

SOCIAL ENGAGEMENT OF ADULTS WITH DISABILITIES AND DIFFERENCES BASED  
ON LEVEL OF FUNCTIONING

By

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Social engagement is a key aspect of a happy, healthy life for all individuals, including adults with intellectual and development disabilities (IDD). The current study analyzed how level of functioning connected to frequency of social activities, activity partners, and friendship, all which are key aspects of social engagement. Over 500 caregivers of adults with IDD took the survey, responding to items about their own characteristics, the characteristics of the adult with IDD (including level of functioning, operationalized as Activities of Daily Living score quartiles), the adults' social engagement (frequency of 20 social activities, frequency of participation with 5 different activity partners, and number of friends in three categories), and potential correlates to the social engagement variables. Adults with disabilities participated in many social activities, but their participation was mostly in social activities happening within the house. Adults with IDD participated in social activities with family the most often, and peers without disabilities least often. Compared to adults with higher levels of functioning, adults with the lowest level of functioning participated in the fewest social activities, had less social engagement outside their family, participated less in disability organization activities, and had fewer friends. Conversely, those with the lowest (versus highest) functioning levels participated in activities with caregivers and professionals more frequently. Also compared to adults with higher levels of functioning, adults with low levels had weaker connections between social

engagement variables. Implications of these findings, for both practice and policy, are given to close the gaps in the social engagement of adults with varying levels of functioning.

*Robert M. Hodapp*

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by

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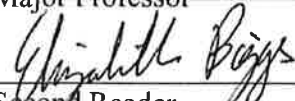
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## TABLE OF CONTENTS

Chapter		
I.	INTRODUCTION .....	1
II.	METHOD .....	7
	Participants.....	7
	Procedure .....	14
	Survey Instrument .....	15
	Variables of Interest .....	16
	Potential Correlates .....	16
	Adult with IDD information.....	16
	Respondent information .....	17
	Data Analysis .....	18
III.	RESULTS .....	20
	Community Involvement .....	20
	Activities .....	20
	Activity Partners .....	21
	Friends.....	22
	Relationship of Community Involvement to Level of Functioning.....	25
	Activities .....	25
	Activity Partners .....	27
	Friends.....	28
	Connections of Variables of Interest .....	29
IV.	DISCUSSION .....	31
	Implications for Practice .....	33
	Implications for Policy and Funding .....	37
	Limitations .....	39
	Conclusion .....	40
	REFERENCES .....	41

## LIST OF TABLES

### Table

I.	Characteristics of Respondents and Adults with Disabilities.....	8
II.	Social Activity Frequency.....	23
III.	Differences in Outcome Variables for ADL Quartiles.....	26
IV.	Correlations among Variables of Interest within Highest Quartile ADL (Top) and Lowest Quartile ADL (Bottom).....	30

## CHAPTER 1

### INTRODUCTION

Families, professionals, and individuals themselves have long highlighted the importance of community engagement of people with intellectual and developmental disabilities (IDD). While these conversations often revolve around inclusive education for children with disabilities, adults with IDD often still find themselves separated from their surrounding communities; compared to other adults, adults with disabilities report being over three times more likely to be lonely and to experience social isolation (Macdonald et al., 2018). Additionally, almost 30% of adults with mild to moderate IDD feel dissatisfied with their amount of social activity (Hall et al., 2005). These findings are especially unsettling in that, for adults with IDD, loneliness shows a strong negative correlation with mental wellbeing (Emerson et al., 2021). Conversely, social support from others comprises a key element of friendships (Spruit & Carter, 2021), and such support generally improves the individual's quality of life (Sanderson et al., 2019).

Beyond feelings of loneliness and dissatisfaction, individuals with IDD often experience daily lives that lack social interaction and community involvement. In one study, for example, Bigby (2008) found that almost half of adults with disabilities who attended a day program had no friends and little social activity during their free time outside of the program. In another study, over half of residential-facility residents had no friends outside the facility or who visited them over the course of a month (Hall &

Hewson, 2006). Outside of interactions with caretakers and day activities, then, many adults with disabilities experience little to no social activity or friendship.

While studies conceptualize community engagement differently, several components seem critical: what activities adults with IDD perform with others, who they do these activities with, and how many friends they have. First, it is important to measure everyday activities performed with others. Mihalia et al. (2017) examined the types of social activities (including 12 activities such as “talk to a friend on the phone”) performed by adults with IDD. They found that “prayer/meditation” was by far the most common daily activity, and a few of the least frequent activities (performed “never” or “yearly”) were “attend a club meeting” (66.1%), “attend parties” (45.2%), go to “organized social events” (35.4%), and “engage in political activity”(83.9%). While this study examined particular social activities, the list excluded many important activities, such as group exercise/sport, going to the movies, and using social media. For this study, social activity was operationalized as how often adults with IDD participated in twenty different activities with peers with or without disabilities. Some of the social activities involved less direct interaction between the adult with the disability and their peer, such as watching TV together, and other social activities involved more active participation with peers, such as talking on the phone. Both types of social activities are important because our social lives entail organized social activities and casual social activities.

