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Literature Review for Authentic Friendship Grant

Introduction

This document is a summary of recent research related to the importance of friendship in the lives of people with intellectual and developmental disabilities (IDD). Even though researchers have recently been taking the views of people with IDD into consideration, people with IDD still gain little participation in research processes. They are hardly ever included in major disability studies, although they have the right to be involved in issues that affect their lives (Garolera, Díaz, & Noell, 2021). It is crucial that the voices of those with lived experience are amplified and supported to discuss matters that directly impact their lives. One area of interest and importance is the building of authentic friendships and relationships. Relationship building and maintenance are a fundamental part of the human experience, yet opportunities for people with intellectual and developmental disabilities to build authentic friendships are not as abundant and supported as with their non-disabled peers.

Although risk may differ across indicators of social disconnection, currently, studies find the highest prevalence for loneliness and isolation among people with poor physical or mental health, disabilities, financial insecurity, those who live alone, single parents, as well as younger and older populations (The U.S. Surgeon General, 2023). Community involvement plays a significant role in opportunities for authentic friendship building. When people with intellectual and developmental disabilities are present in the community, they are more apt to be recognized by others and become known by people who spend time in the same places. Recognition is an important aspect of social

inclusion that occurs through brief exchanges in public spaces such as friendly acknowledgements, offers to assist or when a person's different way of using a space is welcomed by others. Through repeated encounters of recognition, people with intellectual and developmental disabilities may become known to others in the community and are then able to become acquaintances and develop friendships (Hall, 2017). Community involvement and recognition not only create opportunities to develop authentic friendships, but they help keep people with intellectual and developmental disabilities safe in their communities.

Activities That Support People with ID in Building Relationships

Along with opportunities for people with intellectual and developmental disabilities to build authentic friendships, there needs to be activities that are available that can support these experiences. These activities should not just be available but should also be of interest to the person and they should have choices; not just one option because that is not having choice. The Covid-19 Pandemic altered the way that society was able to have and maintain social contact. Social media became a key source of communication for both people with disabilities and their non-disabled peers. Social media can play an important role in supporting the empowerment and participation of individuals and groups by enabling networking, improving self-esteem, and enabling online campaigning among marginalized groups such as people with disability (Caton & Chapman, 2016). Several examples of benefits include technology that can foster connection by providing opportunities to stay in touch with friends and family, offering other routes for social participation for those with disabilities, and

creating opportunities to find community, especially for those from marginalized groups. For example, online support groups allow individuals to share their personal experiences and to seek, receive, and provide social support—including information, advice, and emotional support (The U.S. Surgeon General, 2023).

In a study that involved research work groups in Spain in 2021 regarding the way of relating, online communication was highlighted as one of the main changes that the pandemic has brought about. The physical distancing imposed during home confinement led to increased use of mobile devices and computers to maintain contact and communicate with others. Participants in the focus groups and interviews explained that they had to learn to use applications and platforms such as WhatsApp, Meet, Skype, or Zoom. They positively valued that this learning, in most cases, facilitated by family members and support professionals, allowed them to maintain contact with their friends and family and continue to engage in the process of learning how to utilize technology to stay connected as well as continue their participation in this study (Puyaltó, Beltran, Coll, Diaz-Garolera, Figueras, Fullana, González, Pallisera, Pujolar, & Rey, 2022).

Garolera, Díaz and Noell conducted a study in 2021 of eleven adolescents (8 boys and 3 girls) with IDD aged between 17 and 19 years old about friendships and the barriers and supports they experience in forming friendships. Regarding the benefits of participating in extracurricular activities, although many of the participants did not carry out extracurricular activities during childhood nor did they carry out leisure activities regularly at the time of the interview, they all agreed that participating in activities with other people could be a good way to meet people and, therefore, to make new friends.

The lack of opportunities for community participation could be an element that hinders the establishment of relationships that could lead to authentic friendships.

While extracurricular activities benefit youth and young adults, they are also important for adults to build and maintain social connections that can develop into friendships. People with intellectual and developmental disabilities should have access to community activities like clubs, sports, entertainment, civic associations, and community events relevant to their interests. Spending time with members of the community who share interests provides opportunities for authentic connections which can lead to the natural development of relationships. Existing literature lacks content from adults with lived experience about activities that are available to them, and those that they feel facilitate the process in forming authentic friendships.

Preferences in Relationship Building of People with ID

In addition to having access to opportunities, the preferences that those with lived experience have in developing relationships should be honored and accessible. During a study about friendships and intimate relationships among people with intellectual and developmental disabilities that was conducted by Fulford & Cobigo, in 2018, three main themes were found. The first being how participants know that someone is their friend, second, how they know that someone is their boyfriend/girlfriend and third, what hinders and helps relationships.

