

UNDERSTANDING SOCIAL EXPERIENCES AND  
CURRENT SOCIAL SUPPORTS FOR ADULTS WITH  
INTELLECTUAL DISABILITIES

by

Sara Hearing

A THESIS

Presented to the Department of Family and Human Services  
and the Robert D. Clark Honors College  
in partial fulfillment of the requirements for the degree of  
Bachelor of Arts

May 2022

## **An Abstract of the Thesis of**

Sara Hearing for the degree of Bachelor of Arts  
in the Department of Family and Human Services to be taken June 2022

Title: Understanding Social Experiences and Current Social Supports for Adults with  
Intellectual Disabilities

Approved: Stephanie Shire, PhD  
Primary Thesis Advisor

Adults with intellectual disabilities (ID) are an under studied and an underserved population, especially in regards to social experiences and social supports. This study aimed to use a self-reporting model to provide adults with ID a sense of agency and control asking them about their own social experiences and how they feel about the social supports they receive from their caregivers. This pilot study calls for further research into this important topic as it was found that even those individuals with increased familial support experience loneliness with this study finding 62.5% of participants experiencing loneliness. Adults with ID desire and are requesting more social supports to expand their social networks, increase frequency of social supports given, and more attention to the importance of social supports.

## **Acknowledgements**

I would like to thank Dr. Stephanie Shire, Dr. Elizabeth Raisanen, and Dr. James Muruthi for joining me and supporting me through this journey of developing, facilitating, and writing my own thesis project by serving on my Thesis Committee. Through all of your various perspectives and specialties, I felt encouraged to pursue my own specialty through this project and I appreciate all of your dedication to my work as well as me as a student. I want to especially express my gratitude to my Dr. Stephanie Shire, my Primary Thesis Advisor, for agreeing to advise a student you had never met before and putting so much extra work and effort over the past year in helping this study reach the highest potential it could ever have. I appreciate Dr. Stephanie Shire as well as all of my other professors I have had over the course of my four years at the University of Oregon and the Clark Honors College to help me be the person I am today.

I also would like to thank my mother, Mary Hearing, and father, Sam Hearing, for providing for me, encouraging me, and always supporting me through everything. I would not be here without you both.

## Table of Contents

Chapter 1: Introduction	1
Chapter 2: Review of Literature	3
Importance of Research	3
Defining Friendships	4
Challenges for Caregivers/Lack of Interventions	8
Inter-abled Friendships and Stigma	10
Mental Health	11
Chapter 3: Methods	14
Recruitment	14
Participants	15
Measures: Survey Design	17
Privacy and Collecting Identifiable Information	17
Consent and Assent	18
Survey Question Creation	20
Survey Questions	21
Chapter 4: Results	27
Chapter 5: Discussion	38
Understanding Social Satisfaction	38
Future Social Supports	42
Bibliography	47

## List of Figures

Figure 1.1: How many friends do you have?	29
Figure 1.2: How many <i>close</i> friends do you have?	29
Figure 2: How often do you feel lonely?	30
Figure 3: How often do you see your friends?	32
Figure 4: Do you believe your loved one is lonely?	36
Figure 5: Do you believe your loved one would benefit from more social supports?	36

## **List of Tables**

Table 1: Preferences for Activities with Friends .....	31
Table 2: Social Supports for Friendship Maintenance .....	33
Table 3: Current Social Supports Received to Make Friends .....	34

## **Chapter 1: Introduction**

It has been found that about 44% of adults with intellectual disabilities (ID) experience loneliness (Alexandra et al., 2018). Social interaction is important for all people, but for people with ID, this can be more challenging due to limitations in social skills, discrimination due to disability status, and a lack of access to community or social settings (Brown, et al. 2015). Although research has been conducted on the experience of individuals with ID, there are few studies that report on how adults with ID view friendships (e.g. Hurd et al., 2018; Fulford and Cobigo, 2018; Asunta et al., 2021), links between friendship, mental health, and social inclusion (e.g. Scott and Haverkamp, 2014), and how caregivers can support the social lives of adults with ID (e.g. Bigby, 2012; McConkey and Collins, 2010; Asselt et al., 2014). Due to the prominence of loneliness in the disability community and the potential impact on mental and physical health, further research is imperative to better understand the lived experience of people with ID, identify needs, and then when indicated, facilitate access to interventions to support community and social inclusion for individuals with ID.

According to the American Speech-and-Hearing Association (ASHA), there is an estimated prevalence of 4.94 out of 1,000 adults living with ID internationally in 2011 (Maulik et al., 2011). Although it has been generally agreed upon in the literature that the global prevalence of ID is below 1% (McKenzie et al., 2016). This translates to millions of people across the globe of having ID and needing interventions and services. ID is a lifelong condition meaning these services are instrumental over the course of the lifespan of people with ID rather than just childhood.

Although published studies have described the etiology of ID, physical health complications, and need for support (Lee et al., 2021), what is missing is description of the social needs of adults with ID. As Alexandra et al. (2018) have found, 44% of adults with ID experience loneliness. They also found that loneliness “reflects the perception that one’s emotional and social needs are not being met” and can be a significant predictor for the development of depression and even suicidal ideation (Alexandr, et al., 2018). Focusing on social needs can encourage adults with ID to thrive rather than just survive. The present study aims to start to address this gap in knowledge to better understand the social experiences of adults with ID to provide a broader picture of how caregivers, family, and health providers can support those with ID.



## **Chapter 2: Review of Literature**

While adults with ID have been historically understudied by researchers from a social context, there are key studies and research projects focused on bringing to light the descriptions, plights, and needs of adults with ID regarding their social experiences. Some common subjects focusing on the social experiences of adults with ID include hearing the views of people with ID through research, how those with ID define friendships, challenges for caregivers in implementing social support interventions, and the mental health of adults with ID.

### **Importance of Research**

Social supports are vital to increasing the quality of life of people with ID. The researchers, Brown et al. (2015), discuss how the United Nations Convention on the Rights of Persons with Disabilities determined social inclusion to be a right for people with disabilities in the face of the exclusion and discrimination they typically experience. Many may believe that for people with ID, the most important part of their care is physical care, but social and emotional needs are still vital for their quality of life—just like they are for people without disabilities. Social inclusion is believed to be the gateway to an increased quality of life and should be considered from many avenues like friendships instead of just employment. The risks for not providing social supports are tremendous for people with ID. For example, a systematic review conducted by Alexandra et al. (2018), found that approximately 44% of people with ID and developmental disabilities included in the review reported experiencing loneliness. These authors highlight the deep importance of understanding how loneliness affects

people with ID because they are more at-risk for loneliness and have a lower ability to combat it due to more limited social structures including family and staff.

The impact of social supports for adults with ID has been explored in preliminary published literature based on a preexisting dataset (Scott & Havercamp, 2014). The researchers drew their data from a nationally representative, preexisting dataset, the National Core Indicators (NCI), which allowed them to have a very diverse and expansive population included in the study, but which only collected data at a single point in time. Scott and Havercamp (2014) found that people with ID who had more social supports reported to be less depressed and have fewer instances of other mental illnesses. They also found the incidence of stress of people with ID living in different environments (e.g., group homes, with family, independently, etc.) was improved by having adequate social experiences. As the NCI provides information at only one point in time, further research needs to be conducted to provide a basis for lack of social supports has a causal effect on the mental health of individuals with ID. But Scott and Havercamp (2014) did find that social supports can improve the quality of life of people with ID which is just as important as their physical health.

### **Defining Friendships**

Friendship is a social construct that has varied definitions for individuals and in the extant literature. Yet, it is critical to operationally define friendship because surveys are common tools to collect data on friendships using questions that ask people to respond to what they believe a friend to be. Fulford and Cobigo (2018) focused on questions to understand how they knew someone was a friend, how to know someone is a significant other, and what facilitates and creates barriers to these relationships. They

synthesized eighteen different studies who focused on these three major themes. They focused on these themes because they believed that understanding these questions would help create training sessions to support relationships of people with ID. This study included individuals age 14+, but it is unclear if that participants' age or developmental level influenced their responses. Fulford and Cobigo (2018) found that adults with ID more often desire more friendships and more time with friends compared to adults without ID who reported being more satisfied with the amount of time spent with friends. Respondents reported the necessity for support in seeing their friends on a regular basis to maintain those relationships, and often service agencies were one of the only facilitators available to help them see their friends. Service agencies, in this case, operate as common ground for individuals with ID to find each other and socialize. This is especially important as Fulford and Cobigo (2018) also found that while inter-abled relationships can be successful, individuals with ID "most easily connect" with individuals with similar levels of functioning and experiences. Caregivers also played a large role in the creation and maintenance of friendships as they provided transportation and emotional support. However, respondents also reported some barriers tied to caregiver involvement including feelings of being restricted in their choices over their social lives, a lack of privacy while providers supervised time together, and negative attitudes towards the importance of spending time with friends (Fulford and Cobigo, 2018). Through their approach to ask questions to define friendships for individuals with ID, Fulford and Cobigo (2018) were able to draw important conclusions on the experiences of individuals with ID in their social relationships.

