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INTELLECTUAL DISABILITY (Y LUNSKY, SECTION EDITOR)

Caregiving Experiences and Outcomes: Wellness of Adult Siblings of People with Intellectual Disabilities

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Abstract

Purpose of Review The goal of this paper is to explore the wellness of adult siblings of people with intellectual disabilities (ID) related to caregiving experiences and outcomes, supports for siblings, gaps in the literature, and future directions to advance research in this area.

Recent Findings Findings are shared from the literature on caregiver experiences of adult siblings of people with ID with a specific focus on outcomes related to wellness. Overall, siblings of people with IDD have positive outcomes in childhood while increased anxiety may happen in adolescence; outcomes for adults are mixed and need greater exploration.

Summary First five outcome areas are described related to wellness of adult siblings of people with ID: (1) impact on health and well-being, (2) financial impact, (3) cultural context, (4) sibling relationship quality, and (5) future caregiving. Secondly, supports that enhance wellness for siblings of adults with ID are discussed including peer/emotional support and knowledge of services and supports. Thirdly, gaps are identified and critiqued with ideas shared about ways to address the gaps in future studies such as investing in interventions that include and target adult siblings of people with ID to enhance wellness. Finally, future directions are proposed to advance sibling disability research in order to improve the wellness of adult siblings of people with ID and their families, including the value of doing research with a Disability Studies perspective.

Keywords Siblings · Families · Family support

Introduction

The longest relationship of most people's lives is that with their brothers or sisters, and this sibling relationship can impact people's overall wellness. Siblings influence each other throughout life. They can impact each other's behavior, development, thoughts, and much more from childhood through old age [1]. For siblings of people with ID, the relationship often encompasses various roles and responsibilities related to providing support. Most of the sibling disability research has focused on the experiences of children, though there is a growing body of work on adulthood. Overall, research does not show a negative psychological impact of having a sibling with disabilities. For some siblings, there are many positive aspects to the experience, while some siblings do experience detrimental effects; however, most siblings have a mix of both [2, 3]. It is important to try to learn how to better support the wellness of all siblings and how to enhance the positive aspects of sibling relationships throughout the life course. For siblings who are having a difficult time, there can be a negative impact on the individual, their sibling, as well as their sibling relationship. Therefore, it is important to target the specific needs of siblings who are struggling and learn how to help them [3].

Siblings contribute to each other's socialization and development [1, 4]. Siblings are often the first peer relationship children have and they learn relationship skills that spill over into friendships that they develop [5]. Young siblings often experience typical emotions toward their brothers and sisters with ID. For example, there may be times of jealousy if they perceive their sibling is receiving more attention; simultaneously, some siblings may feel guilt at their negative feelings

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toward their brothers and sisters with ID. Non-disabled siblings may also experience embarrassment or annoyance at atypical behaviors of their sibling with ID. Siblings also help foster the development of their brothers and sisters with disabilities through play and social interaction and modeling [6]. One study concerning children with a sibling who experiences severe emotional disturbances found that they often experience high levels of stress. For these siblings, nurturant caregiving (i.e., having a caregiver that is warm and understanding) was the strongest predictor of positive adjustment for siblings, even after taking into account stressful events and resources in families [7]).

Adolescence is a difficult time of transition and identity development for most people. Individuals are going through physical and emotional changes as well as developing their own identity separate from their family and expanding their own social networks [5]. Having a sibling with ID can confound the experience. Studies have shown that adolescent siblings have reported experiencing anxiety and negative feelings related to their brother or sister's behaviors and their parents' accompanying stress [8••]. Across a number of studies, behavior challenges of a person with disabilities are associated with negative effects for non-disabled siblings [9]. Negative outcomes of siblings in adolescence may be due to embarrassment about their brothers' and sisters' behavior in public, fears about the future and their role, or other factors; this area needs more research to better understand the impact on sibling wellness in adolescence [10].