A second component of social engagement involves who adults with IDD do these activities with (i.e. activity partners). Lippold and Burns (2009) measured social



activity partners by looking at how many people are in an adult's inner, middle, and outer circles, with inner circle defined as interacting often with this person. For adults with IDD, over half of their inner circle was family, 18% staff workers, and only about 22% peers. Such findings aligned with Sanderson et al. (2017), who found that "friends" only made up 26.3% of recreational support outside of family. In addition to providing physical proximity and support, activity partners may engage with the adult with IDD in various activities, although this was not the case for all activity partners. Mihalia et al. (2017) found no significant correlation between the amount of time the adult with IDD was with their caregiver and the amount of social activity they experienced. Thus, while adults with IDD may spend the most social time with caregivers, this time with caregivers did not promote higher participation in social activities like going out to community spaces. To date, however, we operationalized activity partner participation as how often one engages in activities with family, peers with disabilities, peers without disabilities, caretakers/professionals, and disability organizations in their community.

A third component of community involvement is friendship. This domain of variables is crucial, because friendships may result from social activity with peers and lead to further social activity. Silverman et al. (2017) highlighted the importance of friendship for adults with disabilities; in their study, they found that having more friends with disabilities may prevent the risks of low quality of life associated with severe to profound disabilities.

Although people with IDD may benefit from friendships with peers, these friendships may be uncommon. Bigby (2008) found that adults with IDD often nominated disability professionals as friends; 83% of adults indicated a staff member as a friend, and half of the adults were only friends with staff members. The friends of adults with disabilities may mostly be family and paid staff, both of whom are not typical types of friendships in adulthood. Again, it seems necessary to determine how many friends that a person has within their family, with peers with disabilities, and with peers without disabilities.

In addition to basic descriptions, certain personal characteristics of adults with disabilities may relate to community involvement. For example, having severe challenging behaviors, communication difficulties, or daily living challenges were each correlated with less social activity (Emerson & McVilly, 2004; McDonald et al., 2018). One study found that men—as opposed to women—with disabilities had more friends without disabilities (Dusseljee et al., 2011). In addition, people with physical disabilities engaged more with non-family members than those with mild intellectual disabilities (Lippold & Burns, 2009). In short, characteristics of the individual (e.g., challenging behaviors; age, type of disability) may relate to the community engagement of adults with disabilities.

But one personal characteristic that remains under-explored concerns the adult's level of functioning. In one study, adults with mild—as opposed to moderate—ID were more likely to engage in activities during the day that were not specifically for people

with disabilities, and they had more contact with friends with and without disabilities (Dusseljee et al., 2011). In addition, people with lower (versus higher) levels of functioning participated in a less varied set of social activities (Mihalia et al., 2017); although Badia et al. (2011) found no difference in social activity based on level of disability. More generally, studies examining community involvement of individuals of different functioning levels have excluded adults with severe to profound disabilities. Even several of the above-mentioned studies focused solely on adults with mild to moderate disabilities (Dusseljee et al., 2011; Lippolds & Burns, 2009; Svetlana, Marija, & Bojan, 2014). Others included in their study participants with severe or profound disabilities but did not describe findings specifically for this sub-group (Badia et al., 2011; Bigby, 2008).

And yet, while few direct studies exist, adults with severe to profound disabilities may engage in the least number of social activities and interact only with family or paid caregivers. Kanstra, Van der Putten, and Vlaskamp (2014) found that most non-paid people who engaged with adults with profound and/or multiple disabilities were family members, and an additional 9.5% of non-paid people engaging with this population were volunteers. Additionally, people with profound/multiple disabilities only engaged with non-related social partners (on average) about 24 times per year, with most interactions occurring at the person with a disability's residential setting, rather than in the community (Kanstra, Van der Putten, & Vlaskamp, 2014). People with severe intellectual disabilities had fewer friendships than people with no disability and people with mild

intellectual disability, and they were least likely to have a social support that they could count on when in need (Hall et al., 2005). Lastly, while adults with disabilities had low levels of social support overall, those with severe to profound disabilities had the least social support and were judged as having the lowest degrees of social inclusion (Lunksy & Benson, 1999; McConkey, Sinclair, & Walsh-Gallagher, 2005). It may be that those adults with lower (versus higher) levels of functioning differ in community involvement.

In this study, we explored in greater depth the community engagement of individuals with IDD, with special attention to level of functioning. Using a large-scale, caregiver-report survey, we gained information on the activities, friendships, and activity partners of adults with disabilities at four levels of Activity of Daily Living (ADL), roughly equivalent to profound, severe, moderate, and mild intellectual disability. This study had three goals. First, we assessed the degree to which individuals with IDD engaged in specific social activities, who they engaged in social activities with, and how many friends they had within and outside of their family. Second, we compared these variables across four quartiles of functioning levels, including participants with little independence in their daily activities to adults with more typical amounts of independence. Finally, we analyzed how the variables of interest in this study may have differing connections based on level of functioning.