Hurd et al. (2018) focused on individuals who were 18 years of age or older, with ID, and who were aging out of the school environment and transitioning into adulthood. They found three main themes of importance including “meanings of friends and friendships, deepening self-knowledge and negotiating in(ter)dependence” (Hurd et al., 2018). This shows the importance of analyzing by age group to determine any major differences or focuses, specifically differences between populations that are still involved in school settings with natural peer relationships and those living in the community. While there may be some core similarities such as the meanings of friends and friendships, constructs such as interdependence may be more salient in early adulthood. Participants in this research described barriers to socializing as lack of independent transportation, feeling friends’ parents were too overprotective, and tight finances (Hurd et al., 2018). The researchers discussed how instead of aiming for independence, participants worked with family members and caregivers to develop interdependence to have further choice in their social lives while still leaning on others for their needs. An important contribution to research Hurd et al. (2018) found was understanding of their disability identity and how that affects their social lives. One participant labeled an individual who was frequently unkind to her as a friend while other participants were more aware of the ways in which their disability stigmatized them from others around them (Hurd et al., 2018). This is important knowledge to have moving forward to creating interventions and programs for the improvement and increase of social experiences for individuals with ID.

In addition to understanding how to ask respondents about their friendships, another topic of interest is satisfaction with relationships. Friedman and Rizzolo (2018)

asked questions relating to if the respondents have friends, how often they see their friends, do they wish to have more friends, and what they like to do with their friends. They also went more in-depth to find while most participants reported having friends, over half of them also reported various dissatisfactions with those friendships and desired more meaningful connections. Another important topic addressed in this study is the quality of friendships that are voluntary versus those that are more obligatory in nature (e.g., relationships with support staff, family: Friedman & Rizzolo, 2018). A relationship with a staff member is different than a relationship with a person you meet and form a bond with. Asselt-Goverts et al. (2015) noted high quality relationships between clients and caregivers improve the quality of supports and can result in “professional loving care.” In addition, when staff respect and have high quality relationships with their clients, they are more likely to understand their client’s social needs and preferences for social supports (Friedman & Rizzolo, 2018). However, when individuals with ID identify paid caregivers as friends, this can cause distress when caregivers leave their positions because of high turnover in the career and their friendship ends abruptly. The friendship between client and caregiver most likely is non-reciprocal which can confuse and distress clients when the professional relationship ends as they might believe it is their fault the friendship “failed” (Friedman & Rizzolo, 2018). This is an important distinction to make to determine how people with ID can be supported in making friendships and meaningful connections outside of the home.

While gaining understanding of what defines a friend to adults with ID in existing research, two studies were compared—one written for adults with autism and one written for neurotypical adults. To be able to compare how adults with ID define

friendships, it is important to know the definitions and origins of friendships for neurotypical individuals as well. Rosqvist, et al. (2015) focus on the realities of friendships for adults with autism. Dunbar (2018) writes on the neurotypical “anatomy of friendship” and even the possible cognitive demands it takes to maintain friendships. Dunbar (2018) describes the evolutionary meaning and value of friendships and how having friends and social experiences affect “happiness, mental well-being, and longevity.” This article was written from the perspective of a neurotypical individual about neurotypical connections even describing the cognitive demands that friendships have on the individual. Rosqvist et al. (2015) focus on the realities of friendships for adults with autism. They discuss the stereotypes neurotypical individuals have assuming that autistic (and other disabled individuals), do not desire friends and do not want to be included in the community when in actuality this is not the case for all. Many individuals do want friends, however, they may not know how to or want to engage with people in a neurotypical way (Rosqvist et al., 2015). This begs the question about the ability of adults with intellectual disabilities to engage in the type of formal friendships that Dunbar is referring to or if friendships are defined and valued differently suggested by Rosqvist, et al. (2015).

### **Challenges for Caregivers/Lack of Interventions**

Understanding friendships of people with ID is a core challenge for caregivers, in order to help their clients gain social experiences and expand their social networks (van Asselt-Goverts et al., 2014). However, when a caregiver identifies a need for support, there is a lack of accessible evidence-based interventions to provide support (Bigby, 2012). Professionals who work with people with ID are known to be very

innovative in helping their clients in a multitude of ways by creating their own supports and interventions, but often report limitations that impede the implementation of these interventions such as time, money, and resources (van Asselt-Goverts et al., 2014). In particular, people with intellectual disabilities who engage in challenging behavior (e.g., physical aggression, self-injurious behavior, property destruction) may require additional supports to make meaningful connections and may compound underrepresentation in intervention research (Bigby, 2012). Therefore, advocacy is necessary. Bigby (2012) describes people with ID “among the most disadvantaged and socially excluded in society.” These perceptions only make social experiences exponentially more difficult and caregivers are left largely in the dark in how to help.

One way to understand how caregivers perceive their role in helping their clients expand their social networks and the burden on caregivers without evidence based interventions is to ask them directly. Researchers McConkey and Collins (2010) surveyed over two hundred caregivers on how they rank the importance of different supports they provide. Findings indicated providers ranked physical care significantly above supporting their social inclusion. Some caregivers even believed that social inclusion was not part of their job description. This is antithetical to social inclusion as a protected right by the United Nations (Bigby, 2012). Therefore, this perception of some caregivers that social inclusion is outside their purview is extremely concerning based on the importance of social inclusion for the mental health of people with ID (McConkey and Collins, 2010).

Very few concrete interventions have been documented scientific evidence-based to demonstrate that the intervention can help provide opportunities for social

inclusion for people with ID. One practice with emerging evidence is the Special Olympics. Asunta et al. (2021) discuss how participation in Special Olympics, and sports activities in general, can help people with disabilities participate in their community and meet new people. Asunta et al. (2021) discuss the positive impact of the goals of the Special Olympics including the promotion of social inclusion for people with disabilities and encouragement of relationships between those with and without disabilities by creating inter-abled sports teams. A critical contribution of Asunta et al. (2021) is the demonstration that people with ID can reliably self-report social experiences using questionnaires with modifications. The questionnaire was developed and tailored towards the needs of those with ID specifically focusing on simple wording of questions and limited number of questions. Answers from those with intellectual disabilities show different perceptions of their experiences compared to caregivers and other secondary sources which demonstrates a possible gap of understanding between individuals with ID and those speaking for them.

### **Inter-abled Friendships and Stigma**

Inter-abled friendships, relationships (e.g. romantic, platonic, or familial) between individuals with and without disabilities, are another avenue for social connection (Weiss, et al., 2017). Asunta et al. (2013) report that many people with ID have very few connections with those who are not family, staff, or others with ID which may in part be due to stigma and social exclusion (van Asselt-Goverts et al., 2014). A prime example of the study of this type of relationship was conducted by Pottie and Sumarah (2004). This study included four different dyads of relationships including people with ID in the L'Arche intentional community. L'Arche is a national



organization providing homes and day programs for adults with intellectual disabilities to live, work, and socialize with adults without intellectual disabilities who act as “assistants” or caregivers. Here, inter-abled relationships were only possible as caregivers were paid to be friends with adults with ID.

Perceptions of people with disabilities are incredibly important to those without disabilities deciding to have relationships with those with ID. When neurotypical peers were asked why they would befriend a person with a severe disability, the majority responded “altruism” (Friedman & Rizzolo, 2018). Another barrier to quality inter-abled relationships is reciprocity and mutual respect which can be inhibited by prejudices against those with disabilities. In addition to perceptions of people with disabilities by neurotypical individuals, Logeswaran et al. (2019) analyzed how people with ID view themselves in accordance with their disability as well as view their group sense of belonging with their disability. For non-disabled people, disabilities can be very important in how they view others especially in the sense of group belonging. Logeswaran et al. (2019) found many different views across participants including some people accepting their label and others rejecting, some understanding the negative perception of their disability and others not, and some viewing little importance to their disability and others feeling shame and stigmatization. We cannot ignore these perceptions as they can be a real impeding factor affecting the possibility of people with ID creating and maintaining inter-abled relationships.