Research on adult siblings of people with ID has grown, although there is still much more to learn. For example, one of the only longitudinal datasets on adult siblings of people with disabilities comes from Seltzer and her colleagues and has produced numerous research articles about adult siblings. A literature review on adult siblings done in 2010 [11] found 23 studies of adult siblings, while a more recent literature review done in 2017 [8••] found 43 articles on adult siblings, 18 of which were published since 2010. Most studies show that adult sibling relationships with a person with DD seem to have an emotionally close relationship. Factors that impact the relationship include the type and severity of the disability. For example, studies have shown that siblings of people with Down syndrome have closer relationships compared to siblings of people with autism, though the behavior challenges of the person with disabilities seem to have the biggest negative impact on the sibling relationship [8••]. The personal and professional life choices of siblings may be impacted by their experience having a brother or sister with disabilities. One large, web-based sibling survey found that women with a brother or sister with disabilities are less likely to marry, though when they do marry, they have a lower rate of divorce and they often delay having children by several years compared to the general public [12]. In a literature review by Heller and Arnold [11], mixed results were found for sibling impact on career aspirations. A more recent literature review by Hodapp and colleagues [8••] found that it may be that only some siblings feel their sibling experience impacted their career choices, specifically female siblings who were older, had a closer relationship with their brother or sister with disabilities, and were the only other sibling in the family.

The longevity of the sibling relationship often takes on new meaning for siblings that have responsibilities associated with providing support and caregiving, which has implications for wellness. Siblings are projected to become one of the fastest growing groups of family caregivers in the future [13]. Also, people with disabilities are living longer, so this extends the caregiving role, which often transitions to siblings as parents age. Siblings may juggle multiple caregiving roles for their aging parents, their own children, as well as their brother/sister with disabilities. The competing care needs of the people in the sibling's life can be challenging and can impact the overall wellness of the sibling caregiver [11, 14].

Family Systems Theory

This article takes a family systems theory approach to view siblings of people with ID through a holistic lens and in the context of their families. Family systems theory is an applicable theory to provide an overarching framework with which to view the sibling relationship across the life course. The family is a complex and dynamic system that is ever changing. Individual family members are interdependent and they exert influence on one another synergistically all the time [15, 16]. Family systems theory looks at the way each family member is nested in the larger context of the family [15]. Most families are organized as hierarchical systems with parents on top and each relationship as a subsystem within the larger system [16]. Cox and Paley emphasize the value of using a family systems approach in research to examine numerous levels of influence on the family, the reciprocal nature of the relationships as well as the greater forces at work [16].

Since siblings are part of family systems, their relationships with each other impact other members in the family and vice versa. For example, when parent relationships are poor, siblings may not get along with each other as well. If parents are experiencing marital difficulty, this creates stress on the entire family system. This family stress can impact the siblings' relationships [5]. By examining families as a system with processes that change all the time, the numerous forces and influences that impact families can be studied to learn how these dimensions affect wellness [16].

Family Caregiving and Wellness

Caregiving for a family member often has a detrimental impact on the caregiver's physical and emotional health and can create a financial burden [17]. Mothers of children with ASD have higher rates of emotional distress as well as physical health problems in comparison to parents of children without disabilities [6, 18]. A study of caregivers of adults with IDD found a higher prevalence of health-related issues compared to the general population, such as increased rates of arthritis, high blood pressure, obesity, and activity limitations for the caregivers [19]. However, even with higher health challenges, these caregivers perceived their own health as better than that of caregivers in the general population. Additionally, family caregivers of people with ID may experience financial hardship as a result of reducing, forgoing, or losing their job due to their caregiving role [20]. Therefore, there is a mixed picture of the overall wellness of family caregivers. While there is a large research literature on caregiving outcomes for parents of people with ID, there is little research on the health and wellness of siblings of adults with ID.

