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INTELLECTUAL DISABILITY (Y LUNSKY, SECTION EDITOR)

Promoting Wellness in People with Intellectual and Developmental Disabilities Through Relationships

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Abstract

Purpose of Review Social ties are essential to the health and wellness of people with intellectual and developmental disabilities (IDD); however, a better understanding of factors that promote and support the development of social relationships is needed to develop effective policies and interventions to promote wellness.

Recent Findings Three factors that influence the formation and maintenance of social ties for people with IDD are individual capacity, interpersonal supports, and organizational or community supports.

Summary The benefits of a strong social network and the dangers of isolation have been well established in people with and without IDD. Yet, there is a lack of research and planning around how best to support people with IDD in developing and maintaining social relationships. Policy and organizational changes as well as increased research attention is needed to promote the health and wellness of people with IDD by nurturing relationships.

Keywords intellectual disability · developmental · disabilities · wellness · health · social · relationships

Introduction

Social connection is essential to health and wellness [1, 2]. Relationships have a profound impact on morbidity and mortality such that people who are less socially integrated have a higher risk of negative health outcomes including poor mental health, cardiovascular disease, and compromised immune function [3–9]. In contrast, people with strong and supportive relationships with family, friends, or even acquaintances have better physical and mental health, suffer fewer negative consequences following stress, and report higher levels of subjective well-being [10–17]. Relationships serve many functions (e.g., tangible support, emotional support) that contribute to health and happiness. While the evidence documenting the importance of social ties to well-being is vast, there are still some minority groups who are likely to lack social connectedness and experience high levels of loneliness and isolation. One such group is people with intellectual and developmental disabilities (IDD).

Similar to people without disabilities, close social ties have been linked to an increased quality of life and decreased odds of depressive symptoms for people with IDD [18, 19]. On the other hand, loneliness and a lack of social ties have been associated with an increased risk of having a diagnosis of mental illness [20]. Social bonds and relationships have also been conceptualized as an essential component of social inclusion. Simplican, Leader, Kosciulek, and Leahy [21] proposed that social inclusion is comprised of two main domains, interpersonal relationships and community participation. With-in each of these domains various characteristics such as category, structure, and function vary. For example, interpersonal relationship can be with staff, family, or people with or without disabilities. Each relationship may vary in intimacy, from a close partner to a neighborhood acquaintance. This model captures the idea that true social inclusion cannot exist without interpersonal relationships.

While social ties and networks have been shown to be an important component of well-being, research suggests people with IDD face barriers to forming and maintaining relationships. These barriers are apparent in childhood and continue into adulthood. Children with IDD are more likely to report being lonely, having fewer friends and participating in fewer

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social activities compared to children without disabilities [22, 23]. In comparison to people with physical disabilities, adults with IDD report receiving more support from paid staff and family and less from friends [24, 25]. Paid staff are certainly an important source of social support for adults with IDD; in fact, staff practices may be closely associated with quality of life [26]. However, relationships with paid staff are likely to be transient and lack reciprocity. In a thematic synthesis of qualitative research, Fulford and Cobigo [27] found that people with IDD want more close relationships and want to spend more time with friends and romantic partners. Two studies pulling from state and national samples found that people with IDD were more likely than people with other disabilities or people without disabilities to report loneliness and a lack of close social bonds [28, 29]. In their systematic review of leisure activities, Verdonschot, de Witte, Reichrath, Buntinx, and Curfs [30] found that adults with IDD primarily engaged in solitary and passive activities such as resting, watching TV or movies, and listening to the radio and records. They concluded that adults with ID may need support to engage in community activities that offer relationship opportunities.

While research demonstrating the positive impact of social ties is clear, an understanding of both the barriers and the factors that promote the development of social relationships is sorely needed. A better understanding of the complex factors that support or inhibit people with IDD to develop social ties will help to develop effective policies and health promotion interventions. This paper highlights three factors that we believe influence the formation and maintenance of social ties for people with IDD; individual capacity, interpersonal supports, and organizational or community supports. We will end with opportunities for researchers and providers to enhance the social networks of adults with IDD.