## **Mental Health**

A common myth around mental health of adults with ID is that they do not have the intellectual capability to experience mental illness whether it be depression, anxiety,

or other (Eaton et al., 2021; Hartley & MacLean, 2009). Instead, according to Eaton, et al. (2021), prior health professionals ascribed symptoms of mental illness to simply be characteristics of ID instead of a separate diagnosis of mental illness. This dismissive attitude of mental illness in adults with ID contributes to the lack of knowledge surrounding how to support adults with ID thrive in their lives even while living with mental illness. It is only more recently understood by researchers that adults with ID experience mental illness at a higher rate than the general population (Hartley & MacLean, 2009).

The importance of researching mental health in individuals with ID lies in the fact that research has found that the factors associated with and the origins of mental illness in those with ID are different to the general population. For example, Cooper et al. (2007) in a study of approximately 1000 individuals with ID found some common factors associated with depression for the general population (marital status, obesity, not having a career, and living in an area of economic strife) were opposite for those with ID. The researchers postulated that these differences may come from variation in lifestyle characteristics where adults with ID have different perspectives and goals in life compared to the general population. For example, not having a career is a somewhat common experience for adults with ID where only about 34% of adults with ID are employed (Siperstein, et al., 2013). Therefore, if the factors of association with mental illness are different for adults with ID, treatment of these mental illnesses may also differ (Cooper et al., 2007; Eaton et al., 2021). One lifestyle characteristic that may influence mental health is social experience. Negative social experiences or the lack of

social experiences for individuals with ID may be an indicator of mental health (Eaton et al., 2021; Scott & Haverkamp, 2014; Hartley & MacLean, 2009).

One study beginning to understand the link between social experiences and mental health is Alexandra et al. (2018) which focused on loneliness in adults with ID. Loneliness has been found to be a predictor long term predictor for mental health diagnosis in the general population, and for those with ID, this predictor is magnified by their pre-existing vulnerability, either biological or environmental, to mental health diagnoses. Alexandra, et al. (2018) found that adults with ID have more difficulties “initiating self-directed activities” and tend to spend their free time alone as they struggle to initiate social communication and participate in social events on their own. Chronic loneliness may have a risk of increasing depressive symptoms and even suicidal ideation, but Alexandra, et al. (2018) also call for an increase of research in this area to prove this finding even further.

## Chapter 3: Methods

### Recruitment

Recruitment for individuals with ID can be a difficult process. As individuals with ID can be highly susceptible to manipulation and coercion, the recruitment process must be completed carefully to avoid inadvertently coercing participants. The majority of recruitment for this study was done through electronic posting and email where participants were required to reach out to the study investigator for more information. This avoided people who may hold perceived positions of power (e.g., study investigator and agency supervisor) from suggesting study participation.

Using internet searches for agencies that provide services to adults with ID, an email template with a flyer was created and sent to all agencies found through these searches. Agencies were searched by state to gain an understanding about individuals across the country. States with databases or directories for services offered (e.g., National Association of State Directors of Developmental Disabilities Services) facilitated recruitment. For states without centralized resources, Google Maps was used to locate local service agencies which were contacted by email individually either through their website contact form or by a listed contact email.

A goal in the recruitment process was to gain participants from multiple different sources. Any agency that provided services to individuals with ID or had the ability to have contact with them were emailed. Agencies that provided multiple different types of services were contacted, such as independent living agencies, job coach providers, direct support professional brokerages, case management organizations, foster home owners, and more. Between 750 and 1000 individual

agencies were contacted by email during recruitment from September 2021 to February 2022. Approximately one-third of agencies emailed reached out expressing appreciation for the project and that they would be interested in sharing the study flyer. The flyer and project were shared by approximately twenty agencies on their newsletters or social media pages. One agency did request the primary researcher to attend their weekly virtual staff meeting to explain the project and how their direct support professionals could take part with their clients. The project was also shared on the Organization for Autism Research, HEDCO HART Autism Clinic, and Rutgers LifeSpan Lab websites for current studies promoting research for those with autism and intellectual disabilities.

### **Participants**

This study included both adults with ID and their chosen caregivers for support. Eight individuals with ID participated, seven of whom completed the survey with a caregiver. Inclusion criteria for the study were as followed: (a) living in the United States, (b) a minimum eighteen years of age, (c) speak and read English, and (d) had a documented intellectual disability.

The survey recruitment was conducted nationally due to the challenging nature of recruiting participants with ID, a population underrepresented in research. Participants resided in a number of states including: California, Hawaii, Kansas, Missouri, Oregon, Virginia, and Washington.

The minimum age requirement of eighteen was necessary to focus on the adult population of those with ID. There was no participant age limit. Participants ranged in age from 27-50 ( $M=34.88$ ).

Participants were required to speak and read English. This was to ensure that those responding would be able to understand the survey in its original language as translation was not available.

Finally, the study was focused on adults with ID, however, individuals did not need to provide documentation of an intellectual disability to participate to reduce potential barriers to accessibility. Recruitment was aimed to those in the intellectual disability community and the survey was only accessible to those who reached out. Those with other comorbidities were not excluded from this research as many individuals with ID have other diagnoses that affect their social experiences. To get an accurate view of the community as a whole, including all people with self-reported ID despite other diagnoses was important.

All individuals with ID were encouraged to participate regardless of race, ethnicity, gender, socioeconomic status, sexual orientation. Of the eight participants, six identified as white and two identified as bi- or multi-racial. Recruitment intended to reach as many different demographics as possible by contacting agencies in all areas of the country and agencies specifically for minority populations. Of the eight participants, five identified as female and three identified as male. Other demographic information was not collected to protect the privacy of the individual.

The second group of participants included caregivers that provided support to the individual with ID. For the purpose of this study, a caregiver was defined as a paid professional who works with the individual as a client (e.g., personal support workers, direct support professionals, home care aides, foster providers, etc.) or family member..

Six of the seven individuals with ID who completed the survey with a caregiver had a parent for support with one individual having a sister.

The survey did not collect demographic data on the caregivers supporting the individual with ID to avoid collecting further identifying information.

### **Measures: Survey Design**

With an online survey, the study was made accessible nationwide. Being able to recruit across the country opened the possibilities and expanded the population pool available. An online survey was also beneficial for accessibility as it could be completed on any device. The online format increased efficiency, reduced the barrier of mail costs, and protected participant confidentiality as contact information (e.g., home address) was not required to be shared.

In person interviews were also considered as a method of data collection. However, given the presence of the COVID-19 pandemic, in-person interviews were not possible. Further, Zoom meetings were not considered accessible for this population. Some individuals with ID have experience utilizing Zoom, but it was unknown if would be inclusive to all individuals skill levels. Therefore, the medium this research would be done through was an online survey. In-person interviews would inevitably limit the study participants to those in the geographic area of the University of Oregon.

### *Privacy and Collecting Identifiable Information*

As individuals with ID are a vulnerable population, maintaining their privacy and avoiding collecting unnecessary identifiable information was a big concern. The

goal in regard to privacy was to collect the least amount of identifiable information as possible. While planning the survey, it was hoped to only need to collect individual's email addresses from when they reached out to the primary researcher to take the survey. However, this was not realistic as we had no way to connect the survey completed by the individual and the consent given by the guardian. Many individuals with ID are their own guardian and thus did not need another person to give consent for them to participate. But many individuals with ID are not their own guardian and have another adult who acts as their guardian. Thus, first and last names of individuals were collected so that the consent could be connected and tracked to make sure all individuals consented or assented to participate.

The identifiable information was not shared with others outside of the two person research team and was secured within the survey platform by the University of Oregon's dual authentication process enhancing data security.

### *Consent and Assent*

The informed consent process for adults with ID is complex and requires careful attention to both consent and assent for individuals who may not be able to independently provide informed consent. Adults with ID tend to be more susceptible to coercion and manipulation than the neurotypical population, so consent and assent was an important process in the design of this study. Three different paths to full and complete consent will be included: (a) consent/assent of the participant with ID, (b) consent from the caregiver of the individual with the intellectual disability, and (c) consent from the guardian if the participant with ID is not their own guardian. The assent process was also very important to the research team as the assent of the



individual represented, as best to possible, the individual's desire to partake in research and not just the caregiver encouraging or coercing.

As many individuals with ID are their own guardian, it would be disrespectful to undermine their autonomy by requiring a parent or someone else in their life to give consent for them. Because of this, if they are their own guardian, then it is their right to give consent for themselves. Instead of providing an outside guardian with a link to give consent, the participant with ID can give consent for themselves in the original link to the survey.

