochberg, Y. (1995). Controlling the false discovery rates: A practical and powerful approach to multiple testing. *Journal of the Royal Statistical Society*, *57*, 289-300.
- Bigby, C. (2000). *Moving on without parents*. Baltimore, MD: Paul H Brookes Publishing Co.
- Bigby C., Webber R., & Bowers, B. (2014). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work*, *68*, 453-468. doi:10.1080/0312407X.2014.950678
- Blacher, J., & Baker, B. L. (2017). Collateral effects of youth disruptive behavior disorders on mothers' psychological distress: Adolescents with autism spectrum disorder, intellectual disability, or typical development. *Journal of Autism and Developmental Disorders*, 1-12.
- Bray, L., Carter, B., Sanders, C., Blake, L., & Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling*, *100*, 1537-1543.
- Bruininks, R. H., Woodcock, R.W., Weatherman, R. F., & Hill, B. K. (1996). *Scales of independent behavior-revised (SIB-R)*. Chicago, IL: Riverside.
- Burke, M. M., Arnold, C. K., & Owen, A. (2015). The role of advocacy among siblings of individuals with intellectual and developmental disabilities. *Inclusion*, *3*, 162-175.
- Burke, M. M., Fish, T., & Lawton, K. (2015). A comparative analysis of adult siblings' perceptions toward caregiving. *Intellectual and Developmental Disabilities*, *53*, 143-157.
- Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *117*, 33-47.

- Casale, E. G., Stainbrook, J. A., Staubitz, J. E., Weitlauf, A. S., & Juarez, A. P. (2017). The promise of telepractice to address functional and behavioral needs of persons with Autism Spectrum Disorder. *International Review of Research in Developmental Disabilities, 53*, 235-295.
- Cicchetti, D. (1994). Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. *Psychological Assessment, 6*, 284-290.
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: SAGE Publications.
- Doody, M. A., Hastings, P. A., O'Neill, S., & Grey, I. M. (2010). Sibling relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities, 31*, 224-231.
- Dykens, E. M. (2006). Toward a positive psychology of mental retardation. *American Journal of Orthopsychiatry, 76*, 185-193.
- Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation, 35*, 114-123.
- Fujiura, G. T. (2014). The political arithmetic of disability and the American family: A demographic perspective. *Interdisciplinary Journal of Applied Family Studies, 63*, 7-19.
- Grossman, B. R., & Magaña, S. (2016). Family support of persons with disabilities across the life course. *Journal of Family Social Work, 19*, 237-251.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap) - A metadata-driven methodology and workflow

- process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42, 377-381.
- Hayes, S. A., & Watson S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disabilities*, 43, 629-642.
- Hodapp, R. M., Dykens, E. M., & Masino, L. L. (1997). Families of children with Prader-Willi Syndrome: Stress-support and relations to child characteristics. *Journal of Autism and Developmental Disorders*, 27, 11-24.
- Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research*, 51, 1018-1029.
- Hodapp, R. M., Urbano, R. C., & Burke M. B. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and Developmental Disabilities*, 48, 52-62.
- Juárez, P. A., Weitlauf, A. S., Nicholson, A., Pasternak, A., Broderick, N., Hine, J., Stainbrook, J. A., & Warren, Z. (2018). Early identification of ASD through telemedicine: Potential value for underserved populations. *Journal of Autism and Developmental Disorders*, 48, 2601-2610.
- Kuo, Y. (2015). Women's experiences caring for their husbands' siblings with developmental disabilities. *Global Qualitative Nursing Research*, 2, 1-10.
- Lawton, M. P., Moss, M. S., Fulcomer, M., Kleban, M. H. (1982). A research and service oriented multilevel assessment instrument. *Journal of Gerontology*, 37, 91-99.

- McIntyre, L. L. (2013). Parent training interventions to reduce challenging behavior in children with intellectual and developmental disabilities. *International Review of Research in Developmental Disabilities, 44*, 245-279.
- Meyer, D., & Holl, E. (2014). *The sibling survival guide: Indispensable information for brothers and sisters of adults with disabilities*. Bethesda, MD: Woodbine House.
- Orsmond, G. I., Kuo, H., & Seltzer, M. M. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. *Autism, 13*, 59-80.
- Orsmond, G. I., & Fulford, D. (2018). Adult siblings who have a brother or sister with autism: Between family and within-family variations in sibling relationships. *Journal of Autism and Developmental Disorders, 48*, 4090-4102.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 313-320.
- Sanderson, K.A., Burke, M.M., Urbano, R.C., Arnold, C.K., & Hodapp, R.M. (2019). Getting by with a little help from my friends: Siblings report on the amount of informal support received by adults with disabilities. *Journal of Intellectual Disability Research*. Published on-line, 4-19, doi:10.1111/jir.12622
- Seltzer M. M., Floyd F., Song J., Greenberg J., & Hong J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities, 116*, 479–499.