## CHAPTER 2

### Methods

#### *Participants*

This study examined 510 respondents, all of whom were the current or previous caregivers of an adult with disability. Respondents were mostly (> 65%) female, mothers, 51-70 years old, white, and middle-to-upper income. See Table 1. The majority additionally had at least some college or associate degree education, and most respondents had health ranging from “Good” to “Excellent”. Respondents’ hours worked varied, with 21+ hours per week being the most frequent response. Overall, 79.4% of respondents were currently the primary caregiver of the adult with IDD.

**Table 1**

*Characteristics of Respondents and Adults with Disabilities*

**A - Respondent**

<b><i>Relation to person with IDD</i></b>	<b><u>% (N)</u></b>
- Mother: (355)	69.6%
- Father: (41)	8.0%
- Sibling: (36)	7.1%
- Legal Guardian: (56)	11%
- Other: (22)	4.3%
<b><i>Age</i></b>	
- < 40: (18)	3.6%
- 41-50: (53)	10.8%
- 51-60: (203)	41.3%
- 61-70: (179)	36.5%
- 71+: (38)	7.7%
<b><i>Gender</i></b>	
- Female: (431)	88.5%
- Male: (54)	11.1%
<b><i>Race</i></b>	
- White (?)	90%
- Black/African American: (28)	5.6%
- Asian/Pacific Islander/Native American/Other: (22)	4.4%
<b><i>Ethnicity</i></b>	

- Hispanic or Latino(a): (35)	7.0%
<b><i>Health</i></b>	
- Poor: (11)	2.2%
- Fair: (73)	14.4%
- Good: (192)	37.8%
- Very Good: (168)	33.1%
- Excellent: (64)	12.6%
<b><i>Hours worked</i></b>	
- Retired: (126)	24.8%
- Less than 5 hours / unemployed: (86)	16.9%
- 5-20 hours: (66)	13.0%
- 21+ hours: (230)	45.2%
<b><i>Family income</i></b>	
- Less than or equal to \$40,000 (80)	16.5%
- \$40,001-\$60,000: (78)	16.1%
- \$60,001-\$80,000: (81)	16.7%
- \$80,001-\$100,000: (83)	17.1%
- More than \$100,000: (162)	33.5%
<b><i>Highest education</i></b>	
- Up to High School Graduation: (39)	7.7%
- Some college or Associates Degree: (134)	26.3%
- College graduate: (158)	31.0%

- Graduate / professional degree: (173)	33.9%
<b><i>Current marital status</i></b>	
- Single: (54)	10.6%
- Married or Civil union: (345)	67.9%
- Long-term partnership: (10)	2.0%
- Divorced or separated: (76)	15.0%
- Widowed: (23)	4.5%
<b><i>Primary caregiver</i></b>	
- Yes: (405)	79.4%
<b><i>Ability to care</i></b>	
- Both parents deceased: (29)	5.7%
- Poor: (31)	6.1%
- Fair: (37)	7.3%
- Moderate: (87)	17.1%
- Good: (197)	38.7%
- Excellent: (128)	25.1%
<b><i>Disability org involvement</i></b>	
- Mean (SD) (1.02)	3.03
<b>B - Adults with Disabilities Characteristics</b>	
<b><i>Age</i></b>	
- 18-30: (269)	56.8%
- 31-40: (123)	25.9%
- 41-50: (36)	7.6%



- 51+: (46)	9.7%
<b><i>Disability</i></b>	
- Intellectual disability: (359)	70.4%
- ASD: (209)	41.0%
- Speech-language disorder: (180)	35.3%
- Learning disability: (161)	31.6%
- Behavioral disorder: (110)	21.6%
- Epilepsy: (109)	21.4%
- Cerebral palsy: (87)	17.1%
- Down syndrome: (85)	16.7%
- Other health impairment: (83)	16.3%
- Emotional disturbance: (65)	12.7%
- Traumatic brain injury: (25)	4.9%
<b><i>Function level (reported by respondent)</i></b>	
- Independent/Mild: (52)	10.2%
- Moderate: (211)	41.5%
- Severe: (170)	33.4%
- Profound: (76)	14.9%
<b><i>Activities of Daily Living (Quartiles)</i></b>	
- Low (Score: 0-9) (119)	23.4%
- Low-Middle (Score: 10-17) (135)	26.5%
- High-Middle (Score: 18-23) (127)	25.0%

- High (Score: 24+) (128)	25.1%
<b><i>Behavior (ICAP General Maladaptive Index Level)</i></b>	
- Normal: (307)	70.6%
- Marginal: (75)	17.2%
- Moderate-Very Serious: (68)	12.2%
<b><i>Physical Health</i></b>	
- Poor: (19)	3.8%
- Fair: (89)	17.6%
- Good: (200)	39.5%
- Very Good: (150)	29.6%
- Excellent: (48)	9.5%
<b><i>Mental Health</i></b>	
- Poor: (32)	6.3%
- Fair: (144)	28.4%
- Good: (178)	35.1%
- Very Good: (124)	24.5%
- Excellent: (29)	5.7%
<b><i>High school degree</i></b>	
- Did not graduate: (41)	8.0%
- GED/Regular Education diploma: (105)	20.6%
- Special Education diploma: (333)	65.3%
- Occupational Diploma: (5)	1.0%