Building Individual Capacity

One way to support people with IDD in growing and improving their social circles as well as reducing loneliness may be to provide interventions that increase personal capacity. This can include interventions that focus on improving social skills and teaching about healthy relationships. While people with IDD need opportunities to develop relationships, they also need the skills and confidence to take advantage of those opportunities and the knowledge to avoid unhealthy or coercive relationships [31]. Knowledge and skill building surrounding healthy relationships should start in childhood and continue in an age-appropriate fashion throughout the lifespan. People with IDD are particularly susceptible to unhealthy relationships starting in childhood during which they are more likely to think that friendship involves giving items or doing things for others [23]. They are also more likely to be victims of sexual abuse and partner violence throughout their lives [32].

Skill-based interventions may be one way to build social skills and to develop an understanding of healthy versus unhealthy relationships. There have been a variety of studies exploring skill-based interventions for children with IDD, the majority of these interventions have focused on social problem solving, social skill building, and self-management but lack an emphasis on healthy relationship skills [33]. For adults, one cognitive-behaviorally based group intervention targeted skills such as emotion recognition, trust, and negotiation and found an increase in participant's self-concept as well as an increase in reported friendships [34]. Similarly, a friendship and dating program developed to decrease partner violence and increase social skills for developing healthy relationships, found that participation led to an increase in network size as well as decreases in interpersonal violence [35, 36]. While the results of these programs have been promising, these studies are limited by small sample sizes, lack of generalizability, and lack of strong methodologies.

Structured interventions have been designed to directly increase the size and strength of social networks. For example, one study evaluated a group intervention named "I know them!" that was based on a person-centered planning approach [37]. Both individuals with IDD and their support person participated in seven group training sessions that covered current supports, neighborhoods, talents and interests, and making a plan for the future. Both staff and participants reported that this intervention resulted in increased awareness of the importance of social networks, increased feelings of self-awareness and autonomy, and positive changes in social networks for some participants [37]. A qualitative study of a structured social group formed to increase the ability of people with IDD to form friendships with people outside their immediate circle, found that this group improved health and well-being, expanded the size of people's social networks, and fostered a sense of belonging [38]. These approaches, while showing some promise, have not benefited from strong methodological designs. Additionally, many of these interventions rely on staff or family member participation to provide essential supports to help maintain the new relationships and facilitate attendance of events and activities.

Support Persons

The social circles of people with IDD are largely comprised of family members and paid staff members. In addition to providing social support directly, families and paid staff play a facilitative role in the relationships of people with IDD by helping to explore events and activities, visit friends or family, or use community resources such as parks, restaurants, and gyms. Support providers facilitate social relationships for children and adults with IDD by arranging social opportunities, offering social skills guidance, and providing encouragement to establish and maintain friendships. Paid staff also have a crucial role in helping adults with IDD maintain relationships with family members with whom they no longer live. The following paragraphs discuss how both family members and paid staff function in the social circles of adults with IDD.

Perhaps the most important source of support for adults with IDD is their family. According to the 2017 State of the States [39], 71% of individuals with IDD live with family caregivers. Families have the responsibility to support their sons and daughters often without guidance, programmatic assistance, or financial resources from the formal service systems. One study found that while parents of children with IDD recognize the importance of friendships and feel that close relationships positively impact their child's quality of life, they also note that much of the burden for maintaining and supporting those friendships fall to the family [40]. As children with IDD become adults, they often have close relationships with family members [41] characterized by the exchange of support and emotional involvement, especially through difficult experiences such as a break-up [42]. Adults with IDD living with family often engage in many social and recreational activities with their parents and may count their parents' friends among their own [43]. Unfortunately, adults with IDD who live with family have smaller social networks, many having no friends outside of the family [25, 28, 43]. These social circles tend to become smaller and less diverse as adults get older [44, 45]. Currently, 24% of family caregivers are aged 60 or older, making shrinking social networks a real concern [39].

Siblings are an important source of support for many adults with IDD. In describing their relationship with adult siblings with IDD, siblings without disabilities describe strong emotional bonds and low levels of conflict, a pattern that strengthens as the sibling pairs age into adulthood [30, 31, 46]. Assuming caregiving responsibilities for their sibling with IDD fostered emotional closeness with that sibling as indicated by affection, reciprocal sharing, and mutual admiration [47]. Kramer, Hall, and Heller explored reciprocity in sibling relationships and found that adults with IDD enacted their family roles (e.g., as aunt or uncle) in exchange for typically developing siblings leveraging their social capital to improve social inclusion and advocate on behalf of their siblings with IDD [48].