- Seltzer, M. M., Greenberg, J. S., Krauss, M. W., Gordon, R. M., & Judge, K. (1997). Siblings of adults with mental retardation or mental illness: Effects on lifestyle and psychological well-being. *Family Relations*, *46*, 395–405.
- Serewicz, M. C. M. (2008). Toward a triangular theory of the communication and relationships of in-laws: Theoretical proposal and social relations analysis of relational satisfaction and private disclosure in in-law triads. *Journal of Family Communication*, *8*, 264-292.
- Serewicz, M. C. M. (2006). The difficulties of in-law relationships In D. Kirkpatrick, D. Charles, Duck, S., and Foley, M. K. (Eds.), *Relating difficulty: The processes of constructing and managing difficult interaction* (pp. 225 -232), Mahwah, NJ: Lawrence Erlbaum Associates Publishers.
- Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, *29*, 113-132.
- Stancliffe, R. J., Lakin, K. C., Larson, S.A., Engler, J., Taub, S., Fortune, J. R., & Bershadsky, J. (2012). Demographic characteristics, health conditions, and residential service use in adults with Down syndrome in 25 U.S. states. *Intellectual and Developmental Disabilities*, *50*, 92-108.
- Woodman, A. C., Mailick, M. R., Anderson, K. A., & Esbensen, A. J. (2014). Residential transitions among adults with intellectual disability across 20 years. *American Journal on Intellectual and Developmental Disabilities*, *119*, 496-515.

Table 1.

*Demographic Information of Respondents, Spouse, and In-Laws*

		% (N)
<b>Siblings-in-Law</b>		
Age Groups	20-29	26.7% (27)
	30-39	33.7% (34)
	40-49	18.8% (19)
	50-59	12.9% (13)
	60+	7.92% (8)
	Ethnicity:	White, Non-Hispanic
Hispanic		0.98% (1)
Asian or Pacific Islander		3.92% (4)
Other		4.90% (5)
Education:	Some High School- Some College	17.6% (18)
	College Graduate	35.3% (36)
	Graduate or Professional Degree	46.1% (47)
	Other	0.98% (1)
Income	Less than \$40,000	4.0% (4)
	\$40,001-\$60,000	10.0% (10)
	\$60,001-\$80,000	11.0% (11)
	\$80,001-\$100,000	14.0% (14)
	More than \$100,00	61.0% (61)
Health	Fair	.98% (1)
	Moderate	8.8% (9)
	Good	54.9% (56)
	Excellent	35.3% (36)
Disability Insider	Work in Disability Field	14.7% (15)
	Has a Relative with Disabilities	30.4% (31)
<hr/>		
<b>Spouse</b>		
Age Groups:	20-29	25.7% (26)
	30-39	38.6% (39)
	40-49	15.8% (16)
	50-59	11.9% (12)
	60+	7.92% (8)
Number of Siblings:	1	39.2% (40)
	2-3	38.2% (39)
	4+	22.5% (23)
Sibling Status:	Oldest	45.1% (47)
	Middle Older than SIL	16.7% (17)
	Middle Younger than SIL	5.9% (6)
	Youngest	30.4% (31)
Health:	Fair	1.01% (1)
	Moderate	12.1% (12)
	Good	54.5% (54)
	Excellent	32.3% (32)

***Mother-in-Law***


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Age Groups	40-49	6.5% (5)
	50-59	27.3% (21)
	60-69	46.8% (65)
	70+	19.5% (15)
Health:	Poor	7.80% (6)
	Fair	14.3% (11)
	Moderate	24.7% (19)
	Good	40.3% (31)
	Excellent	13.0% (10)

***Father-in-Law***

Age Groups	40-49	4.1% (3)
	50-59	21.6% (16)
	60-69	48.6% (35)
	70+	25.7% (19)
Health:	Poor	6.80% (5)
	Fair	12.2% (9)
	Moderate	25.7% (19)
	Good	43.2% (32)
	Excellent	12.2% (9)

***In-Laws' Ability to Care***

	Both deceased	20.8% (21)
	Poor	5.9% (6)
	Fair	6.9% (7)
	Moderate	7.9% (8)
	Good	24.8% (25)
	Excellent	33.7% (34)

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***Individual with a Disability***

Disability Type:	ID	62.7% (64)
	DS	24.5% (25)
	ASD	23.5% (24)
	Mental Health	13.7% (14)
	Cerebral Palsy	13.7% (14)
	Other Genetic Syndrome	12.1% (13)
	Other Condition	9.8% (10)
	Sensory Impairment (Hearing, Vision)	9.8% (10)
	Health Condition	8.9% (9)
	Unspecified Developmental Disability	7.8% (8)

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Table 2.