Guardianship was reported through a question that tunneled the participant to the correct consent/assent process based on their response. Participants were asked if they are their own guardian. If the individual is their own guardian, they were directed to the question to give consent for themselves by saying, "I Consent" after having the opportunity to read the consent form. The primary researcher also created a video to succinctly describe what the survey was about and explaining they did not have to answer the survey if they did not want to. The video was, in a way, an easy-to-understand verbal translation of the consent document. A transcript of the video was also included as a caption under the video. If the individual is not their own guardian, they will be directed to a question to give assent for themselves. This will promote autonomy and independence in their choices of action.

If the participant was not able to consent for themselves, then consent from a guardian was required. A separate survey link was provided for the guardian to complete. The individual's guardian had the opportunity to read the consent document on their own and in their own time. The consent document was provided as a PDF

within the survey and is available to be downloaded once opened. After reading, they will then select an answer, “I Agree” which will be giving consent for their loved one to participate in the survey. The separate link provided accessibility and ease if the guardian is not the person helping the individual complete the survey.

As the caregiver answers their own set of questions at the end of the survey, they are asked to consent as well. They used the link to the original survey where they went through the same process of reading and selecting the agree answer to give their own consent. Caregivers for this study included parents and an adult sibling.

The research team was available by email and phone for those who had questions about the consent and assent procedure. In addition to being available for questions to ensure understanding of the consent/assent process, questions of understanding were asked to both individuals consenting and assenting to the research. These included: “what will you be asked to do in this research,” “what does voluntary participation mean to me,” and “what does confidentiality mean to me?” These were all questions with correct and incorrect answers to determine if the individuals with ID understood the consent and assent process. After these questions, the individuals were asked if they would like to continue to give them another opportunity to leave the survey if they did not want to participate. The voluntary and enthusiastic participation of adults with ID was a very important part of this research as it is based on the self-reporting and self-advocacy for the benefit of them.

### *Survey Question Creation*

The survey questions were informed by existing literature including Rosqvist et al (2015) and Rosqvist et al 2018. These studies explored the differences, if any, that

exist between the friendships of disabled individuals and able-bodied individuals as well as the value assigned to friendships in general. Further, McConkey and Collins (2010) provided insight on the sections created for desired supports by individuals with ID and the questions for the caregivers to answer.

The final influence used to design the survey questions was the personal experiences of the research team while working with individuals with ID and other developmental disabilities. This area of research is not commonly done with this population, so the goal of this study was to expand the information available. This was done by creating questions that had not been asked in prior research such as questions about inter-abled relationships and interactions with neurotypical individuals. As this was novel to the research team, some questions could have been phrased differently or additional questions could have been asked upon further inspection after the conclusion of the study.

### *Survey Questions*

There were thirty-six questions split into six different sections based on topic that make up this survey. The multiple choice format of the questions were chosen specifically as well to be easily understood and answered by the individuals with ID. The different sections created blocks of questions allowing individuals to focus on one topic at a time and be completed in approximately 30 minutes or less. Participants had their caregivers with them to give them the support they needed, but as many questions as possible were multiple choice format for easy answering while also allowing for freedom of choice without limitations as much as possible. Where applicable, questions

had an “Other” option that could be used to type or use speech to text to answer the question.

The first section of questions on the survey was the collection of demographic questions. Demographic information was collected to characterize the participants. Six questions were asked including: (a) age, (b) hometown, (c) current location, (d) gender identity, (e) race/ethnicity, and (f) disability. The first was age to determine that the individual was indeed an adult as well as to possibly analyze differences between young adults and older adults. Next, it was asked where the individual was from (city and state) to understand differences across states. A follow-up question was where they currently resided if they did move from where they identify they come from. The survey also asked what gender the individual identifies with. The possible answers to this question included male, female, non-binary/third gender, and prefer not to say. In an effort to be accessible, sex was not asked as the gender individuals preferred was most important. The penultimate question in this demographics section was what race or ethnicity individuals identified with. The format of this question was made so that individuals could choose more than one option if they desired. The possible answers to this question include: White, African-American, Latino or Hispanic, Asian, Native American, Native Hawaiian or Pacific Islander, Middle Eastern, Biracial or Multi-racial, Other/Unknown, and Prefer not to say. In future surveys and research, this question might be better split into one question for race and one question for ethnicity. The final piece of identifiable information collection was what type of disability the individual had. This was an open-ended question so the individual would be able to

write what disability they had specifically. This was also a place to write other disabilities they had in addition to their intellectual disability.

The second section of questions aimed to find a definition of what a friend is and what friendships mean to individuals with ID. From the resources that influenced this survey (Rosqvist et al. 2015; Dunbar, 2018), six questions were formed to efficiently gain insight on what a friend or friendship is to participants. The first two questions in this section are “what best describes what a friend is to you” and “what do you look for most in a friend” to start to form what an individual with ID values most in their social experiences. Both of these questions had an “Other” option for personal input if the provided answers were not satisfactory. Participants were asked about the meaning of both (a) a friend and (b) a close friend to differentiate between acquaintances that individuals identify as friends from close friends that may have a meaningful impact on their social experiences. Individuals were asked “how many friends do you have” then “what do you think makes a close friend” then “how many close friends do you have”. The answers to what makes someone a close friend also reveals the thought process between an individual’s personal distinction between what a friend is and what a close friend is. Finally, the last question of this section asked, “who is my closest friend” with response options including their family, a paid caregiver, or a friend outside their family.

The third section transitions to give individuals the opportunity to talk about how they feel about their current friendships. There are only two questions in this section including, “do you want more friends” and “how often do you feel lonely?” The first question’s answers include: yes, no, sometimes, and maybe. Some individuals may

have not thought about this question before, so they maybe option was added. The second question's answers include: never, once a week, 2-3 times a week, 4-6 times a week, and daily. In retrospect, there would have been more options to choose from that ranged between never and once a week to account for those who feel lonely monthly, seasonally, or even annually. This section explored the satisfaction felt by adults with ID about their social experiences. With the statistic stating that 44% of adults with intellectual disabilities experience loneliness (Alexandra et al., 2018), these two questions provide insight into a topic that perhaps is not discussed between individual and caregiver enough.

The fourth section focused on how the participants' disability affected friendships, or how they perceived their disability to affect their friendships with six questions. There is an assumption that individuals with ID are not aware of their disability and how their disability may affect how others see them. This was initially explored with the question, "Do you think your disability makes you different from other people?" Response options included: definitely not, probably not, might or might not, probably yes, and definitely yes. This is followed by questions about the makeup of their friend groups and how they perceive neurotypical individuals to view them. A secondary research question for this study was to collect introductory data on the possibility of increasing inter-abled relationships and understanding the presence current inter-abled relationships existing among participants. This section ends with the question, "do you think you would have more friends if you did not have a disability?" This question specifically wanted to ask if individuals felt that their disability was a

barrier for them creating more friendships or in other ways affects how neurotypical individuals form relationships with them.

The fifth section, and final section for the individuals with ID, acts as both a conversation and a collaboration between the individual with ID and caregiver. This section had seven questions all pertaining to the supports their caregiver give them as well as desired supports they would like from their providers to improve the quality of their social experiences. The first two questions of this section are “how does your caregiver help you make friends” and “how does your caregiver help me connect with my friends I have now?” These are to distinguish the difference between how caregivers support the creation of friends and the maintenance of friendships as many individuals with ID need support in all aspects of social experiences. This then transitions to what supports are given now and what individuals with ID want in the future for both making more friends and connecting with current friends. In all of these questions, a participant could indicate that they did not want more friends to avoid leading individuals’ answers. An additional question was included to ask what types of activities individuals liked to do with their friends including, but not limited to, going on walks, watching television or movies, talking on the phone, and more. While the main objective of this section was to gather data about individuals’ experiences, it also provided an opportunity for more open conversations between individuals and caregivers. This was an opportunity for individuals with ID to advocate for themselves both in research and in their own lives.

