Intimate Relationships of People with Disabilities

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Abstract

Despite the difficulties people with disabilities may have garnering intimate relationships, intimate relationships may be particularly beneficial for people with disabilities as they result in greater self-acceptance, less internalized stigma, and more camaraderie. The aim of this study was to explore the intimate relationships of adults with disabilities (n = 1,443) in its many forms (from intimate friendships to romantic relationships). We particularly explored what factors increased the odds of adults with disabilities having intimate relationships, what supports resulted in increased likeliness to have intimate relationships, and what factors resulted in the presence of favorable intimate relationship outcomes. Our analysis revealed service organizations are key to enhancing the social and intimate relationships of adults with disabilities.

Keywords: people with disabilities; intimate relationships; organizational supports; quality of life

Intimate Relationships of People with Disabilities

> Intimate relationships can be defined as follows:
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> sharing ourselves with another person in a way we would not share with others. Intimate relationships include intellectual, social, emotional and physical components. Intimacy is present when people care and feel deeply about each other… Sometimes intimate relationships result in physical affection and sexuality. Intimacy should not be confused with casual sexual relationships, even though the term "intimate" is often used to mean sexual contact in today's society. Physical closeness is only one aspect of intimacy… Relationships with family and close friends may meet some people's needs for intimacy. Others have a different level of need for intimacy that goes beyond friendships and family ties. (The Council on Quality and Leadership, 2017, p. 58)

Social relationships, especially intimate ones, can enhance ones' quality of life; benefits of social relationships include better emotional well-being, more favorable mental health, increased sense of belonging, stronger self-worth, and lowered stress (Antle, 2004; Fitzpatrick, Newman, Lamb, & Shipley, 1988; Fulford & Cobigo, 2016; Kef, Hox, & Habekothe, 2000; Lafferty, McConkey, & Taggart., 2013; Petrina, Carter, & Stephenson, 2014; Petrina, Carter, Stephenson, & Sweller, 2016; Ward, Atkinson, Smith, & Windsor, 2013). The social support network resulting from intimate relationships can also produce more positive community engagement and community participation, and better conflict resolution skills (Fulford & Cobigo, 2016; Lafferty et al., 2013; Petrina et al., 2014). Petrina et al.'s (2014) study of children with autism found, in children in particular, social relationships can lead to increases in cognitive, social, and emotional development.

Despite the desire for intimate friendships and romantic relationships, people with disabilities face a number of social relationship disparities (Blom, Marschark, Vervloed, & Knoors, 2014; Friedman, Arnold, Owen, & Sandman, 2014; Fulford & Cobigo, 2016; Kef et al, 2000; Nunes, Pretzlik, & Olsson, 2001; Rintala, 1997; Stevens et al., 1996; Wiegerink et al., 2008). One of the largest reasons for these disparities is because of a lack of opportunity to form and maintain intimate relationships (Antle, 2004; Kef et al, 2000; Kreuter, 2000; Marquis & Jackson, 2000; Moin, Duvdevany, & Mazor, 2009). Pottie and Sumarah (2004) even go so far as to describe people with developmental disabilities' social networks as "impoverished" because of the lack of opportunities they have (p. 55).

Historically, people with disabilities were institutionalized and segregated which limited their opportunities. Although deinstitutionalization of people with disabilities is at an all-time high, a large number of people with psychiatric disabilities in particular remain institutionalized at high rates (Bagenstors, 2012; Braddock et al., 2017; Davis, Fulginiti, Kriegel, & Brekke, 2012; Geller, 2006). For example, approximately half of new nursing home admissions are non-elderly people with severe psychiatric disabilities (Aschbrenner et al., 2011). Institutional settings contribute to the isolation of people with disabilities, and limited opportunities they have to make and maintain intimate relationships. However, people with disabilities who live in the community often face physical and social isolation as well (Rossetti et al., 2015; Fulford & Cobigo, 2016). People with disabilities, even those who live in community-based settings, often have fewer opportunities to meet people (Antle, 2004; Bigby, 2008; Kef et al, 2000; Kreuter, 2000; Marquis & Jackson, 2000; Moin, Duvdevany, & Mazor, 2009; Wiegerink et al., 2008; Wiegerink et al., 2006). For example, people with intellectual and developmental disabilities generally are "most at risk of social isolation" (Simplican et al., 2015, p. 21), and as a result, are

more likely to consider paid support staff as their friends (Asselt-Goverts et al., 2015). In fact, half of the people with intellectual and developmental disabilities surveyed by Bigby (2008) had no friends other than staff. This is problematic as Bibgy (2008) notes, "there was no evidence that residents stayed in touch with staff once a staff member left the house, thus given the high level of staff turnover, it is likely that friendships with staff would be short-term" (p. 151).