The role of paid support staff is complex and largely unique to adults with IDD. For people living outside their family home, paid staff may be a primary source of social support as well as facilitating relationships with friends and family. Paid staff may function as individual sources of support (e.g., "Mary, my staff, helped me when I was nervous") and may also function as an extra-individual source of support whereby the individual with IDD report support from staff as a role apart from the individuals serving in that role ("staff help me at work") [49]. Many adults with IDD count paid staff among their friends and value relationships with staff over relationships with other individuals with IDD [35]. This preference is a concern insofar as relationships with paid staff are rarely reciprocal nor are they reliable given and the alarming rate of staff turnover [50]. Although adults with IDD have a right to define important relationships in their lives [51], the tendency to misperceive friendly gestures as friendship could increase their risk of disappointment, abuse, and exploitation from staff or other "friends" [52, 53]. These findings point to a need and a primary prevention opportunity to prepare children and adults with IDD to recognize and participate in reciprocal relationships. While typically developing adolescents report friendships that were characterized by moderate-to-high relationship warmth and closeness, only about half of adolescents with ID described friendships that were warm/close or positively reciprocated [54, 55]. Taken together, these findings point to opportunities to prepare children and adults with IDD to foster and maintain reciprocal social networks.

In addition to being a source of social support, paid staff are also often a primary provider of instrumental supports (transportation, planning, phone calls) that enable people with IDD to access their community and develop and maintain interpersonal relationships. Quality and stability of staff persons may influence the social outcomes of people with IDD for whom they provide supports. Friedman and Rizzolo [56] found that people who had paid staff that were respectful and stable were four times more likely to report having friendships and being able to see their friends. Bigby [57] conducted a longitudinal study of informal social networks among adults moving from a large institutional setting to a community-based setting. Many barriers were identified that limited family contact following the move including a decline in parent's health and retirement; however the barrier cited most often was related to staff turnover. Family members reported that staff were rarely available to support visits and described difficulty in establishing relationships with ever-changing staff.

Despite the clear impact that staff can have on supporting adults with IDD to develop and maintain their social ties, paid staff do not always see this as an essential component of their job. McConkey and Collins [58] found that less than 50% of staff surveyed reported that tasks that promote the formation and maintenance of social ties were a high priority for their role. Staff that worked part-time, in day programs, or as direct care professionals were more likely to say that these tasks were not applicable to their job role. Even when staff members place value on promoting social ties, they report a variety of limiting factors ranging from characteristics of the individual's social network (i.e., too small or complex) to systemic issues such as lack of funds and time [37].

Community Supports

Sports

One example of community supports that promote social engagement is Special Olympics' Unified Sports program. The

Unified Sports program brings together athletes ages 12–25 with and without IDD to train and compete on sport teams. The two main goals of this program are to develop social inclusions and to facilitate participation in sports. In 2016, nearly 1.4 million people took part in a Unified Sports program across the globe either as an athlete or a supporting partner (http://annualreport.specialolympics.org/). These teams were formed through schools, Special Olympic clubs, and mainstream athletic clubs. McConkey et al. [59] conducted a qualitative study with participating athletes, coaches, and community partners across five European countries to explore factors that contributed to the goal of social inclusion through participation. One factor that was noted to increase social inclusion and friendship was the sense of inclusive and equal bonds. Participants noted that coaches actively encouraged the development of friendships between athletes was a facilitating factor [59].

Social Programs

The Next Chapter Book Club [60, 61] was developed to encourage friendship and lifelong learning in adolescents and adults with intellectual and developmental disabilities. Next Chapter Book Clubs provide opportunities for people with IDD to meet once a week to read together, learn to read, talk about books, and make friends in a relaxed, community setting. The Next Chapter Book Club: a group of five to eight adults with IDD, regardless of their reading skills, gather with two volunteer facilitators in a local bookstore, coffee shop, or cafe to read aloud and discuss a book for 1 h a week. Strategies are used to support members based on their communicative and literacy abilities including encouraging members to take turns, to respond to one another, and treating events in books as bridges to stories about member's lives. Similar to the Next Chapter Book Club, the Beyond Words Book Clubs provide a social setting in which adults with disabilities can enjoy reading together from the Books Beyond Words series and make friends. Local libraries often host these book clubs and start-up materials are made available to assist new groups in forming. These book clubs are low cost programs that can be adapted to many community settings and provide meaningful opportunities for adults with IDD to develop friendships [62].