The final section of the survey was reserved for the caregivers to share their experiences and knowledge about their client or loved one. There were eight questions in this section with the first being very basic in asking what their role or title is. This

survey was originally created with paid caregivers in mind, but options were expanded to make this survey more accessible to those who may not have the ability to have paid caregivers. Next, drawing from McConkey and Collins (2015) research on the role caregivers have and how they view their responsibility in their client's life, this question was, "what do you see as your main job with your client?" This question was open-ended for the caregiver to write from their own words. They also could write their answer for the next question on "how do you help support your client socially?" The juxtaposition of these questions will reveal the priority social supports has for caregivers. The next two questions in this section discussed if caregivers wanted to provide more social support and, if so, what barriers were hindering them from doing so. These barriers ranged from not enough time to do not know how to "Other" and writing their own answer. Questions that were also important in this section entailed asking caregiver's about their knowledge about their client specifically by asking if they thought their client was lonely and if they would benefit from more opportunities to participate in social experiences. While self-reporting was the main objective for this study, the second-hand knowledge that caregivers have is also important in getting a wider picture. Finally, there was an open-ended question asking if they had anything else to add, specifically asking about the experience of taking the survey with their client or loved one. Again, this research also aimed to provide opportunities for open conversation and benefiting the individuals taking the survey as much as possible.



## Chapter 4: Results

### Participants

The ID community varies from person to person. Not all people with ID look the same, and therefore research with only eight individuals from this population must be taken into consideration to the context of who makes up the participant pool. Ideally, in future research the participant pool would be much larger to gather more determinable results. But understanding the context of where the results from this survey came from is important.

Demographic information collected included: age, gender identity, race/ethnicity, hometown, and type of disability. The age range varied between 27 years-old and 50 years-old with a mean of 34.88 years-old. The gender identity makeup of this participant pool consisted of five individuals self-reporting as female and three individuals reporting as male. No individuals identified as nonbinary. Most individuals identified as white making up 75% of the total (n=8). The other race/ethnicity individuals self-reported as was biracial or multi-racial with two individuals making up 25% of the total. While the survey was based in Eugene, Oregon, only one individual came from Oregon. Other locations included: Modesto, California, Richmond, Virginia, Warrensburg, Missouri, Aiea, Hawaii, Edgewood, Washington, and two individuals reporting from Wichita, Kansas. This is the most diverse participant characteristic in this survey. Finally, participants were asked about their disability—both comorbidities and their ID diagnosis. The most common disabilities reported were autism (n=3), and general, unspecified ID (n=2) including comorbidity of autism and ID (n=1). Other disabilities reported (n=1) included: anxiety, Attention-Deficit Hyperactivity Disorder,

Auditory Processing Disability, depression, Down Syndrome, epilepsy, hearing impairments, learning disabilities, and Obsession Compulsion Disorder. Many individuals with ID have comorbidities that may affect their social lives so including individuals with multiple disabilities is representative of the community as a whole (Cervantes & Matson, 2015; Prasher & Madhavan, 2017).

### **Section 1: Defining Friendship and Identifying Friends**

The first batch of questions focused on defining friendship and understanding the quantity of friends that individuals have currently to understand participants' experiences with friendship prior to the survey. In this study, 50% (n=4) of participants reported having more than ten friends and 37.5% (n=3) of participants reporting have four to six friends. These numbers dropped when asked how many of these are *close* friends with 50% (n=4) of participants reported having one to three close friends, 25% (n=2) of participants reported having four to six close friends, and 25% (n=2) of participants reported having more than ten close friends. No individuals reported having zero friends or zero close friends. Adults with ID reported that they valued friends who are nice to them as well as someone who they can talk to. When distinguishing between a friend and a close friend, six participants cited someone who I spend a lot of time with as the most important difference between a friend and a close friend. Finally, out of the eight participants, seven individuals reported their closest friend being either their parent or someone in their family.

Figure 1.1: How many friends do you have?

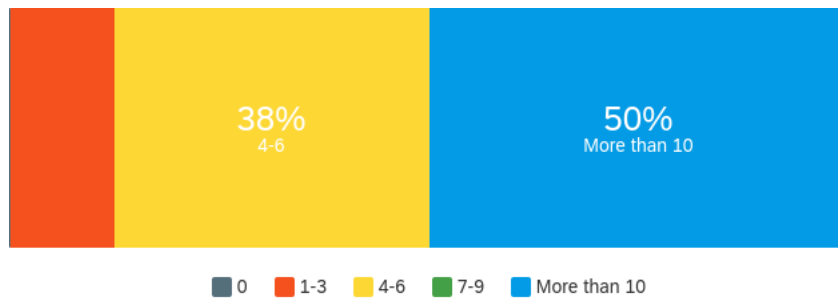
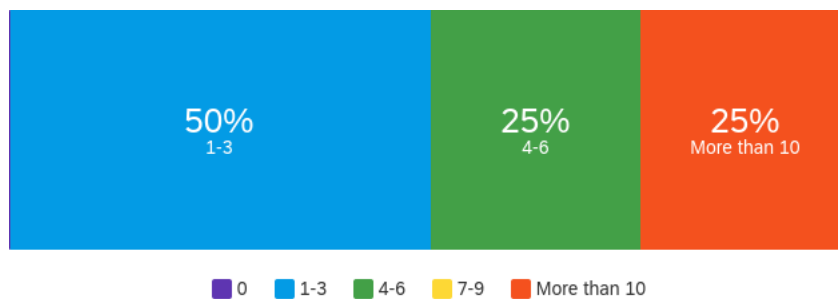


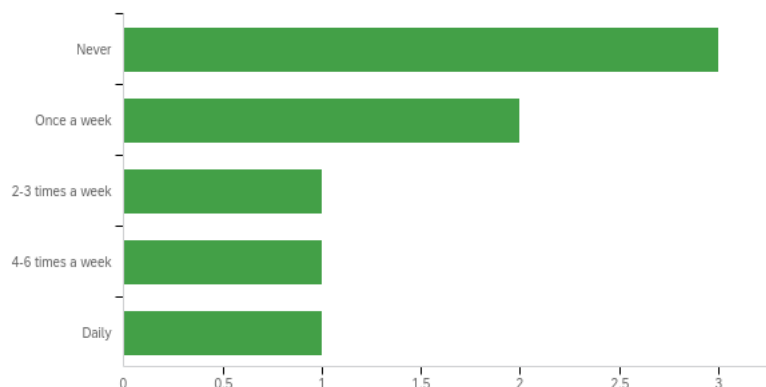
Figure 1.2: How many *close* friends do you have?



## Section 2: Satisfaction with Social Relationships and Loneliness

Section 2 included two questions focused on participants' satisfaction or mindset towards their friends and social relationships. Individuals were asked if they wanted more friends. Half of participants (n=4) reported, "yes" and three individuals reported "sometimes." Therefore, 87.5% of participants at some point in their lives have desired more friendships. The second question asked how often participants feel lonely. Responses varied with three participants reporting "never," two reporting "once a week," one reporting "two to three times a week," one reporting "four to six times a week," and one reporting "daily."

Figure 2: How often do you feel lonely?



### Section 3: Perspectives on the Role of Disability in Social Relationships

Discussing the social experiences of individuals with ID cannot be done without the necessary context of ableism. The third block of questions focused on participants' mindset towards their disability and how they perceive their disability to affect their social experiences. Six individuals reported that they believed “probably yes” or “definitely” that their disability made them different from others. Participants also reported that people without disabilities are nice to them and sometimes nice to them, but no participants reported they felt people without disabilities were not nice to them. This is a very simplistic question to discuss the complex topics of discriminatory experiences and ableism, but this question provides some insight into individual perspectives. While all individuals reported that they felt people were nice to them, half (n=4) reported they felt that people do not want to communicate with them based on their disability and over half (n=5) of individuals believed they would or might have more friends if they did not have a disability.

#### **Section 4: Activities with Friends**

One of the main goals of this project was to understand how caregivers currently support adults with ID in their social experiences. Questions included: (a) what they liked to do with their friends, (b) how their caregivers help them connect with their current friends, and (c) how their caregivers help them make friends. Participants were able to choose all options that were applicable to them.