Outcomes for Siblings of Adults with ID

Health and Well-Being Impact As with mothers of adults with ID, the health and well-being of siblings may be impacted by having a brother or sister with ID. Studies have shown mixed outcomes. In a literature review of 23 studies, Heller and Arnold found that there were mixed results concerning psychosocial outcomes for siblings of adults with ID [11]. Eight studies reported positive outcomes which included reports of good health, low depressive symptoms, and positive feelings about their sibling relationship. Five studies showed negative outcomes including greater pessimism of siblings compared to parents, more family distress reported, and more negative feelings toward their sibling relationship. In studies comparing sibling groups by type of disability, it was found that having a sibling with autism [14] or mental illness [21], compared to ID, had a greater detrimental effect on the non-disabled sibling in terms of health and depressive symptoms. A mixed methods study of 112 family caregivers, including 24 siblings, found that caregivers attributed a number of difficulties that they experienced specifically to their caregiving role, including impacts on emotional well-being, problems sleeping, back problems, being physically tired, and weight issues [22].

One of the biggest influences on sibling well-being seems to be related to the behavioral challenges of the brother or sister with disabilities and the impact these behaviors have on the entire family [23, 24]. Better coping and problem-solving skills have been associated with better well-being for siblings [25].

Financial Impact Caregiving often has a negative financial impact on family caregivers, including siblings [25]. Sonik, Parish, and Rosenthal used a nationally representative dataset to examine the material hardship of sibling caregivers of people with IDD [26]. They found that sibling caregivers were more likely to experience material hardship and have low income (i.e., make less than $48,060 for a household with two people), live in households that experienced some food insecurity, and receive public benefits. Additionally, these researchers found a possible correlation between education level and caregiving and reported that siblings who had lower levels of education seemed to provide more caregiving [26]. Hodapp and colleagues [8••] literature review from found mixed results for studies comparing the education level and employment status of siblings of people with disabilities.

Cultural Context The cultural context of caregiving is important to take into account since it can also influence aspects of health and wellness [13, 25, 27]. The culture of the family and the way that the parents understand disability can influence the way siblings are taught to respond and interact with their brothers/sisters with disabilities [6]. The culture and ethnicity of families influence the meaning they ascribe to disability and shapes the way they think about caregiving roles [13]. Most studies that examine minority caregivers of adults with ID have found poorer health when compared to white caregivers [28, 29•]. This includes more chronic health conditions, limitations due to health conditions, and lack of appropriate health care [30, 31]. There is little research on the impact of having a sibling with ID on siblings who are from minority racial ethnic populations.

Impacts on Sibling Relationship Quality There are also some factors that affect the quality of the sibling relationship for brothers and sisters with and without disabilities. In Heller and Arnold's literature review, the sibling relationship quality was impacted by numerous factors [11]. Ten of the studies found the majority of non-disabled siblings sampled reported a positive relationship with their brother or sister with ID. The factors that contribute to relationship quality include the type and degree of disability, the gender and age of the person with disabilities, and the geographic proximity. For example, a few studies found that siblings with a brother or sister with Down syndrome tended to report a more positive relationship with their sibling than siblings of people with autism or mental illness.

Future Caregiving Most studies show that siblings of adults with ID anticipate a future caregiving role as parents age [11, 32–34]. More often, sisters anticipate a greater caregiving role in the future than do brothers [8, 11, 32, 35]. Siblings are more likely to consider a future role when (a) they are the only other sibling, (b) they have a closer relationship with their brother/sister with disabilities [35], (c) their mother is in poor health, and/or (d) they have a sister with a less severe level of disability [11]. Predictors of future caregiving include closer geographic proximity, when the person with ID is female, having more sibling contact, providing more support to their brother/sister with disabilities, and having a more positive feeling about the rewards of caregiving [34]. With increased caregiving roles, siblings will likely need increased supports.

Supports for Siblings

There is very little known about what supports contribute to wellness for siblings of people with ID. In adulthood, peer/emotional support as well as information about services and support are two areas of need paramount in the research that may enhance overall wellness for siblings of people with ID [36].

Peer/Emotional Support Emotional support received from peers can enhance the well-being of sibling caregivers. In a number of studies, siblings have expressed a need for peer support [34, 36, 37]. For example, in qualitative interviews with siblings of people with ID, siblings expressed the value in connecting with other siblings of people with ID for peer support [37]. This includes participating in sibling support groups, attending sibling conferences, and being part of online communities for siblings. Benefits reported include receiving information from a peer perspectives that is especially relevant to their role as well as receiving emotional support through empathy of shared experiences. These types of connections fill needs that siblings report that their families cannot.