Conclusions

Opportunities

While research highlighting the benefits of a strong social network and the dangers of isolation has been studied in people with and without IDD, there is a lack of research and planning about how to best support people with IDD in developing and maintaining meaningful relationships. Based on this review, the following suggestions for changes at the research, organizational, and policy level are recommended.

Research on relationships for people with IDD is still very limited and largely qualitative in nature. While qualitative studies provide essential insights and experiences of people with IDD, research is needed to rigorously examine outcomes of different interventions and policy changes to determine best practices. Additionally, social well-being and relationship research in the IDD field has relied almost exclusively on input from proxy reporters such as staff, parents, and siblings. This is despite the growing body of literature highlighting the discrepancies between self and proxy report for subjective factors such as social support [63, 64]. The input of people with IDD is critical to understanding their needs and preferences. The perspective of adults with disabilities themselves must inform future research on health outcomes and interventions related to social ties and relationships. Research is needed that explores methods and technologies to allow people with IDD to provide input about their social relationships and well-being.

At the organization level, staff training is needed to build capacity and understanding of the importance of social contact for adults with IDD. Venema, Otten, and Vlaskamp [65] found that staff's attitudes, experienced competencies, and professional identity predicted their commitment to facilitating relationships and community inclusion. Bigby [57] suggested assigning responsibility to paid staff. In this view, a skilled inclusion/relationship worker would be responsible for mapping individuals' family constellations, creatively tackling the continuing engagement of families, as well as developing individual strategies for fostering friendships. This idea is also supported by Friedman and Rizzolo [56] who found that "When organizations know the person's preference and need for friends, people with IDD have 15 times higher odds of having friend outcomes. When organizations provide support to assist people with developing, maintaining, and enhancing relationships, people with IDD are approximately 30 times more likely to have positive social outcomes". It is not surprising that when organizations provide in-depth training and supports for staff or community volunteers, positive change happens as exhibited by participants in the Unified Sports program citing coaches an important facilitator of social bonds [58, 59]. These qualitative studies show that staff, coaches, and other support persons are essential to helping people with IDD establish, navigate, and maintain relationships. Organizations can prioritize providing supported opportunities for people with IDD to spend time with their friends, family, or other important social connections.

At the policy level, IDD services are often individualized to the needs and preferences of the individual receiving services through what is sometimes termed an Individualized Support Plan (ISP). Ideally, this plan is developed in a person-centered manner with the individual with IDD at the core and with input from parents and others in his or her circle of support

[66]. An ISP is a written document that identifies what a person wants to do in his or her daily life and what support he or she needs to do it [67]. Furthermore, it contains specific goals and active strategies for the person. As we have discussed, social contact is essential to well-being and quality of life; however, few plans had specific goals or strategies relating to contact with family or friends [68]. Small changes in the ISP planning process, such as connecting people with IDD to community organization that provide social opportunities, could affect meaningful change for adults with IDD. The DD service delivery system could develop and incorporate active strategies to support health promotion initiatives including nurturing and building informal social networks for these adults [37, 68, 69].

Policy changes are sorely needed to address the ongoing staffing shortage in the IDD service field. Friedman and Rizzolo [55] found that high staff turnover resulted in fewer relationships for people with IDD. Sadly, a recent study found the DSP turnover rate was 44.8% per year and the average vacancy rate to be 9.4% among DD provider organizations [50]. This workforce failure must be addressed for the health and well-being of adults with IDD. Additionally, it should be noted that families are the main providers for people with IDD and receive very little support [39]. Prioritizing the social well-being of adults with IDD necessitates ongoing support for their families and opportunities to build and maintain a rich social network. In considering policy opportunities to promote social ties for people with IDD, it is important to remember the many adults with IDD in our communities who have neither close family nor support from the developmental disability system.

Because strong social ties have a significant impact on physical health, mental health, and quality of life outcomes, it is important to give research and policy attention to groups that are vulnerable to social isolation, such as people with IDD. Though intervention and policy research is emerging, it is yet to receive the widespread attention of other aspects of health and wellness. We believe that strong social networks are essential to health and well-being and deserve to be recognized as a core component of well-being and social inclusion for people with IDD. We encourage researchers, policy makers, and service providers to effect changes in order to better support people with IDD to develop and maintain the social ties essential for health and well-being.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interests.

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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