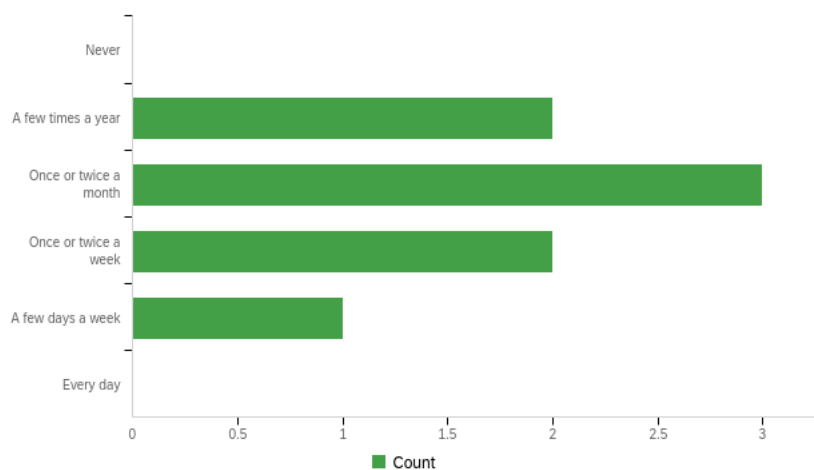
<b>Activity:</b>	<b>Responses (n=8):</b>
<b>Visit my friends</b>	8
<b>Talk or text with my friends on the phone</b>	7
<b>Watch TV and movies with friends</b>	7
<b>Go on walks with my friends</b>	6
<b>Go shopping with friends</b>	6
<b>Play games with friends</b>	4
<b>Go to community events with my caregiver</b>	3
<b>Meet new people in the community</b>	2
<b>Other:</b>	“Eating, cooking, and volunteering” “Slumber parties and working together” “Travel, but COVID restrictions”

Table 1: Preferences for Activities with Friends

All eight individuals like to visit with friends and seven individuals answered they liked to watch television and movies as well as communicate on the phone.

However, when asked a follow up question on how many times participants did these things with their friends, only one individual reported “a few days a week,” two individuals reported “once or twice a week,” three individuals reported “once or twice a month,” and two individuals reported “a few times a year.” This may reveal that individuals with ID desire interaction with friends and have preferred activities, but many are not able to regularly participate in these activities.

Figure 3: How often do you see your friends?



Supports participants receive to maintain connections with friends may not regularly occur based on the frequency follow-up question, but participants do receive supports across the requirements for social facilitation from organization to conclusion of the social experience.

**Social Supports:**

**Responses (n=8):**

**Helps transport me to see my friends** 5

**Organizes events for us to be together** 2

**Helps me think of things to talk about** 2

**Supervises meetings with my friends** 0

**Other:** “Talk about ideas I have for when I get together with a friend”

“Right now much is via Zoom”

Table 2: Social Supports for Friendship Maintenance

In addition to how caregivers support them in maintaining friendships, they were also asked how their caregivers support them in making friends. When asked how their caregiver helps them make friends, only one individual responded their provider does not help them make friends. Participants in this study receive a comprehensive set of social supports in making friends as noted in the self-report. Other answer options are listed in Table 3 below.

<b>Social Supports:</b>	<b>Responses (n=8):</b>
<b>Helps me learn social skills</b>	5
<b>Takes me into the community</b>	5
<b>Helps me meet more people</b>	4
<b>Takes me to group events</b>	4

**My provider does not help me make friends** 1

**Other:** “Assists on Zoom meetings and in my job”

Table 3: Current Social Supports Received to Make Friends

### **Section 5: Supporting Social Relationships**

There was also a difference in caregiver support for making new friends and maintaining friendships. Individuals reported caregivers helping make friends in a variety of ways from learning social skills to taking individuals into the community. For maintaining friends, most individuals only had support with transportation. Responses to the multiple-choice questions about possibilities for further social supports included requesting to learn more social skills (n=1), introduction and transportation to group events (n=2), more time in the community to have fun (n=5), and help meeting more people in general (n=2). In this final section for the individuals to answer, they also engaged in a more complex thinking activity where they worked with their caregivers to create a list of ideas for how they could support them in making new friends. A few individuals reported finding more friends in classes or jobs, attending more events in the community, and even wanting more inclusion from neurotypical individuals. This list they created with their caregiver was both for them to create together for personal use and for the research team to assemble a list for caregivers looking for ideas of how to better support their clients. Half of individuals (n=4) reported they wanted their caregiver to support them more in their social relationships with two individuals



reporting they might want more support. Seventy five percent of participants in some capacity desire more support in their social lives.

Results from the caregiver answered questions demonstrated a common curiosity in wanting to better support their loved ones. All caregivers of the individuals were family members with six being parents and one being a sibling. One individual with ID did not complete the survey with a caregiver. When asked if they wished if they could provide more social support for their loved one, five responded “yes,” one responded “no,” and two responded “maybe.” The “maybe” answer was included for those who may not know the importance of social supports or have not thought about it before. When caregivers were asked about how they currently support their loved one socially, in an open-ended question they reported providing opportunities for engagement, community inclusion time, facilitating Zoom meetings, ensuring friends understand their loved one’s needs, arranging for another caregiver, searching for resources online, and being there for them emotionally.

Follow-up questions were then asked to caregivers to determine possible barriers to providing social supports and their perception about the importance of social supports for their loved ones. Caregivers indicated that barriers included: not enough time (n=6), the COVID pandemic limited social gatherings (n=2) and other support providers availability (n=2). Caregivers were also asked about their opinions about their loved ones’. They were asked if they thought their client was lonely with most providers answering towards the positive side including “might or might not” (n=3), “probably yes” (n=3), and “definitely yes” (n=1). Caregivers were then asked if they believed their

loved on would benefit from more opportunities to participate in social experiences and half cited “probably yes” and half cited “definitely yes.”

Figure 4: Do you believe your loved one is lonely?

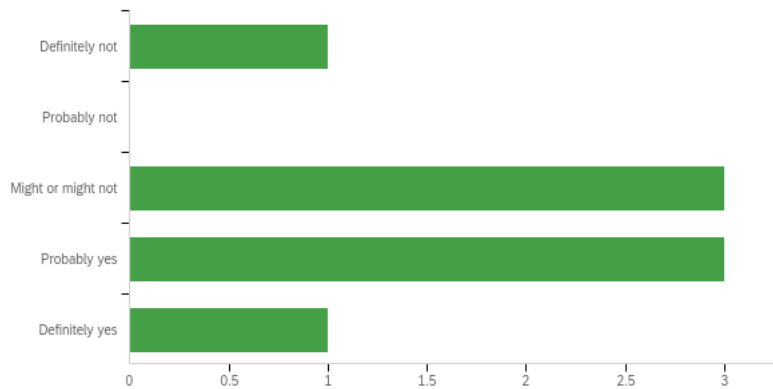
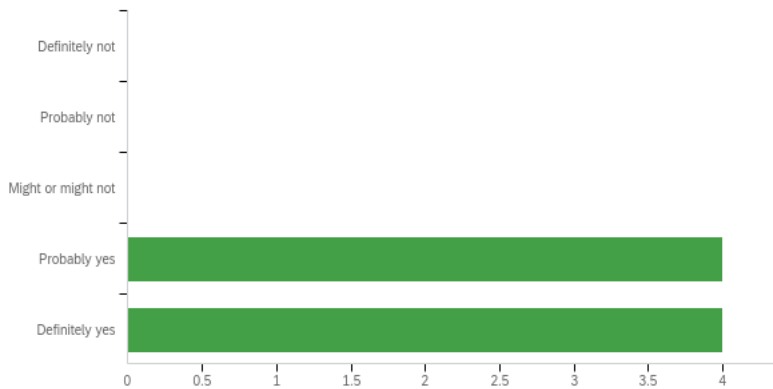


Figure 5: Do you believe your loved one would benefit from more social supports?



The self-reporting of this survey is incredibly important to reveal an individual’s personal perception, but the knowledge of caregivers is also important as they may have more insights that the individual themselves cannot discern. Finally, additional comments left by caregivers included their appreciation for the survey about this topic and their loved ones’ excitement to take part in the survey. One caregiver wrote, “I appreciate giving (name) a voice with this survey.” Another wrote, “My son was so excited to participate in this survey. He loves to feel as though he is contributing to something bigger than himself.”

This demonstrates a desire for more conversations to take place about this topic as it is an underrepresented topic in research and in the human service field.

## **Chapter 5: Discussion**

This study found that while participants received a variety of social supports as a group, the majority of participants also expressed a desire for more social supports to increase quality of life and decrease loneliness. This study produced several possible support options suggested by participants as well as provided participants the opportunity to have a sense of agency in asking for what they need, including further research and attention to this topic.

### **Understanding Social Satisfaction**

#### *Loneliness*

Alexandra et al. (2018) found that 44% of adults with ID experience loneliness—a discrepancy between their expectations for relationships and their real experience as well as unmet social and emotional needs. In this pilot study, 62.5% (n=5) of participants reported experiencing loneliness from once a week to daily. It is important to understand the people with ID who are in communities struggling with loneliness and who do not have the opportunities to change it. This survey was answered by individuals who have loved ones who found this resource and took the time to complete the survey. Even with such dedicated support, a number of individuals still struggle with loneliness. Individuals with more parent and familial involvement may have more opportunities for social experiences and social support, but a gap remains. For example, individuals living in group homes may feel differently. In many ways, those with ID are part of an unreachable, or at least difficult to reach, population which affects our understanding of their needs and how best to support them.