Affiliation with sibling groups like the Sibling Leadership Network (SLN) can foster peer support for siblings [25, 36]. The SLN is a US nonprofit dedicated to providing siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families [38]. The SLN currently has over 6000 members and 26 states with sibling chapters where adult siblings can connect with siblings in their state and local areas. There are a number of sibling organizations that have been established around the world. These include The Sibling Collaborative in Canada (http://www.planningnetwork.ca/en-ca/Resources/26822/The-Sibling-Collaborative), Sibs in the United Kingdom (www.sibs.org.uk), and Siblings Australia in Australia (siblingsaustralia.org.au). Through increased awareness of the importance of sibling support, more sibling groups and networks are being established to provide spaces for siblings to connect with each other and receive emotional and peer support from people who likely share similar experiences and can understand and empathize with each other.

Knowledge of Services and Supports Information is a top need expressed by adult siblings and a lack of knowledge may contribute to greater anxiety. Knowledge of and ability to access services may address some of the emotional needs of siblings by helping them to feel less anxious [37]. The needs for different types of information are constantly changing throughout the life of siblings and their families [37]. There are three main areas of knowledge needs for adult siblings related to a current or future caregiving role: (1) how to provide care for their brother or sister with IDD, (2) how to navigate disability and aging systems, and (3) how to get support for themselves.

In a quantitative analysis of 139 adult siblings of people with ID who responded to a web-based survey, respondents reported that information, especially about planning for the future, as well as support groups were central support needs [34]. A further analysis of the same survey used a qualitative approach to analyze the open-ended questions and revealed that the top request of siblings was for support to connect them with peers to share information [36]. Respondents reported that they needed information about how to navigate disability services, support for their caregiving role, and the formal support system to address their needs as siblings. Siblings also requested information and support for their families to plan for the future, such as information on the financial and legal aspects, guardianship transition, and estate planning [36]. There is a lack of coordination between the aging and disability service systems which make navigating services and supports especially challenging for families [33]. The learning curve for siblings is very steep because they have not lived the day to day details over a lifetime the way parents do; yet, information is not always passed down from parents to siblings [36].

Future planning is a process that helps families start the difficult dialog about what the future will hold and facilitates information-sharing between parents and siblings. However, most siblings have not been involved in planning for the future [34, 39] and they express anxiety about what the future holds and are craving information to help them prepare [36, 37]. Engagement in future planning has shown positive outcomes for the wellness of all family members, including decreased family caregiver burden and increased choice-making for people with ID [39].

Research Gaps

More research is needed to further examine the wellness of siblings of people with ID throughout the life course. There are a number of gaps in the research about adult siblings of people with ID that should be understood and addressed in future studies. Much of what is known about siblings of people with ID is based on selective samples that are not representative of the population. Most samples are primarily composed of white people of European descent [11, 14, 21, 33, 37, 40••] and female respondents [33, 36, 37, 40••]. Also, some studies have used Internet-based surveys which tend to attract samples with higher socioeconomic statuses compared to the general population [11, 35]. Self-selection bias is a problem in much of the sibling disability research with the use of convenience samples [23, 34]. Often, the siblings that volunteer to participate in studies are more involved with their brother/

sister with disabilities and more connected to the disability service system [33, 36, 37]. This means that much of the findings are based on samples that are not generalizable to the larger sibling population.

More research is needed to learn about siblings from diverse racial and ethnic groups as well as lower socioeconomic levels and the potential needs specific to these groups that could be targets of support and interventions. It is important to take the cultural context into account for sibling research. Also, research should examine the experiences of siblings who are not involved with their brother/sister with disabilities to understand their choices and outcomes. Finally, the perspective of people with disabilities about their sibling experience is largely lacking [32, 36, 40••]. One published study that did include the perspective of people with ID interviewed eight sibling pairs and primarily focused on the supportive role that siblings play in the lives of their siblings with ID after parents pass away [27]. However, this study was limited to very involved sibling pairs.