- Other: (26)	5.1%
<b><i>ITP in high school</i></b>	
- Yes: (104)	20.5%
- No: (352)	69.4%
- Don't know: (51)	10.1%
<b><i>Hours worked</i></b>	
- Less than 5 hours / unemployed: (360)	70.6%
- 5-20 hours: (108)	21.4%
- 21+ hours: (35)	7.0%
<b><i>Job</i></b>	
- Part-time in the community: (176)	35.4%
- Full-time in the community: (13)	2.7%
- Part-time in a sheltered workshop: (61)	12.7%
- Full-time in a sheltered workshop: (20)	4.2%
- Volunteer in the community: (231)	46.4%
<b><i>Live at home</i></b>	
- Yes: (357)	72.0%
<b><i>Living situation</i></b>	
- With parents or siblings: (334)	65.5%
- Group home: (78)	15.3%
- Independently: (53)	10.4%
- Other: (45)	8.8%

The average age of the adults with disabilities was 31.96 years old (SD=11.79). Participants had 22 different disability diagnoses, and adults could have more than one indicated disability on the survey. The most common disabilities were intellectual disability (70.4%), autism spectrum disorder (41.0%), and speech-language disability (35.3%). The functioning level of the adults ranged from independent to profound, with the most common label being “moderate” to “severe” (74.9%). Most adults with disabilities had “normal” maladaptive behavior (70.6%) and were generally in the “good” to “excellent” physical (78.6%) and mental (65.3%) health range.

Regarding employment, most adults with IDD did not work (70.6%), and when the adults did work, only about a quarter (24.5%) worked more than 20 hours per week. Regarding residence, 65.5% of adults lived with family, and only about 10% lived independently.

### *Procedure*

A survey, originally designed to examine residential living and respite care for adults with disabilities, was created and included a wide range of variables on multiple issues (including community involvement). The survey was piloted with a variety of participants, including family members of people with IDD and professionals that work with adults with IDD. Using these participants’ feedback, we then revised the survey and gained approval from our university’s IRB.

To reach a large audience of potential participants, the survey was created and distributed using a web-based platform called Research Electronic Data Capture (REDCap). This platform allowed for secure and confidential data collection (Harris, Taylor, Payne, Gonzalez, & Conde, 2009). To recruit participants, flyers were distributed over email to individual members of the disability community, professionals within the disability community, and disability organizations that could inform potential participants about the survey. These organizations could use email lists, social media pages, live events, and more to inform potential participants. At the end of the survey, participants were redirected to another REDCap survey, where they could enter their email address into the raffle for one of ten \$25 gift cards. The email addresses were kept confidential and were not connected to their responses to the survey study. Once the survey had closed in April 2018, ten email addresses were randomly selected from the list to receive one of the \$25 gift cards through their email.

### *Survey Instrument*

The survey was divided into four sections, including information about (1) demographics of the respondent and family, (2) the adult with a disability, (3) current and future residential placements, and (4) respite care services utilized by the family. For ease of presentation, we begin describing the variables of interest (social activities, activity partners, and friendships).

### *Variables of Interest*

Respondents answered how often the adult with IDD engaged in 20 different activities with peers on a five-point Likert scale: (1) “never,” (2) “rarely, 1-2 times a month,” (3) “sometimes, once a week,” (4) “often, 2-3 times a week,” and (5) “almost always.” These 20 questions included disability-related activities like Special Olympics and Best Buddies, exercise activities like bicycling/skating/skateboarding and walking/hiking, and other activities such as going to a concert and using social media. There was a strong connection between the 20 activities; Cronbach’s alpha score for the 20 items was .850.

Respondents additionally rated how often the adult participated with peers with disabilities, peers without disabilities, family members, caretakers/professionals, or disability organizations. Respondents answered on a five-point Likert scale: (1) “never,” (2) “rarely, 1-2 times a month,” (3) “sometimes, once a week,” (4) “often, 2-3 times a week,” and (5) “almost always.”

Finally, respondents answered how many friends the adult with IDD had without disabilities, with family members, and friends with disabilities. Respondents answered on a five-point Likert scale: (1) “one friend” (2) “two friends”, (3) “three friends” (4) “four friends and (5) “Five or more friends.”

### *Protentional Correlates*

***Adult with IDD Information.*** First, respondents answered basic demographic questions about the adult with IDD, such as gender, age, physical health, mental health,

and maladaptive behaviors. Then, they reported their functioning abilities and daily living skills, which were key variables for the analyses in this study. Respondents first identified the adults' levels of functioning (from (1) "independent" to (5) "profound"), and then answered 17 Activities of Daily Living (ADL) scale questions, which measured the amount of support the adult with IDD needed to perform each item (from (0) "does not do at all," to (1) "does with help," to (2) "independent or does on own" (Lawton & Brody, 1969). There was a strong inverse correlation between reported functioning level and total activities of daily living (ADL) scores,  $r(506) = -.856, p < .001$ . This inverse correlation indicated that the total ADL score may be an accurate measure of level of functioning.