*Specific Life Outcomes:* “How has marrying a spouse who has a brother/sister with disabilities affected...”

Items	Outcome Groups			<i>F</i>	<i>p</i>	<i>Post-hocs</i>
	Negative( <i>SD</i> )	Mixed ( <i>SD</i> )	Positive( <i>SD</i> )			
Your marriage	1.40 (.632)	2.26 (.666)	2.45 (.541)	17.91	.000*	B & C > A
Your relationship with your in-laws	1.53 (.743)	2.25 (.803)	2.56 (.644)	12.01	.000*	B & C > A
Desire to advocate	1.93 (.594)	2.57 (.502)	2.77 (.425)	17.72	.000*	B & C > A
Your parenting	2.00 (.535)	2.21 (.600)	2.51 (.579)	5.56	.005*	C > A
Your career	1.73 (.458)	2.14 (.494)	2.12 (.471)	4.38	.015*	B & C > A
Your relationship with your own parents	1.93 (.458)	2.10 (.539)	2.18 (.560)	1.23	.290	
Your relationship with your own siblings	2.27 (.458)	2.12 (.478)	2.14 (.566)	.454	.636	
Your free time	1.47 (.640)	1.68 (.583)	1.71 (.572)	1.05	.355	
Your friendships with non-family members	1.80 (.414)	1.94 (.422)	2.00 (.524)	1.03	.359	
Your knowledge about disabilities	2.80 (.561)	2.89 (.323)	2.90 (.298)	.501	.607	
Your knowledge about disability services	2.80 (.561)	2.86 (.355)	2.83 (.382)	.119	.888	
Knowledge about disability organizations	2.67 (.617)	2.74 (.505)	2.77 (.465)	.813	.447	

Notes: Analyses were conducted by computing new variables for each of the 12 life factors with new variables, Worse, Same, or Better. Worse category combined Much worse, Worse, and A little worse; Same consisted of one response option (“same”); Better combined A little better, Better, and A lot better. In mean scores (see above), Worse = 1; Same = 2; Better = 3. For post-hoc analyses, Negative Outcome = Group A; Group B = Mixed ; Group C = Positive.

\*Significant after B-H correction at  $p < .05$ .

Table 3.

*Prior Expectations and Anxieties of the Respondent*

Item	Outcome Groups			<i>F</i>	<i>p</i>	<i>Post-hocs</i>
	Negative( <i>SD</i> )	Mixed ( <i>SD</i> )	Positive( <i>SD</i> )			
<b>A. "To what extent would brother/sister-in-law with disabilities change your life in regards to..."</b>						
Before marrying, I thought being a SIL would be...	2.53 (.516)	3.26 (.701)	3.92 (.860)	21.62	.000*	C>B>A
Perform direct caregiving for bro/sis w dis	1.67 (.900)	2.63 (1.44)	3.06 (1.32)	6.64	.002*	B&C>A
Provide support for spouse to be in orgs & help dis cause	1.40 (.632)	2.66 (1.49)	2.73 (1.27)	6.58	.002*	B&C>A
Help spouse advocate for more services	1.53 (.915)	2.77 (1.70)	2.81 (1.36)	4.93	.01*	B&C > A
Provide support for spouse to care for brother-sister w dis	2.13 (1.19)	3.11 (1.37)	3.12 (1.31)	3.58	.032	
Help spouse advocate for SIL	2.13 (1.30)	3.14 (1.50)	3.00 (1.36)	2.90	.060	
Help spouse w bro/sis w disabilities	2.47 (1.13)	3.06 (1.37)	3.33 (1.44)	2.32	.104	
Where you would live	1.53 (.743)	2.23 (1.56)	2.23 (1.40)	1.63	.202	
Type of job	1.14 (.363)	1.06 (.236)	1.35 (.883)	2.08	.131	
Change in degree you'd work	1.27 (.799)	1.11 (.323)	1.25 (.813)	.482	.619	
How you relate to spouse's family	2.87 (1.46)	2.66 (1.37)	2.81 (1.53)	.152	.859	
Perform household tasks	1.27 (.799)	1.51 (.981)	1.44 (1.02)	.337	.715	
Help in caring for own children	1.53 (.915)	1.76 (1.16)	1.58 (.977)	.423	.656	
<b>B. "Before marriage, to what extent did you..."</b>						
Considered effects of marrying into a dis family	3.13 (1.41)	2.94 (1.39)	2.18 (1.26)	4.96	.01*	A&B> C
Worried about own children having disabilities	3.47 (1.51)	2.34 (1.39)	2.41 (1.30)	4.06	.02*	A> B&C
Felt need to discuss disability issues with spouse	3.20 (1.42)	2.83 (1.43)	2.41 (1.40)	2.12	.126	

Notes: SIL= Sibling-in-law

A. 1- Not Much → 5- Very Much B. 1- Didn't give it any thought → 5- Thought a lot about it; for post-hoc analyses, Group A = Negative Outcome Group; Group B = Mixed; Group C = Positive. \*Significant, using B-H correction, at  $p < .05$ .