Under the first theme the following indicators were noted: they liked the way the person acts and looks, they like doing things together, they are similar, they can talk to each other, support one another and how friendships made them feel. Under the

second theme the following was noted: they like the way they act or look, they like being together, how relationships make them feel, they support one another, expressing feelings in romantic ways and physical intimacy.

Under the third theme the following was noted: living independently allows greater ability to see friends and intimate partners, safety concerns regarding physical safety or past negative experiences (ex. financial exploitation) presented issues, minimal finances and little control over money restricted them from spending time with intimate partners, access to public transportation to maintaining friendships and intimate relationships, services and programs provide opportunities to meet new people and maintain relationships, staff and family members provide support and advice about relationships, caregivers can restrict choice making within participants' relationships, a lack of privacy due to being accompanied by caregivers on dates and outings and caregivers either provided support or contributed to stress in navigating difficult situations in relationships.

Uplifting and amplifying the voices of those with lived experience about what hinders and helps relationship building is critical. Without this information, building authentic friendships within their respective communities will not be accessible to people with intellectual and developmental disabilities. In the analysis of the available literature and resources on the web there are toolkits and information regarding friendship building and how to foster those preferences for children with disabilities. But there is little information on how to support this process for adults with intellectual and developmental disabilities. Adults with IDD and their non-disabled peers would both

benefit from resources being available to facilitate the process of building and nurturing relationships.

Challenges and Barriers to Building and Maintaining Friendships

There is much information in the literature regarding the challenges and barriers adults with IDD experience in building and maintaining friendships. People with lived experience then must cope with a lack of opportunities to develop and maintain friendships. Research has already shown that some of the obstacles people with disabilities face regarding friendship are the lack of time they can spend with their friends, the lack of privacy, transportation problems and not having enough money to go out (Garolera, Díaz, & Noell, 2021).

With restricted access and opportunities to meet other people in their respective communities, people with IDD are susceptible to experiencing the negative results of a lack of community involvement. Similarly, among people with intellectual disabilities, mental and physical health concerns may be exacerbated by feelings of loneliness. Those who experience more feelings of love in intimate relationships have higher emotional well-being. However, people with intellectual and developmental disabilities are less likely to receive emotional support and report higher levels of loneliness, as well as those who see their friends less frequently (Fulford & Cobigo, 2018). In the Surgeon General's 2023 Report on America's Epidemic of Loneliness and Isolation there was little focus on people with disabilities and their experiences with loneliness, how they manage it and what emotional support they receive in this process although they recognize that lacking social connection is as dangerous as smoking 15 cigarettes

a day. This is another example of how people with intellectual and developmental disabilities are left out of research regarding topics of discussion that they experience at higher rates in comparison with the general population.

Additional challenges found that impact friendship building is having access to opportunities for connection in virtual spaces. This has become something of high importance after the Covid-19 Pandemic as social connection was only available via social media, especially for those with complex medical needs who were at higher risk of experiencing severe complications if they contracted the Covid-19 virus. Even after the height of the pandemic passed, living in this post-pandemic environment, some people still prefer to avoid crowded indoor spaces, socially distance from others and wear masks. Evidence indicates that people with intellectual and developmental disabilities are less likely than the general population to have access to computers or the internet, and therefore social media. Barriers to internet access for people with intellectual disability include financial and economic hardship; societal attitudes and social exclusion; lack of government policy or strategy; support, educational, and training barriers (e.g., caregivers' expertise, time, and attitudes); individual cognitive, physical, and sensory impairments; the complexity of existing devices and internet sites; and the lack of involvement of people with intellectual disability in accessibility studies (Caton & Chapman, 2016).

Along with individual access to opportunities for creating authentic friendships, the family members, staff and allies in their life can play a role in that experience. Staff and family caregivers have indicated that they need more training to support relationships of people with intellectual and developmental disabilities. Thus, there is a

need to understand how caregivers can better support the development and maintenance of friendships and intimate relationships for this population. Stakeholders need to understand how people with IDD define relationships to develop policies, programs and services which meet the needs and fulfil the rights of those with intellectual and developmental disabilities. It is also important to understand which factors support and impede relationship development and maintenance for these individuals, to enable caregivers to better assist people with IDD (Fulford & Cobigo, 2018).