Additionally, respondents answered questions about the adults' transitions to and experiences in adulthood. These questions included school related questions including type of high school diploma and post-secondary education. Additionally, these questions asked about adults' employment, including how many hours the adult works. Last in this domain, respondents answered questions about the adults' residential life, including where the adult with a disability lives, with whom they live, how far they live from their parents, what support they receive in this setting, and where the adult will live in the future.

***Respondent Information.*** Respondents answered questions on a wide range of personal topics. Participants were asked about their role concerning the adult with a disability (mother, father, sibling, etc.) (primary caregiver: "yes" or "no"), their age, their

gender, race, ethnicity, state of residence, and then health from “poor” to “excellent.” Studies have indicated this that one question regarding health is a strong indicator of actual health (Idler & Benyamini, 1997). Then, caregiver respondents were asked how many hours they worked, total family income, and highest level of education.

### *Data Analysis*

To examine community involvement variables, we first divided variables of interest into three categories: frequency of participating in different social activities, frequency of participating in activity with five partner types, and number of friends in three categories.

To compare participation between the 20 social activities, we conducted a repeated measures ANOVA, with follow-up, paired samples t-tests, comparing frequency of each activity with frequency of participation in the overall average activity. Given that there was a significant Cronbach’s alpha for the 20 social activities, we created a total and average score of all the activities to compare the frequency of each activity to this average score.

To compare participation across the five activity partner groups, we conducted repeated measures ANOVA. As there was not a significant Cronbach’s alpha for the five types of activity partners (.673), our analyses did not group the scores across the activity partners.



To compare number of friends between the three types of friends, we conducted repeated measures ANOVA. Again, Cronbach's alpha for the three types of friends was not significant (.649), so our analyses did not group the scores across the number of friends.

For the second goal of this study, we then compared the different community involvement variables based on level of functioning, which was measured based on ADL scores ranging from 0 (does not do any of the 17 activities at all) to 17 (does all 17 activities with support) to 34 (does all 17 activities independently). Total ADL scores were then divided into quartiles of similar participant size, on a scale potential ranging from 0-34: (0-9) low-quartile, (10-17) low-middle quartile, (18-23) high-middle quartile, (24-34) high-quartile. As noted earlier, ADL quartile scores were mostly aligned to traditional mild-moderate-severe-profound intellectual disability categorizations. Thus, the low-quartile ADL group was 96.6% severe to profound (40.3% / 56.3%), low-middle quartile was 91.9% moderate to severe (31.9% / 60.0%), high-middle-quartile was 90.5% moderate to severe (63.5% / 27.0%), and high-quartile was 89.0% mild to moderate disabilities (23.4% / 65.6%).

These four ADL quartiles were compared for each of the three categories of variables of interest in this study. To determine if there was a significant difference in the results for the target variables between the ADL quartiles, two-way repeated measures ANOVAs were conducted for each of the three categories of community involvement variables (four ADL quartiles by frequency of 20 social activities, frequency of 5 activity

partners, and number of friends in 3 friend types). Additionally, the two-way ANOVAs indicated if there were significant interaction effects between each of the three categories of community involvement and ADL quartiles.

For the third goal of the study, comparisons between the low-quartile ADL and high-quartile ADL group were conducted to see if the connections between outcome variables significantly differed for these two groups (such as the connection between time spent with family members and the number of friends within the family). Fishers R-to-Z tests were conducted between the low and high quartile ADL groups, as well as a binomial test to see if the high-quartile ADL group had significantly more stronger correlations between variables of interest compared to the low-quartile ADL group.

## CHAPTER 3

### RESULTS

#### *Community Involvement*

##### *Activities*

Adults with disabilities, on average, participated in an activity with a peer between “never” and “rarely” ( $M=1.90$ ,  $SD=.56$ ). On average, adults performed about nine of the twenty social activities at least rarely ( $M=9.00$ ,  $SD= 4.61$ ), and they additionally did

about five of the twenty activities on a weekly basis ( $M=5.04$ ,  $SD=3.75$ ). A small percentage of participants participated in zero of the twenty activities (4.8%).

There was a significant difference in participation frequency across the twenty activities,  $F(19,8265)=179.47$ ,  $p<.001$ . Seven activities were performed significantly more often than the average activity ( $p<.01$ ); ten activities were performed significantly less often than the average activity ( $p<.01$ ). Of the seven most frequent activities, six involved social activities that often happen within or around a home (TV/movie, hanging out, walking, talking on the phone, making food, and social media). Of the ten least frequent activities, all were social activities that often happen outside of one's home (such as going to a museum, participating in Special Olympics, and being part of a book club).

#### *Activity Partners*

Almost everyone participated in an activity at least rarely with a family member (97.2%), but smaller percentages participated at least rarely with a peer without disabilities (74.6%) or a disability organization (77.4%). Examined differently, almost a quarter of participants never performed an activity with peers without disabilities or with disability organizations. Daily, many participants performed an activity with any of the partner options (59.4%), but a much smaller percentage (29.1%) performed an activity daily with peers with or without disabilities.