While physical inclusion, such as in schools, has led to more opportunities for social inclusion, physical inclusion in itself does not necessarily lead to more intimate relationships for people with disabilities (Bowen, 2008; Wong, 2008). Attitudinal barriers towards disability may also make fostering intimate relationships difficult (Antle, 2004; Gill, 1996; Kreuter, 2000; Moin, Duvdevany, & Mazor, 2009; Taleporos & McCabe, 2003; Wiegerink et al., 2006). Intimate relationships depend on mutual affection and respect – reciprocity (Pottie & Sumarah, 2004) Yet, when Hendrickson, Shokoohi-Yekta, Hamre-Nietupski, and Gable (1996) surveyed approximately 1,200 students without disabilities, the majority said they would become friends with a person with a severe disability only because of 'altruistic' reasons (Wong, 2008). The stigma associated with disability may serve as a serious barrier to developing an intimacy within relationships as there is a lack of mutual respect and reciprocity.

Specific to sexuality, people with disabilities face barriers regarding access to sexual health services and lack of privacy to express their sexuality (Friedman et al., 2014; Taleporos & McCabe, 2003). Attitudinal barriers from staff and agencies supporting people with disabilities may also hinder their ability to have romantic and other intimate relationships (Antle, 2004; Browne & Russell, 2005; Friedman et al., 2014; Gill, 1996; Moin, et al., 2009; Taleporos & McCabe, 2003; Wiegerink et al., 2006). Professionals play a key role in hindering or facilitating

social inclusion and intimate relationships, especially in terms of expanding social networks (Asselt-Goverts et al., 2015; Abbott & Howarth, 2007).

Despite the difficulties people with disabilities may have garnering intimate relationships, intimate relationships may be particularly beneficial for them compared to people without disabilities. According to Chernomas, Clarke and Marchinko's (2008) study of women with psychiatric disabilities, having intimate relationships with other people with disabilities can result in greater self-acceptance, less internalized stigma, and more camaraderie. Moreover, intimate relationships with peers with disabilities may aid people with disabilities as they navigate a world which prioritizes able-bodied people. Friends with disabilities "in a similar situation to oneself can result in sharing information with others who can understand and negotiate the 'system,' whether it is formal mental health services, social services, and self-help groups, or other networks such as food banks and church groups" (Chernomas et al., 2008, p. 448).

The aim of this study was to explore the intimate relationships of adults with disabilities because of both the importance of intimate relationships for adults with disabilities, and the barriers they often face in terms of opportunities to create and maintain intimate relationships. In doing so, we particularly explored what factors increased the odds of adults with disabilities having intimate relationships, what supports resulted in increased likeliness to have intimate relationships, and what factors resulted in the presence of favorable intimate relationship outcomes. This study analyzed secondary Personal Outcome Measures® (The Council on Quality and Leadership, 2017a) data from approximately 1,400 people with disabilities to explore these relationships, making it one of the largest studies of intimate relationships of adults with disabilities. While most previous research has tended to focus on disability, and either friendship

or romantic relationships, our study recognizes different types of intimate relationships can fulfill the needs of different people. Moreover, based on our review of the literature, we believe our study is the first to examine in depth the role disability service organizations can play in facilitating adults with disabilities' formation and maintenance of intimate relationships.

Methods

Participants

The secondary survey data utilized in this survey were transferred to the researchers with no identifiers; as such the author's institutional research board (IRB) determined it was exempt from full review. Participants were originally recruited over approximately two years (January 2015 to December 2016) through organizations, including local, county, and state governments, in the United States that provide any of the following services to people with disabilities: service coordination; case management; family or individual supports; behavioral health care; employment and other work services; residential services; non-traditional supports (micro-boards and co-ops); and, human services systems. This process resulted in the data from 1,443 adults with disabilities from 21 states (Table 1).

While age, gender, and guardianship status were relatively evenly distributed, the majority of participants were White (73.7%), and utilized verbal/spoken language as their primary communication method (82.3%) (Table 1). The most common residence types were provider owned or operated homes (50.0%), own homes/apartments (21.4%), and family homes (15.5%), with fewer adults with disabilities living in other settings. The majority of participants were single and had never been married (90.4%), with fewer participants single and married in the past (4.4%), or married or in a civil union (3.3%). In terms of daily support needs, the majority of participants (60.0%) had around the clock (24 hour) support. Two other metrics

related to disability severity were complex medical needs and comprehensive behavioral support needs, which impacted 12.1% and 19.8% of participants respectively.