Insufficient Interventions There is a huge gap in the sibling disability research concerning interventions for adult siblings of people with disabilities. More interventions can help enhance wellness to support siblings and their families throughout the life course and especially during the difficult time of caregiving transitions. One of the only literature review articles to discuss sibling support interventions for adults reinforced that the few interventions available for adult siblings have not been researched [41•]. Some of the intervention strategies for adult siblings include sibling support groups, conferences for siblings, and training and education for adult siblings. There is no current research on interventions that target only adult siblings of people with disabilities [11]. One of the only research-based interventions in the literature, which was designed to intentionally include siblings along with families of people with disabilities, is *The Future is Now* [39, 42]. Research should examine the effectiveness of current interventions for adult siblings and help develop new interventions that support siblings, especially as they get older and become more involved in caregiving for their brothers/sisters with disabilities.

Targeted interventions to sibling groups with specific needs could be particularly effective in enhancing wellness. For example, since behavioral challenges of the disabled sibling seem to be one of the biggest causes of negative sibling relationships, focusing on positive behavior supports may be the biggest benefit. Also, interventions are likely to be important for caregiving transitions as families age [39]. For older families, future planning interventions may be especially urgent. Starting this process earlier with families can be beneficial so that they have more time as a family to think through preferences and options in order to find the right fit for the person with ID and make decisions that are suitable for all family members.

Disability Studies Perspective Disability Studies provides a new lens to view siblings of people with disabilities and can contribute to the advancement of sibling disability research. Meltzer and Kramer note that this approach can bring out unexplored research questions about siblinghood in exciting new ways [43]. Many of the conceptual models used for family research have looked at the person with disabilities as the “stressor” that impacts the rest of the family, instead of as an actual member of the family [3, 43]. Most of the studies use a medical model approach based on ideas of normativity and compare siblings in typical developing relationships to those with a brother/sister with disabilities. The focus should shift from focusing on diagnostic labels to instead examining the behavioral differences and support needs of siblings. Disability Studies can help change the conversation about siblings of people with disabilities and shed light on new ways to do research with people with disabilities and their families.

The interdisciplinary nature of Disability Studies has trained researchers to think in creative ways about social problems and to uncover solutions that will improve people’s lives.

Collaboration across disciplines can enhance learning in multiple fields. For example, sibling disability researchers have much to learn from researchers in family studies doing work with typically developing sibling relationships as well as from gerontology [44]. By crossing networks and disciplines knowledge about supports and interventions that have been effective with one population could be applied to knowledge about siblings of people with ID.

Conclusion

This paper explored the caregiver experiences and outcomes related to wellness of adult siblings of people with ID. This topic is under-examined and there is a need for more research about the adult sibling relationship. Five factors were discussed that contributed to wellness for siblings. First, a mix of outcomes is shown on the impact on health and well-being with the behavior of the person with ID having the biggest negative impact. Second, caregiving has a financial impact, though there are few studies that examine siblings specifically. Third, the cultural context can impact sibling relationships and should be taken into account for future research. Fourth, sibling relationship quality seems to be influenced by factors such as the type and degree of disability, the gender and age of the person with disabilities, and the geographic proximity of the siblings. Fifth, future caregiving, both anticipated and current, can impact the sibling relationship and increase the need for support. However, there is not much research on the supports that enhance wellness for siblings of adults with IDD. Two areas of potential support were discussed including peer/emotional support and knowledge of services and supports. Gaps in the sibling disability research were identified including the lack of diverse samples in sibling disability research and the need for more representative samples for greater generalizability to the larger population. Additionally, there are no intervention studies specifically for siblings of people with ID and few interventions that include siblings. Future directions for research include investing in interventions as well as incorporating a disability studies perspective in future research.

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Compliance with Ethical Standards

Conflict of Interest Catherine Keiling Arnold is the Executive Director of the Sibling Leadership Network. Tamar Heller serves as board member of the Sibling Leadership Network.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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