The frequencies of participation varied across the five different activity partners,  $F(4,1956) = 119.35$ ,  $p < .001$ . The effect size was large,  $\eta^2 = .196$ . The most

frequent activity partners were family members, and the least frequent were peers without disabilities and disability organizations. Adults with disabilities performed activities with family members significantly more than all the other activity partner options: peers with disabilities,  $t(503) = -7.39, p < .001$ , peers without disabilities,  $t(499) = 19.34, p < .001$ , caretakers/professionals,  $t(497) = 3.68, p < .001$ , and disability organizations,  $t(496) = 17.01, p < .001$ .

### *Friends*

Adults with disabilities averaged about eight friends. These friends were 21.89% peers without disabilities, 42.46% peers with disabilities, and 35.65% family members. When friends within the family were included, few adults had zero friends (3.5%), but when family members were not included, almost a sixth of participants (17.2%) had zero friends.

Differences also occurred in number of friends across the three friend types,  $F(2, 966) = 128.65, p < .001$ . The effect size, measured as the partial eta-squared, was large (.196). The adults with IDD had almost twice as many friends, on average, within their family ( $M=3.24$ ) compared to with peers without disabilities ( $M=1.67$ ). See Table 2.

**Table 2***Differences in Outcome Variables for ADL Quartiles***A – Activity**

	Low (1)	Low-Middle (2)	Middle-High (3)	High (4)
TV / Movie	3.05 (1.65)	3.50 (1.60)	3.80 (1.44)	4.03 (1.34)
Hang Out	2.17 (1.41)	2.71 (1.50)	2.65 (1.49)	2.87 (1.28)
Shopping	2.13 (1.10)	2.51 (1.12)	2.61 (1.02)	2.87 (1.14)
Walk/ Hike	2.02 (1.30)	2.50 (1.32)	2.33 (1.19)	2.69 (1.37)
Talk on Phone	1.41 (.97)	2.10 (1.30)	2.68 (1.40)	3.38 (1.46)
Make Food	1.21 (.57)	1.99 (1.25)	2.74 (1.39)	3.26 (1.37)
Social Media	1.30 (.92)	1.62 (1.20)	2.45 (1.62)	3.18 (1.70)
Crafting	1.75 (1.02)	1.98 (1.14)	2.15 (1.17)	2.21 (1.36)
Exercise	1.33 (.77)	2.16 (1.30)	2.15 (1.24)	2.33 (1.34)
Games	1.47 (.84)	1.83 (1.03)	2.10 (1.06)	2.15 (1.21)
Museums	1.65 (.81)	1.85 (.88)	1.86 (.79)	1.97 (.91)
Bowling	1.43 (.69)	1.82 (.78)	1.94 (.96)	1.99 (.99)
Special Olympics	1.29 (.69)	1.80 (1.06)	1.98 (1.27)	1.97 (1.26)
Live Event	1.53 (.74)	1.67 (.72)	1.66 (.72)	1.81 (.83)
Dancing	1.40 (.67)	1.64 (.87)	1.66 (.83)	1.83 (1.01)
Team Sports	1.07 (.31)	1.30 (.71)	1.21 (.63)	1.68 (1.14)
Best Buddies	1.08 (.48)	1.24 (.61)	1.26 (.66)	1.53 (.96)
Bike / Skate				
Other reading group	1.03 (.22)	1.11 (.42)	1.13 (.54)	1.33 (.87)
NCBC	1.01 (.09)	1.06 (.32)	1.03 (.25)	1.16 (.58)
Total Social Activity	30.09 (7.28)	37.45 (9.29)	40.23 (10.60)	44.68 (11.78)

**Table 2***Differences in Outcome Variables for ADL Quartiles***B – Activity Partners & Friends**

	Low (1)	Low-Middle (2)	Middle-High (3)	High (4)
<b>Activity Partners</b>				
With Peers with	3.04 (1.50)	3.30 (1.34)	3.34 (1.31)	3.06 (1.33)
With Peers without	2.08 (1.21)	2.45 (1.22)	2.58 (1.21)	2.75 (1.32)
With Family Members	3.52 (1.28)	3.73 (1.12)	3.76 (1.10)	3.88 (1.05)
With Caretaker or Professional	3.86 (1.40)	3.83 (1.39)	3.11 (1.50)	2.91 (1.58)
Organized by Disability Organization	2.18 (1.25)	2.62 (1.22)	2.66 (1.23)	2.76 (1.23)
Average (Activity Partner)	2.94 (.87)	3.19 (.80)	3.07 (.85)	3.08 (.91)
<b>Friends</b>				
Friends with Disabilities	2.05 (2.08)	2.57 (2.09)	2.97 (2.04)	3.21 (2.02)
Friends without Disabilities	1.27 (1.78)	1.63 (1.96)	1.61 (1.83)	2.10 (1.95)
Friends within Family	3.11 (1.79)	2.99 (1.96)	3.26 (1.74)	3.61 (1.74)
Average # of friends	2.16 (1.37)	2.36 (1.60)	2.60 (1.37)	2.97 (1.48)

## *Relationship of Community Involvement to Level of Functioning*

### *Social Activity*

There was a significant main effect of ADL quartile on participation in the 20 social activities,  $F(3,435) = 41.23, p < .001$ . For most of the twenty activities, the frequency of participation increased as ADL quartile increased; the highest-quartile ADL group had the highest average participation in 19 out of the 20 activities. Furthermore, the low-quartile ADL group had the lowest average participation in all 20 activities. Results of a post-hoc test indicated that the four ADL quartiles all had significantly different average activity scores, with increasing level of function corresponding to significantly higher average activity scores. Furthermore, the variety of social activities differed based on ADL quartile; adults with high-quartile ADL participated, at least rarely, in over twice as many activities as the low-quartile ADL group,  $t(211) = -10.63, p < .001$ . See Table 3.