Personal Outcome Measures® Survey

The Personal Outcome Measures® (The Council on Quality and Leadership, 2017a) was developed by the Council on Quality and Leadership (CQL), an international non-profit disability organization, in order to determine the quality of life of people with disabilities, and plan supports to improve individual outcomes. Rather than defining quality in relation to organizational standards, the Personal Outcome Measures® is a set of indicator assessments which focus on person-centered quality of life, including self-determination, choice, self-advocacy, and community inclusion. The current version of the Personal Outcome Measures® includes 21 indicators related to person-centered supports and quality of life of people with disabilities, divided into five factors: my human security; my community; my relationships; my choices; and, my goals. *Human security* includes the following indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people are treated fairly; people are respected; people experience continuity and security; and, people exercise rights. *Community* includes the following indicators: people interact with other members of the community; people live in integrated environments; people participate in community life; and people use their environments. *Relationships* includes the following indicators: people have intimate relationships; people have friends; people remain connected to natural support networks; people decide when to share personal information; and, people perform social roles. *Choice* includes the following indicators: people choose where and with whom to live; people choose services; and, people choose where to work. Finally, *goals* includes the following indicators: people realize personal goals; and, people choose personal goals.

Personal Outcome Measures® administration happens in three tiers. The first step includes certified Personal Outcome Measures® interviewers having a conversation about each of the topics with the person with disabilities, all the while following specific open-ended prompts related to each indicator. In the second step of the Personal Outcome Measures® the interviewer asks someone who knows the participant with disabilities best, such as a direct support professional, follow-up questions about whether supports are in place to help the person achieve their desired outcomes. As the measure is person-centered, if there are any discrepancies between the second interview and the person with disabilities, the person with disabilities' answers are the ones used. In the third phase of the Personal Outcome Measures®, the interviewer completes the questions about personal outcomes and individualized organizational supports based on the information gathered from steps one and two, and observations of the person with disabilities in various settings if needed. Record reviews are completed as the final step to fill in any gaps or verify information. The Personal Outcome Measures® interviewers are required to have at least an 85% reliability rate prior to collecting data (The Council on Quality and Leadership, 2017b).

Originally developed based on focus groups about what really matters to people with a wide range of disabilities, the Personal Outcome Measures® has been continually refined through initial pilot testing, 25 years of administration, commission of research and content experts, a Delphi survey, and feedback from advisory groups (The Council on Quality and Leadership, 2017a). The Personal Outcome Measures® has been found to be reliable and have construct validity (see Friedman, 2017 and The Council on Quality and Leadership, 2017b).

Variables and Analysis

This study particularly focused on the Personal Outcome Measures® indicator "people have intimate relationships." The main variables of this study were "intimate relationships outcomes present" and "intimate relationships organizational supports in place." Following the above procedure, suggested questions for the information gathering discussion with the participant for "intimate relationships outcomes present" included:

- Who are you closest to?
- Is there someone with whom you share your personal thoughts or feelings?
- Whom do you trust to talk with about private concerns and feelings?
- Who is there for you when you need to talk?
- With whom do you share your good and bad feelings?
- Is this enough for you? (The Council on Quality and Leadership, 2017a, p. 59)

Then to determine if the "intimate relationships" outcome was present, based on the conversation participants must: (1.) have intimate relationships; and, (2.) be satisfied with the type and scope of intimate relationships (The Council on Quality and Leadership, 2017a). If they have both of these items, the outcome is considered present; if not, it is considered not present. If the participant does not have intimate relationships due to personal choice the outcome is considered present as well.

To decide if the intimate relationships individualized organizational supports were in place, the interviewer was provided the following suggested question to guide the discussion with the participants' staff:

- Do you know how the person defines intimacy? What is that definition?
- Do you know if the person has the type and degree of intimacy desired?
- How do you support the person's choices for intimate relationships?

- How do you learn about the person's desires for intimacy?
- How do you know if the person needs support to develop or maintain intimate relationships?
- If the person needs support, what has been arranged?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to forming intimate relationships with others?
- What organizational practices, values, and activities support this outcome for the person? (The Council on Quality and Leadership, 2017a, p. 59)

Then to determine if the "intimate relationships" supports were in place based on the conversation, the organization must: (1.) know and understand the person's preferences for intimate relationships; (2.) assist the person to explore and evaluate experiences in order to make informed choices about intimate relationships; (3.) provide support for the person to pursue, form, and maintain intimate relationships; and, (4.) address any barriers to the person having intimate relationships (The Council on Quality and Leadership, 2017a). All of four of these features must be in place for the support to be considered in place.

In accordance with our study's aims, three Personal Outcome Measures® intimate relationship indicator items were then used as dependent variables. Our first dependent variable (DV) was if participants reported having intimate relationships (no (0) or yes (1)). To explore factors that impacted if adults with disabilities had a relationship, binary logistic regression models were performed with this DV (intimate relationship status), and a wide range of independent variables (IVs). We selected IVs after reviewing the literature on disability, and intimate relationships, friendship, and romantic relationships, such as about inclusion,

relationship disparities, and needs, as well as research on the status of people with disabilities and quality of life (e.g., Asselt-Goverts et al., 2015; Barnes & Mercer, 2003; Bigby, 2008; Chernomas et al., 2008; Fulford & Cobigo, 2016; Hendrickson et al., 1996; Kafer, 2013; Kempton & Kahn, 1991; Knox & Hickson, 2001; Lafferty et al., 2013; Linton, 1998; Marquis, & Jackson, 2000; McCarthy, 2014; Ostrove & Crawford, 2006; Tilleya, Walmsleya, Earlea, Atkinsona, 2012; Trent, 1994; Ward et al., 2013; etc.). In addition to the demographic variables described above, IVs included factors about participants' disabilities, living situations, supports, and intimate relationships (Table 1). As the aim was to explore variables with significant relationships rather than build the best model, the IVs were entered separately with the DV in each model. Bonferroni correction (.0015) was used to counteract running multiple models. For models with statistically significant findings, odds ratios were utilized to determine probability.