While the Covid-19 Pandemic unveiled alternative methods for sustaining previous relationships and creating new ones, there were also some barriers that people with IDD experienced during this time as well. In the study conducted in Spain it was found that most of the participants agreed that, even though technology has allowed them to maintain their friendship and partner relationships, they have not been able to meet the need to maintain physical contact with the people they appreciate. In fact, various participants agree that, in the wake of the pandemic, relationships have become considerably dehumanized and have cooled down. This has caused distress in some cases and in others, it has posed new challenges such as that of being able to experience physical contact once again with people who were close (Puyaltó et. al, 2022).

Another layer of barriers that impedes upon people with IDD building and fostering authentic friendships is the ableism. Historically ableism has had devastating impacts on the disabled community, it has shaped society's perception of disability and continues to limit or outright deny opportunities and access to people with IDD to the

greater community. Ableism has impacted nondisabled people's exposure to people with disabilities, specifically people with IDD, resulting in a disconnect and lack of genuine attempts to build friendships with people with IDD and lean into a "savior complex" approach to building friendships. Although friendships between people with IDD and nondisabled people do occur, and can be meaningful, reciprocity may be lacking; while nondisabled peers may find people with IDD likable and sociable, friendship requires mutual affection. Friendship often depends on trust, life-sharing, fidelity, maintenance, and mutual respect. Reciprocity may be a missing element from relationships with many nondisabled peers. Prejudicial disability attitudes may make cultivating reciprocity and mutual respect difficult for people with IDD (Intellectual and Developmental Disabilities). For example, when 1200 students without disabilities were surveyed, the majority noted 'altruism' was the main reason they would befriend a person with a severe disability. As a result, authenticity may be lacking and creating a barrier to developing friendships (Friedman & Rizzolo, 2017).

Best Practices for Building and Maintaining Authentic Friendships

Due to the limited existing research and resources available from online resources surrounding building and maintaining authentic friendships, best practices would best be determined by those with lived experience. People with IDD should conduct and be involved in qualitative research that can provide findings that can inform best practices. As of now the best practices for families, friends and allies is to continue to support and uplift the experiences of people with IDD. For families, friends and allies to support them in determining what are some of the best ways to build and maintain

authentic friendships through practical application of skills in relationships building. Having frequent opportunities in the community, whether that be in places of employment, supports and services, and locations and events for leisure and entertainment, can uplift and provide chances to form authentic friendships.

IM4Q Findings

There is limited data and findings in available literature from the perspective of those with lived experience about building and maintaining authentic friendships. IM4Q data gathered by the Institute on Disabilities at Temple University from 2018 to 2022, relating to friendships and maintaining relationships raised some points of interest and concern. In 1997, Pennsylvania's Office of Developmental Programs (ODP) developed a multi-year plan that represented a significant effort to convey its vision, values and goals for the coming years. As a result, recommendations were made to create a subcommittee of individuals, families, providers, advocates, administrative entity staff and ODP staff to create an independent monitoring program across the state of Pennsylvania. At the same time, a national project was developed to identify performance indicators that states could collect to determine the status of their system via the experiences of individuals, families, and providers delivering supports. Pennsylvania aligned the project created by ODP's subcommittee with the newly developed National Core Indicators to create the Independent Monitoring for Quality (IM4Q) Program (Institute on Disabilities, 2018).

In IM4Q findings from 2018 – 2019, people with IDD who were surveyed relating to relationships and the results showed that 86% of individuals who responded were able to visit friends whenever they wanted. Of those who said they were not able to see

friends whenever they wanted to, 25% said it was hard to find time to see friends. 25% reported they could not see friends because of transportation issues, 5% reported it was due to a lack of staff, 7% reported there were rules and restrictions that created barriers. 2% reported that money/cost of spending time with friends was an issue, and 36% reported another reason. Of that year's participants, 84% were always able to contact family when they wanted to.

Regarding community participation, 51% of people said they visited with family and friends. 16% of the time they reported they went along, 47% of the time was with family, 23% was with staff, 13% was with friends and 1% was with housemates or coworkers. 82% said they spend enough time visiting with friends, 17% wanted more time but only 1% wanted less. With respect to whether participants went out in the community alone or with other people, 81% went out alone, 34% went out with friends and family, and 34% went out with staff or staff and housemates. 90% of individuals always had a way to get to where they wanted to go.