**Table 3***Social Activity Frequency*

	Never	Rarely	Sometimes	Often	Almost Always	M (SD)	Compared to Average
TV / Movie	17.7%	10.5%	8.9%	19.1%	43.7%	3.61 (1.55)	>
Hang Out	30.8%	23.1%	16.1%	14.5%	15.5%	2.61 (1.44)	>
Shop	22.2%	25.6%	33.1%	14.5%	4.6%	2.54 (1.12)	>
Walk / Hike	34.1%	23.7%	19.3%	14.3%	8.6%	2.40 (1.32)	>
Talk on Phone	40.6%	20.3%	12.5%	11.5%	15.1%	2.40 (1.48)	>
Make Food	42.9%	18.5%	15.3%	11.7%	11.7%	2.31 (1.42)	>
Social Media	59.5%	8.0%	7.6%	8.2%	16.6%	2.14 (1.58)	>
Crafting	45.1%	26.4%	14.7%	8.3%	5.4%	2.02 (1.19)	
Exercise	51.7%	17.6%	12.8%	14.2%	3.8%	2.01 (1.25)	
Games	48.0%	27.6%	15.2%	5.8%	3.4%	1.89 (1.08)	
Museums	40.5%	40.1%	15.2%	3.6%	.6%	1.84 (.85)	<
Bowling	45.1%	34.6%	16.5%	2.6%	1.2%	1.80 (.89)	<
Special Olympics	62.1%	11.6%	16.6%	6.8%	3.0%	1.77 (1.13)	<
Live Event	47.1%	42.1%	7.8%	2.8%	.2%	1.67 (.76)	<
Dancing	55.5%	30.6%	9.7%	3.0%	1.2%	1.64 (.87)	<
Other Team Sports	83.2%	6.8%	6.0%	3.2%	.8%	1.32 (.79)	<
Best Buddies	83.0%	9.5%	4.9%	1.6%	1.0%	1.28 (.72)	<
Bike / Skate	87.1%	9.1%	2.6%	1.0%	.2%	1.18 (.54)	<



Other reading group	91.6%	4.4%	2%	1.4%	.6%	1.15 (.57)	<
NCBC	96.2%	1.8%	1.6%	.2%	.2%	1.06 (.36)	<

*N's for individual items from N=495 to 503.*

Average item score = 1.90

*All variables greater than average item (>) and less than average item (<) at p<.01*

Two of the greatest differences across ADL quartile were for frequency of talking on the phone and using social media with peers. For “talking on the phone”, there was a significant difference between all four ADL quartiles, with low-quartile ADL group using the phone the least and high-quartile ADL group using the phone the most,  $F(3, 498)=51.16, p<.001$ . For “using social media”, the two low quartile ADL groups used social media significantly less than the high-middle-quartile ADL group, who also had significantly lower frequency than the high-quartile ADL group,  $F(3, 494)=44.79, p<.001$ .

In addition to the significant main effects, there was a significant interaction effect between type of social activity and ADL quartiles,  $F(57, 8265)=8.50, p<.001$ . While the average activity participation increased with increases in ADL, certain social activities did not demonstrate this same increase in frequency as ADL quartile increases.

#### *Activity Partners*

Although ADL quartiles did not differ based on frequency of average activity partner type,  $F(3, 486) = 1.74, ns$ , there was a significant interaction effect between ADL quartile and activity partners,  $F(12, 1944) = 9.94, p < .001$ . Specifically, the low-quartile ADL group had the lowest participation with four of the activity partner groups (peers

with and without disabilities, family members, and disability organizations), but, the low-quartile ADL group had the highest participation with caretakers or professionals.

Furthermore, the high-quartile ADL group had the most frequent participation with three of the five activity partners (peers without disabilities, family members, and disability organizations). See Table 2. When activity with caregivers or professionals was removed, adults with low-quartile ADL were significantly more likely to do zero weekly social activities with activity partners (14.9%), compared to the low-middle (3.1%), middle-high (3.2%), and high-quartile ADL groups (7.1%),  $\chi^2(9, N=498) = 37.99, p < .001$ .

### *Friends*

The main effect of ADL quartiles on number of friends was significant,  $F(3,479) = 1429.49, p < .001$ . For each of the three types of friends and for the total number of friends, the average number of friends went up from the low-quartile ADL group to the high-quartile ADL group (except for friends without disabilities, in which the middle two ADL groups had about the same average number of friends). There was not a significant interaction effect between type of friend and ADL quartile,  $F(6,479) = 1.68, NS$ .