The second DV of our study asked if individualized supports were in place to facilitate intimate relationships (not in place (0) or in place (1)). To explore factors that impacted if adults with disabilities had organizational supports in place, binary logistic regression models were performed with this DV (intimate relationship supports in place), and the same IVs as previously mentioned. The IVs were entered separately with the DV in each model. Bonferroni correction (.0015) was used to counteract running multiple models. For models with statistically significant findings, odds ratios were utilized to determine probability.

The third and final DV asked if the intimate relationship outcome was present (not present (0), present (1)). (For the outcome to be considered present the person must be have intimate relationships if they want them, *and* be highly satisfied with their present intimate relationships. This distinguished the third DV from the first DV, as the person could be in an intimate relationship but be dissatisfied with that relationship.) To explore factors that impacted

if adults with disabilities had intimate relationship outcomes present, binary logistic regression models were performed with this DV (intimate relationship outcomes present), and the same IVs as previously mentioned. The IVs were entered separately with the DV in each model. For models with statistically significant findings using Bonferroni correction (.0015), odds ratios were utilized to determine probability.

Results

The majority of participants (57.4%) had intimate relationships (Table 1). However, nearly one-third of participants with intimate relationships (27.8%) were not satisfied with the relationships' type or scope. As a result, less than half of participants (45.9%) had intimate relationships outcomes present.

In terms of organizational supports, the majority of the organizations knew the persons' preferences for intimate relationships (58.7%), however only about half provided support for participants to pursue, form, and maintain intimate relationships (50.7%), assisted participants to explore and evaluate experiences in order to make choices about intimate relationships (49.9%), or addressed barriers to intimate relationships (47.5%). As a result, slightly less than half of participants (45.2%) had intimate relationships supports in place (Table 1).

Intimate Relationship Status

In order to determine factors that increased the odds of adults with disabilities having intimate relationships, binary logistic regressions were run between the IVs and intimate relationship status (DV). The binary logistic regressions between the following variables all significantly predicted intimate relationship status: housemates with disabilities; total housemates; comprehensive behavioral support needs; daily support; organization knows preferences for intimate relationships; organization assists participants to explore and evaluate

experiences in order to make choices about intimate relationships; organization provides support for participants to pursue, form, and maintain intimate relationships; organization addresses barriers to intimate relationships; and, intimate relationships - supports in place (Table 2).

Having a comprehensive behavioral support need decreases the odds of having an intimate relationship. Moreover, as the number of housemates with disabilities increases, the odds of having intimate relationships decreases for adults with disabilities. Similarly, as the number of total housemates increases, the odds of adults with disabilities having intimate relationships decreases.

The binary logistic regression models also revealed the large impact organizations can have in regards to intimate relationship status of adults with disabilities. There are significantly higher odds of adults with disabilities having intimate relationships when organizations know their preferences, assist them in making choices, support their relationships, address barriers, and put individualized supports in place for intimate relationships.

Individualized Supports in Place to Facilitate Intimate Relationships

In order to determine factors that increased the odds of adults with disabilities being in an intimate relationship, binary logistic regressions were run between the IVs and intimate relationship supports (DV). The following variables produced significant models with intimate relationship supports in place: marital status; residence type; housemates with disabilities; housemates total; daily support; not in relationship by personal choice; organization knows preferences for intimate relationships; organization assists participants to explore and evaluate experiences in order to make choices about intimate relationships; organization provides support for participants to pursue, form, and maintain intimate relationships; organization addresses barriers to intimate relationships; and, intimate relationships - supports in place (Table 3).

There was a significant relationship between residence type and intimate relationship supports being in place. Adults with disabilities who lived with host families/family foster care, provider-operated homes, private-operated intermediate care for adults with developmental disabilities (ICF/DD), or state-operated Home and Community Based Services (HCBS) group homes all had lower odds of having intimate relationship supports in place than people who live in their own homes or apartments. Moreover, as the number of total housemates and housemates with disabilities increases, the odds of having supports in place decreases.

Those adults with disabilities who are married or in a civil union have higher odds than those who are single and never married for having intimate relationship supports present. Those adults with disabilities who are not in a relationship by personal choice have higher odds of having supports in place than those people who want to be in a relationship. There are also vast increases in odds of supports being in place when organizations know preferences, assist choices, support relationships, and address barriers.