Expansion of social networks has been an emerging social intervention to increase an individual's opportunities for social experiences and combat loneliness as it has been estimated that individuals with ID have an average of 3.1 people within their social networks compared to 125 for the general population (Alexandra et al., 2018). Many individuals with ID may only have social networks consisting of family members and paid caregivers. These relationships are important, but may not represent a fully reciprocal relationship. For this group of individuals with ID, many reported having developed social networks, but still suffering from loneliness. Another intervention that may be useful in combatting loneliness in individuals with ID may be increasing frequency of social supports in working to maintain the quality of social networks rather than purely expanding social networks (Asselt-Goverts et al., 2015). The individual who reported feeling lonely daily also reported seeing their friends a few times a year. This connection between loneliness and frequency of social experience should be researched further.

#### *Recruitment and Access to the Population*

For this study, recruitment primarily took place over email to agencies and services that are in contact or work with individuals with ID or their family. This method was inefficient, as evidenced by a low response rate from agencies and few consenting participants compared to the total number of agencies contacted via email. The research team reached out to between 750 and 1000 different agencies and individuals who work with adults with ID receiving approximately 100 to 200 responses resulting in eight participants. In a review of participation in ID research, Cleaver et al. (2010) discuss the importance of multiple modes of contact for recruitment encouraging

direct contact as most effective. Research studies which had higher participation had “direct access to participants, the data collection was non-invasive and consent was required from substitute decision-makers only” (Cleaver et al., 2010). While the data collection process was non-invasive through the online survey for this study, without direct access to participants to guide their participation and introduce the study to them, the survey was difficult to distribute.

Ideally, this survey, and research in general, would be conducted without the effects and limitations of the COVID-19 pandemic which barred direct access to participants. In addition, while less complicated, limiting participation only to individuals who need “substitute decision-makers” who can engage in consent for them limits the participation pool and lessens the autonomy of individuals with ID. It is inappropriate to require an individual who is their own guardian to have someone else have that type of control subjected on them. While recruitment was difficult and complex, both the safety and the dignity of adults with ID were prioritized in this research.

#### *Participation of Paid Caregivers*

Individuals who participated in this study all had caregivers who were family members including parents and siblings with the exception of one participant who responded independently. This survey was originally designed to target paid caregivers, including, but not limited to, Personal Support Workers and Direct Support Professionals. However, no paid caregivers responded. This survey provided an activity for caregivers to engage with their clients to connect and learn from them. It is possible that paid caregivers did not see this as part of their role. Studies have documented that

paid caregivers prioritize physical care tasks over social supports (McConkey & Collins, 2010) while parents and family members may have a more vested interest in supporting the overall quality of life of their loved ones. However, the lack of participation from paid caregivers could also represent the overburdened nature of the role, especially during the COVID-19 pandemic. Service agencies were one of the hardest hit fields when the pandemic started as it already had a struggling infrastructure with a high-turnover rate estimated at 48.4% in 2018 (Pettingwell et al., 2022; Houseworth et al., 2020). Those who left their jobs as caregivers, 38% left before the role in under six months, another 21% left prior to one year (Houseworth et al., 2020). High turnover rates in homes and care agencies affect the overall quality of care for individuals as new staff are constantly being trained and many organizations are dangerously understaffed. It has been found in prior research that high turnover of staff increases individuals' feelings of sadness and difficulty in developing relationships and trust in new staff (Houseworth et al., 2020). If caregivers themselves cannot develop relationships with their clients, there is increased struggle in helping clients form relationships with others. In addition, parents in the current study cited finding reliable help during the pandemic, not having enough time in general, and transportation as their main barriers to providing more social support. The need for increased workers in this field has the potential to increase the quality of physical and social supports for individuals with ID. However, it also has the possibility to prevent challenges within the family caring for their loved one, such as coordination and responsibility of care, social isolation, and disrupted family relationships (Thompson et al., 2014; Wang, 2012).

## **Future Social Supports**

### *Desire for Community: Barriers to Access*

Participants expressed a desire for an increase of community involvement demonstrating the need for individuals to feel a sense of belonging in their communities—in addition to access. One individual purely wrote they felt that “inclusion goes both ways” indicating the need for both individuals and events to be inclusive to all people. Many individuals with ID do not have access to community events because of either physical barriers, financial barriers, sensory barriers, and more.. Two individuals also mentioned a desire for a mentor figure to help them make friends and integrate into their community. One individual was able to register for a program to have a mentor available to them, but once registration was completed there were not enough interested people to become mentors. One challenge is that community stakeholders who develop these events may not be aware of the needs of individuals with ID. Understanding barriers to social experiences and the needs of individuals with ID will allow stakeholders to create interventions and events that are helpful for individuals with ID. For the mentor program that a participant was not able to join due to not having enough mentors available, understanding the demand for social supports can improve the preparedness of founders of these programs and lessen the disappointment of those who were not able to participate.

### *Need for Social Supports*

The secondary goal of this study was to explore care resources for caregivers to look to when they are looking for new supports for their clients or loved ones. Prior



research has found that many caregivers, including family caregivers, indicate a desire for more training on how to support social experiences for their clients and family members (Fulford & Cobigo, 2018).

When individuals were asked about the supports they either currently receive or provide, supports ranged across social experience facilitation from teaching social skills to organization and preparation of events to transportation. When asked about current supports to connect with friends, at least one individual chose all answers besides caregivers supervising meetings with friends. Participants also endorsed organizations of events and meetings, and transportation. In contrast, caregivers prioritized supports for the creation of friends over the maintenance of friends. This discrepancy between the perspective of individuals with ID and their caregivers on what supports are desired may indicate a need for more attention to be given to maintaining connections with current friends to combat loneliness and increase satisfaction with social experiences.

Parents and siblings represented in this study, are incredibly resourceful in creating and implementing person-centered supports specifically designed for their loved one. One parent mentioned an especially helpful support they developed and advocated for together was to approach their religious community's board members to have a meeting about how their groups could be more inclusive to adults with ID. While attending youth group meetings, for example, a member of the group would sit with and informally support the individual with ID during meetings such as where to sit and what is happening. This type of intervention needs a lot of dedication and self-advocacy which many individuals do not necessarily have available to them. But this experience is also evidence of communities being open to making inclusive changes when the need

is understood. The individuals with ID involved in this study are comprehensively supported based on their responses to this survey. Their answers also demonstrate how individuals with ID receive and need supports throughout all aspects of social facilitation from brainstorming to organization to the experience itself. Each part of the process is important to ensure a positive social experience.

### *Limitations and Future Directions*

This study was limited in its online capacity and narrow participant pool as a consequence of difficult recruitment. Future studies could include face to face in person contact, compared to an online survey, with researchers traveling to care agencies to speak directly with individuals with ID and their caregivers. A sense of trust and cooperation could be developed from face-to-face access, but distance would also be necessary to avoid manipulation or coercion. If possible, a warm handoff could be conducted between agency workers and the research team while visiting their location. According to the Agency for Healthcare Research and Quality, this would allow trust to be transferred from original caregivers to the research team and encourage participation in the study (2017). The research team could also include more people from across the country to replicate the national presence this study had while keeping travel costs down.

The study was also limited in its scope of questions due to the nature of the survey. With the use of in person or virtual interviews with individuals with ID, follow-up questions could have been introduced in response to answers to original questions. For example, after asking individuals if people without disabilities are nice to them, a

follow-up question could ask in what ways they were nice or mean to them as well as how it made them feel. This would have allowed a more in-depth picture to be found.

In addition to follow up questions, another limitation with the scope of questions was the absence of a question to determine what living situation individuals resided in. Prior research has been found differences in the social experiences and social satisfaction of individuals with ID depending on where they live (e.g., living with family, group foster homes, independent living: McConkey and Collins, 2010; Fulford and Cobigo, 2018; Wilson et al., 2016; Alexandra et al., 2018; Asselt-Goverts et al., 2014). These sources have found that adults living at home tend to receive more social supports compared to those residing in group foster homes. Without this question included in this study, no determination can be made relating to living arrangement. While the caregivers supporting individuals in this study were parents and a sibling that supports the idea of increased familial involvement in participants' lives, many families still have strong relationships with their loved ones if they live outside the home, such as in a group home.