There were minimal changes in the data for 2019 – 2020, but for years 2020 – 2021 and 2021 – 2022, the ongoing COVID-19 Pandemic was determined to have had potentially impacted the findings based upon the results and ratings collected from the data since socialization restrictions were in place in many areas. Compared to the 2019 – 2020 report, more than three-quarters of the survey sample in the 2020 – 2021 report reported that they were able to see family and friends whenever they wanted. Less than 1 in 10 reported that they were never able to see family and friends. It is worthy of note that the Covid-19 pandemic continues to restrict travel and socialization for some

people. There was a 12% decrease in people who said transportation issues kept them from seeing friends.

According to the 2020 – 2021 report, most people who were surveyed during the 2020 – 2021 Fiscal Year reported limited time going out in their communities. When they did go out, people most frequently go to supermarkets, go out to restaurants to eat, and go shopping. As has been the trend in recent years, people report wanting to participate in community events more frequently, though people very rarely report they want to go out into the community less frequently. The proportion of people wanting to go out more increased significantly in 2021, possibly influenced by the Covid-19 Pandemic. When people engage in community activities, they most often go with family or staff. In terms of transportation, 9 out of 10 people report that they can get where they want to go. People also largely report that they have all the adaptive equipment they need in their home.

From the 2021 – 2022 IM4Q it was reported there was a 3% increase in people who said they could see their friends whenever they wanted to (73% to 76%). Community inclusion numbers were lower than they had been prior to the pandemic. This may be due to regulations put in place during the pandemic that are slowly changing. There may be changing attitudes about socialization influenced by the pandemic. It is also possible that people have less of an opportunity to engage in community activities because of the ongoing staff shortage issues (“staffing crisis”). Compared to the 2020 – 2021 report there was a 9% increase in people who reported that they went out into the community for entertainment frequently and a 5% increase in those who went out into the community occasionally. People who reported they went

out “enough” increased for several activities across the sample, including visiting friends and neighbors which increased from 61% to 69%, going to a supermarket from 72% to 79%, going out to restaurants 56% to 69% and going shopping from 64% to 73%.

Recommendations

Through analysis of the available literature the following points of interest were determined to be helpful recommendations. There needs to be more opportunities for community involvement for people with IDD as it has been demonstrated that community involvement creates safety for people with IDD. It would be beneficial for all for there to be age-appropriate resource toolkits, for forming authentic friendships to be developed for adults with IDD. These resource toolkits could include the following: information about places in their local community to meet new people, activities in their communities that can foster opportunities to build friendships, online forums and groups on social media to connect with others, groups and civic centers that can be joined to support building relationships with non-disabled peers. Activities should be planned with direct feedback from people with IDD that support building and maintaining authentic friendships. Given the changes that have occurred for socialization due to the Covid-19 Pandemic, people with IDD should be given the chance to voice how they would like to create friendships. This should include if they would prefer to have opportunities to create friendships in virtual spaces, in person or a hybrid format.

It would be beneficial to survey participants at the midpoint and end of the grant to determine what community activities have facilitated friendship building and made them feel safer in their respective communities. The available research from the

perspective of people with IDD and participation of conducting the research from people with IDD is sparse. The community at large would benefit from qualitative research being conducted with and by people with IDD about their experiences with relationship building. A deeper analysis of this information can facilitate the process of better supporting and providing access to activities that support the building and maintenance of authentic friendships.

Conclusion

People with IDD have fought long and hard to have access to the same resources and opportunities as their non-disabled peers. There still exist barriers that prevent full participation and belonging in their respective communities. Some of these barriers include but are not limited to, access and support to live independently, safety concerns regarding physical safety or past negative experiences (ex. financial exploitation), minimal finances and little control over money, access to public transportation, services and programs to provide opportunities to meet new people and maintain relationships, staff and family members that can provide support and advice about relationships, restrictions created by caregivers, and a lack of privacy when visiting with friends or intimate partners. These barriers have shown to impede upon the process and opportunities for people with IDD to build and sustain authentic friendships. These barriers can increase loneliness which can have grave consequences upon emotional, mental, and physical well-being.

People with IDD need to have access to activities and resources that support the process of meeting people within their respective communities to have opportunities to develop and foster connections which can naturally develop into authentic friendships.

There exists a gap between the limited research that exists, analysis of that research and research that has been conducted by people with IDD and available resources. This gap must begin to be bridged to create resources and experiences that can foster authentic relationships. Families, friends, staff and allies should elevate and amplify the voices of those with lived experience to inform research that can support these opportunities for authentic friendships. They should not only be heard but included in the processes of research. Resources in virtual and in-person settings should be made available to develop age-appropriate toolkits that can support these processes. People with IDD deserve the same opportunities and liberties as their non-disabled peers to relationships and access to their communities. They should not just be included in the process but at the center of it.

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