Intimate Relationship Outcome Present

To determine factors that increased the odds of intimate relationship outcomes being present (having intimate relationships if they want them *and* being satisfied with their intimate relationships), binary logistic regressions were run between the IVs and outcomes present (DV). The following regression models had a significant relationship with intimate relationship outcomes: marital status; residence type; housemates with disabilities; housemates total; daily support; organization knows preferences for intimate relationships; organization assists participants to explore and evaluate experiences in order to make choices about intimate relationships; organization provides support for participants to pursue, form, and maintain

intimate relationships; organization addresses barriers to intimate relationships; and, intimate relationships - supports in place (Table 4).

Those adults with disabilities who are married or in a civil union have higher odds than those who are single and never married for having intimate relationship outcomes present. As the number of total housemates and housemates with disabilities increases, the odds of having outcomes present decreases. There was a significant relationship between daily support and outcomes being present; those with twenty-four hour support have lower odds of outcomes being present than those who only receive support as needed.

Findings also revealed residence type significantly impacts the odds of outcomes being present. According to our findings, those who live in a family home have higher odds of outcomes being present than those who live in their own house or apartment. Meanwhile, those who live with host families/family foster care, and provider-operated homes have lower odds of having intimate relationship outcomes present than people who live in their own homes/apartments.

Again, organizations play a significant role in increasing the odds of outcomes being present. There are significantly higher odds of adults with disabilities having intimate relationship outcomes present when organizations know their preferences, assist their choices, support their relationships, address barriers, and put individualized supports in place.

Discussion

In addition to the general benefits provided by intimate relationships, such as love, comradery, and closeness, intimate relationships are especially fruitful for adults with disabilities as they can help them deal with ableist attitudes, promote a sense of disability community and pride, and support them as they navigate the service system. However, adults with disabilities

often experience fewer opportunities to create and maintain intimate relationships. For this reason, this study explored not only what factors affected the likelihood of adults with disabilities having intimate relationships, but also what types of supports promote positive intimate relationship outcomes.

Mirroring past research about opportunities for intimate relationships, residence type played a role in the intimate relationships of adults with disabilities in our study. We found that those who live with more housemates with disabilities and total housemates are less likely to have intimate relationships, have supports in place, and have outcomes present. This finding is perhaps not surprising as many adults with disabilities have a lack of privacy, particularly for intimate relationships, romantic and otherwise (Friedman et al., 2014; Knox & Hickson, 2001; Taleporos & McCabe, 2003). Knox and Hickson (2001) suggest organizations and support professionals "be cognizant of these issues and ensure that the privacy that they may take for granted in their own lives is afforded to the people for whom they work" (p. 288). In fact, we found living setting significantly related to the odds of supports being in place, and outcomes being present. These findings likely relate to community access. Moreover, while most of the settings produced lower odds than living in ones' own home, our findings revealed living in a family home equates with higher odds of having intimate relationship outcomes present. One reason those in family homes may be more likely to have outcomes present than those in their own houses/apartments may be because of the relationships with their family members in the house. Relationships with their family members in the house may be meeting their needs for intimacy. It is also likely that people living in family homes receive additional support from family members to cultivate and maintain other intimate relationships.

While there were not significant differences between any of the disability types and peoples' likelihood to have intimate relationships, supports in place, or outcomes present, those variables related to severity of impairment were found to have a significant relationship with intimate relationships. For example, those with more complex behavioral support needs are less likely to have intimate relationships those without these needs. Moreover, those who receive more daily support – presumably because they have more severe impairments – were less likely to have intimate relationships outcomes present. While it may be that adults with more severe disabilities have impairments in some of the very areas needed to foster intimate relationships (Bogdan & Taylor, 1989; Kudlick, 2013) making relationships difficult without supports, it is also likely that these disparities are related to historical attitudes and stereotypes about people with disabilities (Browne & Russell, 2005; Chance, 2002; Gill, 1996). Historically, people with disabilities have been denied many rights, such as the right to marry, based on ideas of competence. Some of the earliest constructions of disability in the United States were tied to "a failure of the will" and sexuality of people with disabilities was only acknowledged in the context of pathology (Trent, 1994, p. 16). This pathologizing resulted in institutionalization, and later forced sterilization of people with disabilities across the nation (Kempton & Kahn, 1991; Tilleya et al., 2012; Trent, 1994). As a result, there were not only limited opportunities for people with disabilities to foster intimate relationships, but also systemic conceptualizations of people with disabilities as not capable of or interested in relationships were reinforced (Browne & Russell, 2005; Chance, 2002; Gill, 1996).