Table 4.

*Voices of the Respondents*

Theme	Quote
<b>In-Law Family Dynamics</b> 65% (52/80)	<p>“Growing up as they did shaped them (and their expectations of what family [is] like) in deep and hidden ways that you both will continue to discover for years to come.”</p> <p><i>Communication:</i>            “Communicate all plans before a caregiver passes.”</p> <p><i>Agreement/Appreciation:</i>            “I greatly admire my husband and his parents for all they have endured and all of the actions they have taken to ensure my sister-in-law's health and well-being.”</p> <p><i>Disagreement/Challenges:</i>            “As a newcomer, I also view my sister-in-law as able to be much more independent, or having more potential than is currently ascribed to her. It's strange to me that her parents treat her as a child in many ways, some of which are necessary, but many of which seemingly are not, and just haven't changed or evolved from when she was much younger.”</p> <p><i>Reflection Involving SIL:</i>            “How capable he is of doing things on his own as well as how much he enjoys spending time with us.”</p>
<b>Improving Disability Knowledge</b> 51.1% (41/80)	<p>“[Being a sibling-in-law] opened my eyes to the reality of disability and the effects it can have not just on the person with the disability but also on those around them.”</p> <p><i>Furthering/Gaining Education:</i>            “What is considered high functioning is a lot different than what I expected. I was under the impression that it meant the condition was barely noticeable, but in contrast it refers more so to the ability to do functions of daily living, not as much noticeability.”</p> <p>“Research. Talk to people and gain more information about what you are about to get into. It's not easy.”</p>

**Improving  
Disability  
Knowledge  
(cont.)**

51.1% (41/80)

“Educate yourself on the disability and on disability services that may be available.”

*Disability “Insider:”*

“I am thankful that my knowledge of disabilities and the education of individuals with disabilities has allowed me to improve the possible outcomes of my sibling-in-law with disabilities.”

*Seeking Support:*

“We are starting to look for other places of support and understanding...Even just hearing from others who are having similar struggles has been comforting.”

*Advocacy:*

“Advocate as much as you can to help your disabled in-law be as independent as possible.”

*Government:*

“The lack of care and support from Illinois state and the Federal Government is shameful.”

**Family/Future  
Planning**

40% (32/80)

“When we first talked about my spouse's brother and what our reality would be after her parents were no longer able to care for him I was somewhat concerned with how this would affect our family in the future.”

*Finances:*

“How much money will we have to spend on my BIL [brother-in-law]? No matter how much money you have, you still have a budget. How could we afford another person and one that has special needs?”

“Everyone says ‘go get respite care’ but respite sitters are \$25 an hour- that is not an expense we can do.”

*Kids:*

“It has affected our family planning. We are most likely not having children because we have to care for my sibling in law.”

*Living Arrangements/ Caregiving:*

“It has affected our choices of career and where we live because we have been planning ahead for the time when we will take on primary care taking responsibility for my spouse's sister.”

<p><b>Marriage Considerations</b> 35% (28/80)</p>	<p>“In general, the presence of a sibling-in-law with a disability has brought me and my wife closer.”</p> <p>“Exhausting, time consuming leaving my spouse too exhausted to expend time with me.”</p> <p><i>Communication with Spouse:</i> “I knew about my spouse's sibling and her importance to my spouse from day 1, she was always part of ‘the package’.”</p> <p><i>Being Supportive:</i> “Be more proactive about finding ways to support and help. My spouse has, at times, felt unsupported because I was waiting for her to ask me for help, when I should have been more proactive in figuring out what help is needed and offering to do it.”</p>
<p><b>Positive Internal Growth</b> 27.5% (22/80)</p>	<p>“Being the spouse of someone with a disability has really helped me learn patience and compassion.”</p> <p>“It's taught me to be more compassionate and caring toward people. It's taught me to appreciate life.”</p>
<p><b>Positive Statements</b> 22.5% (18/80)</p>	<p>“[He] has had a great impact on our lives in a very good way. I wasn't prepared for any of it, I didn't expect much of it but we have certainly enjoyed all of it.”</p> <p>“It is a world expanding experience.”</p>
<p><b>Negative Statements</b> 13.8% (11/80)</p>	<p>“...things with my brother-in-law just keep getting worse. I would've expected us to hit bottom at some point over the last decade, but it only ever gets worse.”</p> <p>“The whole family loves her, and they'd never say otherwise, but overall, she just makes life a lot more difficult.”</p>

Figure 1.

Aspects of positive internal growth by sibling-in-law outcome groups.