One way to bring information to community stakeholders is to listen to those with ID. Many times, individuals with ID are not consulted when decisions are made about their lives and providers do not ask them what they want or need. According to Ed Roberts, the founder of World Institute on Disability,

When people with disabilities come to the conclusion that they have the right to be in the community, to have a say in how that community treats them, they are beginning to develop a consciousness about taking control of their lives and revisiting all attempts to give others that control. (Charlton, pp. 13).

Those with ID need to be asked what they need and included on advocacy boards to begin to gain control over their lives. The self-reporting aspect of this survey was, therefore, vital to hear this list of possible supports from the individuals themselves. This survey was a way for individuals to both self-report to the research team what they need and self-report to their caregivers as well. This process can embolden individuals to learn how to self-advocate.

### *Conclusion*

This study highlights the need for further discussion and research into the social experiences and social supports of adults with ID. This was expressed through the answers to questions expressing loneliness, their desire for more friends, and their participation in the survey. Comments were left by caregivers at the end of the survey. One parent commented they appreciated giving their child a voice. Another wrote, “My son was so excited to participate in this survey. He loves to feel as though he is contributing to something bigger than himself.” An individual with ID also independently sent a video, filmed by their guardian, to the research team. She said, “I am super excited to do your survey and I am so honored you are taking the time to ask people about me with IDD.” Not only is there a need for more research on the social experiences of individuals with ID, but they are asking to have their voices heard.

## Bibliography

- Agency for Healthcare Research and Quality. *Warm Handoff: Intervention*. AHRQ. <HTTPS://www.AHRQ.gov/patient-safety/reports/engage/interventions/warmhandoff.html>
- Loneliness in people with intellectual and developmental disorders across the lifespan: A systematic review of prevalence and interventions. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 643–658. DOI: 10.1111/jar.12432
- American Speech-Language-Hearing Association. *Intellectual Disability*. ASHA. <https://www2.asha.org/PRPSpecificTopic.aspx?folderid=8589942540&section=Overview>
- Asselt, G. A. E., Embregts, P. J. C. M., Hendriks, A. H. C., & Frielink, N. (2014). Experiences of support staff with expanding and strengthening social networks of people with mild intellectual disabilities. *Journal of Community & Applied Social Psychology*, 24(2), 111–124. DOI: 10.1002/casp.2156
- Asselt-Goverts, A., Embregts, P., & Hendriks, A. (2015). Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research*, 59(5), 450–461. DOI: 10.1111/jir.12143
- Asunta, P., Rintala, P., Pochstein, F., Lyyra, N., & McConkey, R. (2021). The development and initial validation of a short, self-report measure on social inclusion for people with intellectual disabilities—A transnational study. *International Journal of Environmental Research and Public Health*, 18(5), 25–40. <https://doi.org/10.3390/ijerph18052540>
- Bigby, C. (2012). Social inclusion and people with intellectual disability and challenging behaviour: A systematic review. *Journal of Intellectual & Developmental Disability*, 37(4), 360–374. DOI: 10.3109/13668250.2012.721878
- Brown, R. I., Cobigo, V., & Taylor, W. D. (2015). Quality of life and social inclusion across the lifespan: challenges and recommendations. *International Journal of Developmental Disabilities*, 61(2), 93–100. DOI: 10.1179/2047386914Z.00000000092
- Charlton, James I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.
- Cleaver, S., Ouellette-Kuntz, H., & Samar, A. (2010). Participation in intellectual disability research: A review of 20 years of studies. *Journal of Intellectual Disability Research*, 54(3), 187–193. <https://doi.org/10.1111/j.1365-2788.2010.01256.x>

- Cooper, S., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). An epidemiological investigation of affective disorders with a population-based cohort of 1023 adults with intellectual disabilities. *Psychological Medicine*, *37*, 873-882. DOI 10.1017/S0033291707009968
- Eaton, C., Tarver, J., Shirazi, A., Pearson, E., Walker, L., Bird, M., Oliver, C., & Waite, J. (2021). A systematic review of the behaviours associated with depression in people with severe-profound intellectual disability. *Journal of Intellectual Disability Research*, *65*(3), 211-229. DOI 10.1111/jir.12807
- Friedman, C., & Rizzolo, M. C. (2018). Friendship, quality of life, and people with intellectual and developmental disabilities. *Journal of Developmental & Physical Disabilities*, *30*(1), 39–54. <https://doi-org.libproxy.uoregon.edu/10.1007/s10882-017-9576-7>
- Fulford, C., & Cobigo, V. (2018). Friendships and intimate relationships among people with intellectual disabilities: A thematic synthesis. *Journal of Applied Research in Intellectual Disabilities*, *31*(1), e18–e35. DOI: 10.1007/s10882-017-9576-7
- Hartley, S. & MacLean, W. (2009). Depression in adults with mild intellectual disability: Role of stress, attributions, and coping. *American Journal on Intellectual and Developmental Disabilities*, *114*(3), 147-160. DOI 10.1352/1944-7588-114.4.147
- Houseworth, J., Pettingell, S. L., Kramme, J. E. D., Tichá, R., & Hewitt, A. S. (2020). Predictors of annual and early separations among direct support professionals: National core indicators staff stability survey. *Intellectual and Developmental Disabilities*, *58*(3), 192-207. <http://dx.doi.org/10.1352/1934-9556-58.3.192>
- Hurd, C., Evans, C., & Renwick, R. (2018). “Having friends is like having marshmallows”: Perspectives of transition-aged youths with intellectual and developmental disabilities on friendship. *Journal of Applied Research in Intellectual Disabilities*, *31*(6), 1186–1196. DOI: 10.1111/jar.12493
- Lee, K., Cascella, M., & Marwaha, R. (2021, August 11). *Intellectual disability*. NCBI. <https://www.ncbi.nlm.nih.gov/books/NBK547654/>
- Logeswaran, S., Hollett, M., Zala, S., Richardson, L., & Scior, K. (2019). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research in Intellectual Disabilities*, *32*(3), 533–542. DOI: 10.1111/jar.12566
- Lunsky, Y. & Benson, B.A. (2001). *Journal of Intellectual Disability Research*, *45*(2), 106-114. DOI 10.1046/j.1365-2788.2001.00334.x

- McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, 54(8), 691–700. DOI: 10.1111/j.1365-2788.2010.01295.x
- McKenzie, K., Milton, M., Smith, G., & Ouellette-Kuntz, H. (2016). Systematic review of the prevalence and incidence of intellectual disabilities: Current trends and issues. *Current Developmental Disorders Reports*, 3, 104-115. DOI: 10.1007/s40474-016-0085-7
- Pettingell, S. L., Houseworth, J., Tichá, R., Kramme, J. E. D., & Hewitt, A. S. (2022). Incentives, wages, and retention among direct support professionals: National core indicators staff stability survey. *Intellectual and Developmental Disabilities*, 60(2), 113-127. <http://dx.doi.org/10.1352/1934-9556-60.2.113>
- Pottie, C., & Sumarah, J. (2004). Friendships between persons with and without developmental disabilities. *Mental retardation*, 42(1), 55–66. [https://doi.org/10.1352/0047-6765\(2004\)42<55:FBPWA>2.0.CO;2](https://doi.org/10.1352/0047-6765(2004)42<55:FBPWA>2.0.CO;2)
- Scott, H. M., & Havercamp, S. M. (2014). Mental health for people with intellectual disability: The impact of stress and social support. *American Journal on Intellectual and Developmental Disabilities*, 119(6), 552-64. DOI: 10.1352/1944-7558-119.6.552
- Siperstein, G., Parker, R., & Drascher, M. (2013). National snapshot of adults with intellectual disabilities in the labor force. *Journal of Vocational Rehabilitation*, 39, 157-165. DOI 10.3233/JVR-130658
- Smiley, E., Cooper, S., Finlayson, J., Jackson, A., Allan, L., Mantry, D., McGrother, C., McConnachie, A., & Morrison, J. (2007). Incidence and predictors of mental ill-health in adults with intellectual disabilities. *The British Journal of Psychiatry*, 191, 313-319. DOI 10.1192/bjp.bp.106.031104
- Thompson, R., Kerr, M., Glynn, M., & Linehan, C. (2014). Caring for a family member with intellectual disability and epilepsy: Practical, social, and emotional perspectives. *Seizure*, 23(10), 856-863. <https://doi.org/10.1016/j.seizure.2014.07.005>
- Wang K. Y. (2012). The care burden of families with members having intellectual and developmental disorder: a review of the recent literature. *Current opinion in psychiatry*, 25(5), 348–352. <https://doi.org/10.1097/YCO.0b013e3283564>