Implications for Policy and Practice

Despite deinstitutionalization being at an all-time high, due in large part to a lack of community infrastructure and transinstitutionalization, people with disabilities still face a lack of

opportunities for social inclusion, such as community inclusion or intimate relationships (Braddock et al., 2017; Cullen et al., 1995; Forrester-Jones et al., 2002; Ligas Consent Decree Monitor, 2016, 2017; Ward et al., 2013). Structures, and the policies that support them, need to be changed to address the lack of opportunities people with disabilities face. For example, segregated settings limit people with disabilities' potential and opportunities for community inclusion and by extension social capital. Thus, structural capacity both social and community inclusion need to be expanded and systemic barriers need to be addressed, particularly in accordance with the rights granted to people with disabilities by the Americans with Disabilities Act (ADA), *Olmstead v L.C.,* and the Medicaid HCBS Settings Rule.

Intimate relationships may also hinge on disability service organizations' commitment to them. Our most important findings were about the role organizations play in inhibiting or supporting the intimate relationships of adults with disabilities. To our knowledge, this is the largest study that examines the impact of organizations on adults with disabilities' intimate relationships. Our findings reveal organizations can play a critical role in promoting the intimate relationships of adults with disabilities. Adults with disabilities are vastly more likely to have intimate relationships *and* be satisfied with those relationships (i.e., have the outcome present) when organizations understand their preferences for intimate relationships, assist them in exploring choices about intimate relationships, support them while pursuing and maintaining intimate relationships, and address any barriers related to intimate relationships. For example, we found the odds of intimate relationship outcomes being present are eight to ten times greater when organizations know people's preferences, assist people to make choices, and address barriers. Moreover, the odds of intimate relationship outcomes being present are 20 times higher when organization put individualized supports in place.

Organizations can implement lost cost solutions to facilitate the intimate relationships of people with disabilities. Relying on organizations for services and supports, "often links changes in people's lives to organizational changes. Organizations provide continuity and security for people through the service process" (The Council on Quality and Leadership, 2017a, p. 25). One of the first steps is a cultural shift of the organization which recognizes that people with disabilities, like all people, need intimate relationships. There should be clear policies and procedures that promote healthy relationships. Doing so will help staff understand the procedures and be more comfortable speaking about intimate relationships rather than basing their opinions on assumptions (Abbott & Howarth, 2007). According to one self-advocate "professionals sometimes are scared to talk about it [sexuality] because they don't know what's appropriate and what's not" (Friedman et al., 2014, p. 527). The organizational shift should also include outreach to parents about people with disabilities about rights and responsibilities so that they do not become a barrier.

In addition, organizations can also educate people about intimate relationships, romantic relationships, and sex. People with intellectual disability in particular may benefit from more sex education because they frequently do not receive it (Cuskelly & Bryde, 2004; Dukes & McGuire, 2009; Pownall, Jahoda, & Hastings, 2012). Thus, this education would not only serve as a way to let people with disabilities know that their wants and needs are not taboo – serve to normalize these needs – but also expand their knowledge about healthy relationships. In addition to more traditional forms of sex education about anatomy, sex, and safety, education should cover friendship and reciprocity, respecting others, and online interactions and social media, as all are necessary components of creating and fostering intimate relationships (Browne & Russell, 2005; Moras, 2015; Planned Parenthood of Northern New England, & Green Mountain Self-

Advocates, 2009; Seymour & Lupton, 2004; Ward et al., 2013). It would be especially beneficial for education to be less isolated and incorporate engagement and non-traditional models.

Another way for organizations to support intimate relationships is to get people into the community where they can make connections. Organizations should provide supports so people with disabilities are able to do things that interest them, such as clubs or religious organizations, where opportunities for natural supports and intimate relationships flourish. Finally, organizations also need to consider any individualized accommodations that may be necessary for intimate relationship outcomes to be present. For example, people with certain mobility impairments may need help with positioning during sex or they may need support to figuring out what works best for their body. While not all agencies need to be experts on how to provide these supports, they should be willing and able to connect the person with disabilities with a qualified expert, such as a sex facilitator.

Limitations

A number of limitations should be noted when interpreting our findings, particularly related to our sample. The majority of our participants were White, and had intellectual and developmental disabilities, which is not a representative of the disability community. Our sample was also not representative of the United States in general because while 21 states were represented, the majority of participants were from three states (New York, South Dakota, and Tennessee). Another limitation is that the majority of participants used verbal/spoken language as their primary method of communication; participants using alternative communication methods such as sign language, communication devices, or facial/body expressions may have different experiences with intimate relationships. As this was a secondary data analysis, we did not have the ability to ask additional questions or add additional research variables. Finally,

although Bonferroni correction was used to control for the use of multiple models, Bonferroni correction is a conservative measure.

Conclusion

Intimate relationships can provide people with disabilities the support needed to thrive in the community. As people with disabilities face a plethora of barriers that negatively impact their intimate relationships, such as lack of opportunity or privacy, it is especially important for support professionals, and provider organizations to help promote the creation and maintenance of these relationships. We have found organizations key to enhancing the social and intimate relationships of adults with disabilities, and by extension their quality of life. Our findings demonstrate that agencies must also make these initiatives person-centered and individualized rather than one-size-fits-all in order to maximize equity – to ensure equal access to intimate relationship opportunities for adults with disabilities if they should want them.

While today there are more nuanced understandings of people with disabilities, disability is still intertwined with ideas of "personal pathology, of individual difficulties and of dependency in the face of care" (Goodley, 1997, p. 369). Regarding sexuality and romantic intimate relationships, there are still dominant narratives of women with disabilities as potential victims, and men as potential aggressors (McCarthy, 2014). Therefore, to ensure people with disabilities can have intimate relationships if they should want them, it is not enough to create opportunities; attitudes and stereotypes about disability must be dismantled in policy and practices. Doing so will result not only in a collective understanding of people with disabilities as capable of and interested in intimate relationships, but also more reciprocity from potential social relationships and networks.

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Table 1

Demographics and Descriptive Statistics (n = 1,443)

Variable	*n*	*%*	Variable (continued)	*n*	*%*	*m (SD)*
Age range			Primary method of communication			
18 to 24	101	7.0	Verbal/spoken language	1188	82.3	
25 to 34	269	18.6	Face/body expression	174	12.1	
35 to 44	237	16.4	Other	33	2.3	
45 to 54	290	20.1	Communication device	16	1.1	
55 to 64	267	18.5	Sign language	14	1	
65 to 74	126	8.7	Guardianship status			
75+	40	2.8	Independent decision making	415	28.8	
Gender			Assisted decision making	507	35.1	
Man	763	52.9	Full/plenary guardianship	446	30.9	
Woman	667	46.2	Other	37	2.6	
Disabilities			Residence type	37	2.6	
Intellectual/developmental disability	1341	92.9	Own home/apartment	309	21.4	
Seizure disorder/neurological problems	294	20.3	Family's house	223	15.5	
Mood disorder	202	14.0	Host family/family foster care	25	1.7	
Anxiety disorders	180	12.5	Provider operated house or apartment	722	50.0	
Behavioral challenges	165	11.4	Private ICF/DD	25	1.7	
Other mental illness/psychiatric diagnosis	161	11.2	State operated HCBS group home	43	3.0	
Personality/psychotic disorder	151	10.5	State operated ICF/DD	25	1.7	
Obesity	100	6.9	Other	28	1.9	
Physical disability	96	6.7	Complex medical needs	174	12.1	
Impulse-control disorder	88	6.1	Behavioral support needs	286	19.8	
Hearing loss - severe or profound	63	4.4	Weekly support			
Limited or no vision - legally blind	46	3.2	On call - support as needed	32	2.2	

Other disabilities not listed	46	3.2	0 to 3 hours/day	70	4.9	
Alzheimer's disease or other dementia	31	2.1	3 to 6 hours/day	100	6.9	
Brain injury	30	2.1	6 to 12 hours/day	164	11.4	
Eating disorder	10	0.7	12 to 23 hours/day	82	5.7	
Prader-Willi syndrome	4	0.3	24/7 - around the clock	866	60.0	
Race			Other	50	3.5	
White	1064	73.7	Total housemates			4.47 (3.29)
Black or African American	255	17.7	Housemates with disabilities			3.94 (3.46)
American Indian or Alaska Native	64	4.4	Nondisabled housemates			0.52 (1.22)
Hispanic, Latinx, or Spanish Origin	36	2.5	Intimate relationship status (yes)	828	57.4	
Asian	14	1.0	If have relationships, satifisied with type and scope (yes)	583	72.2	
Other	7	0.5	Intimate relationships outcome present	662	45.9	
Native Hawaiian or other Pacific Islander	2	0.1	Lack of relationship due to personal choice	143	9.9	
Marital status			Organization knows preferences for intimate relationships	847	58.7	
Single, never married	1305	90.4	Organization assists participants to explore and evaluate experiences in order to make choices about intimate relationships	720	49.9	
Single, was married in the past	63	4.4	Organization provides support for participants to pursue, form, and maintain intimate relationships	732	50.7	
Married or civil union	47	3.3	Organization addresses barriers to intimate relationships	685	47.5	
			Intimate relationships - supports in place	652	45.2	

Note. Participants could have more than one disability. ICF/DD = Intermediate Care Facility for People with Developmental Disabilities. HCBS = Home and Community Based Services.

Table 2

Results of the Binary Logistic Regression of Intimate Relationship Status

Model	*-2LL*	*df*	χ^2	Odds ratio (95% confidence interval)
Housemates with disabilities***	1656.63	1	22.68	0.92 (0.89-.95)***
Housemates total***	1661.41	1	16.89	0.93 (0.90-.96)***
Behavioral support needs***	1737.49	1	25.55	0.50 (0.38-.65)**
Daily support (ref: on call - support as needed)***	1681.28	6	29.87	
0 to 3 hours/day				1.01 (0.40-2.59)
3 to 6 hours/day				0.78 (0.32-1.89)
6 to 12 hours/day				1.01 (0.43-2.34)
12 to 23 hours/day				1.61 (0.62-4.17)
24/7 - around the clock				0.55 (0.25-1.20)
Other				0.60 (0.23-1.59)
Organization knows preferences***	1499.57	1	217.08	6.09 (4.74-7.82)***
Organization assists choices***	1491.64	1	220.31	5.97 (4.66-7.65)***
Organization supports relationship***	1457.48	1	235.18	6.44 (5.01-8.28)***
Organization addresses barriers***	1538.94	1	157.64	4.48 (3.51-5.71)***
Individualized supports in place***	1511.95	1	238.49	6.59 (5.10-8.53)***

* p<.05, **p<.01, ***p<.001.

Table 3

Results of the Binary Logistic Regression of Intimate Relationship Supports in Place

Model	*-2LL*	*df*	χ^2	Odds ratio (95% confidence interval)
Marital status (ref: single, never married)***	1813.21	2	20.80	
Single, was married in the past				1.08 (0.65-1.79)
Married or civil union				4.40 (2.17-8.92)**
Residence type (ref: own home/apartment)**	1912.29	7	23.72	
Family's house				0.79 (0.56-1.11)
Host family/family foster care				0.39 (0.16-0.93)*
Provider operated house or apartment				0.65 (0.50-0.84)**
Private ICF/DD				0.32 (0.13-0.80)*
State operated HCBS group home				0.45 (0.23-0.87)*
State operated ICF/DD				1.77 (0.74-4.21)
Other				0.72 (0.33-1.56)
Housemates total***	1839.60	1	28.18	0.92 (0.88-0.95)***
Housemates with disabilities***	1838.32	1	27.69	0.92 (0.89-0.95)***
Daily support (ref: on call - support as needed)**	1855.90	6	22.24	
0 to 3 hours/day				1.31 (0.55-3.10)
3 to 6 hours/day				0.52 (0.23-1.16)
6 to 12 hours/day				0.77 (0.36-1.67)
12 to 23 hours/day				0.83 (0.36-1.91)
24/7 - around the clock				0.52 (0.25-1.06)
Other				0.63 (0.26-1.55)
Personal choice to have no intimate relationship***	552.03	1	96.22	7.89 (5.21-12.26)***
Organization knows preferences***	1081.34	1	720.67	111.68 (60.24-207.06)***
Organization assists choices***	825.49	1	971.11	126.74 (79.83-201.22)***
Organization supports relationship***	779.23	1	999.64	209.41 (116.82-375.38)***
Organization addresses barriers***	911.59	1	869.54	67.64 (46.75-97.86)***

* p<.05, **p<.01, ***p<.001.

Table 4

Results of the Binary Logistic Regression of Intimate Relationship Outcome Present

Model	*-2LL*	*df*	χ^2	Odds ratio (95% confidence interval)
Marital status (ref: single, never married)***	1911.06	2	16.45	
Single, was married in the past				0.91 (0.55-1.52)
Married or civil union				3.56 (1.83-6.91)***
Residence type (ref: own house/apartment)***	1897.61	7	31.45	
Family's house				1.50 (1.06-2.12)*
Host family/family foster care				0.40 (0.16-0.99)*
Provider operated house or apartment				0.72 (0.55-0.94)*
Private ICF/DD				0.69 (0.30-1.58)
State operated HCBS group home				0.77 (0.40-1.48)
State operated ICF/DD				1.84 (0.79-4.28)
Other				0.69 (0.30-1.47)
Housemates with disabilities***	1837.97	1	23.02	0.93 (0.90-0.96)***
Housemates total***	1844.74	1	16.85	0.93 (0.90-0.97)***
Daily support (ref: on call - support as needed)***	1837.77	6	34.67	
0 to 3 hours/day				0.67 (0.27-1.68)
3 to 6 hours/day				0.73 (0.32-1.66)
6 to 12 hours/day				0.85 (0.0.39-1.85)
12 to 23 hours/day				0.75 (0.32-1.74)
24/7 - around the clock				0.40 (0.18-0.83)*
Other				0.68 (0.27-1.68)
Organization knows preferences***	1473.01	1	322.83	10.64 (7.93-14.28)***
Organization assists choices***	1449.37	1	341.52	9.48 (7.31-12.30)***
Organization supports relationship***	1403.21	1	368.97	10.92 (8.34-14.29)***
Organization addresses barriers***	1473.94	1	299.89	8.00 (6.22-10.30)***
Individualized supports in place***	1340.41	1	610.61	19.93 (15.21-26.11)***

* p<.05, **p<.01, ***p<.001.