### *Connections of Variables of Interest*

Given that the most significant and consistent differences occurred between the low-quartile ADL group and high-quartile ADL group, we compared the correlations between the variables of interest with highest versus lowest quartile. Adults with high-quartile ADL, compared to low-quartile ADL, had significantly stronger correlations among variables of interest. Compared to adults in the low-quartile ADL, 31 of the 36 connections across social engagement variables were higher for the adults with high-quartile ADL, binomial  $p < .0001$ . See Table 4. For example, adults with high-quartile ADL had a significantly higher correlation between the frequency of activity with peers with disabilities and number of friends with disabilities,  $r(124) = .695$ ,  $p < .001$ , than noted in the low-quartile ADL group,  $r(111) = .416$ ,  $p < .001$ , Fisher's  $r$  to  $z$  test,  $z = -3.16$ ,  $p < .001$ .

**Table 4**  
Correlations among Variables of Interest within Highest Quartile ADL (Top) and Lowest Quartile ADL (Bottom)

	Total Activity	With peers with disabilities	With peers without disabilities	With family members	With caretaker or professional	With disability organization	Friends without disabilities	Friends with family	Friends with disabilities
Total Activity		.488**	.530**	.372**	.304*	.498**	.494**	.215	.511**
With peers with disabilities	.347**		.438**	.254*	.381**	.772**	.392**	.235*	.695**
With peers without	.428**	.395**		.422**	.224	.354**	.545**	.230*	.406**
With family members	.197	.103	.103		.111	.269*	.263*	.251*	.243*
With caretakers	.183	.283*	.290*	.263*		.374**	.210	.229	.272*
With disability organization	.459**	.689**	.360**	.090	.336**		.332**	.209	.610**
Friends without dis.	.110	.021	.364**	-.012	.112	.032		.434**	.451**
Friends with family	.222	.137	.127	.212	.232	.098	.233		.365**
Friends with dis.	.250	.416**	.196	-.08	.205	.332**	.261*	.360**	

\*= $p < .01$ , \*\*= $p < .001$

Highest quartile on the top →  $N = 104$  to  $128$

Lowest quartile on the bottom →  $N = 103$  to  $118$

## CHAPTER 4

### DISCUSSION

This study offered a general summary of the social lives of adults with disabilities, and additionally highlighted that the social lives of adults with low functioning disabilities differed greatly from adults with high functioning disabilities. Given these findings, policy makers and advocates need to acknowledge that the social challenges for adults with low ADL are not the same as adults with high ADL, and therefore the social interventions and policies should reflect the different needs and gaps.

Our first finding related to the social engagement of all adults with disabilities. Social engagement was measured in three ways: (1) frequency of participation in 20 social activities, (2) frequency of participation with five different activity partners, and (3) number of friends across three friendship types. Adults with disabilities participated in a variety of social activities (nine on average), and their average participation in an activity was between never and rarely. The adults most often participated in activities that happen within the home, such as hanging out and watching TV/movies, significantly more often than the average activity. In contrast, the adults participated in activities that often happen outside of the home, such as Best Buddies, significantly less often than the average activity.

Adults with disabilities also participated in activities with family members most often (between sometimes and often), and they participated in activities with peers

without disabilities and disability organizations the least often (between rarely and sometimes). Regarding friends, adults with IDD had an average of about eight friends, and they had the most friends within the family and the least friends with peers without disabilities.

A second major finding pertained to how the three categories of community involvement differed based on level of functioning. Regarding participation in the twenty social activities, adults with higher ADL scores participated more frequently in social activities than adults with lower ADL scores, which was similarly found in a study by Mihalia et al. (2017) but not by Badia et al. (2011). This difference may have occurred, because Badia et al. (2011) studied adults in Europe, and Mihalia et al. (2017) and the current study studied adults in the US. Most noticeably, the high-quartile ADL group used social media and talked on the phone with peers much more frequently than the low-quartile ADL group.

Compared to the frequency of participation with different types of activity partners for adults with lower ADL, adults with higher ADL participated more frequently in activities with peers with disabilities, peers without disabilities, and family members. These findings aligned with findings in previous studies by Dusseljee et al. (2011) and Kanstra, Van der Putten, and Vlaskamp (2014). But unexpected differences were also found; adults with higher ADL participated more frequently with disability organizations than adults with lower ADL scores. Conversely, adults with lower ADL scores participated more frequently in activities with caretakers or professionals than adults with

higher ADL scores. Inferring based on these results, it is possible that disability services for adults with lower ADL focus on individualized professional support, while disability services for adults with higher ADL focus on disability organization involvement.

Regarding types of friends, adults with higher ADL had more friends with peers with disabilities, peers without disabilities, and family members compared to adults with lower ADL.

Finally, the third major finding was that the connections between social engagement variables were almost always stronger within the group with higher ADL than within the group with lower ADL. Of particular concern, the connection between frequency of activity with peers with disabilities and the number of friends with disabilities was significantly stronger for adults with higher levels of functioning. This finding indicates that, within the low (versus) high ADL group, social activities may not be as effective in promoting the formation of friendships.

Taken together, these findings have important implications for practice, policy, and future research.

### *Implications for Practice*

Regarding practices, instruction, and interventions, three noticeable considerations are evident. As found in our study, adults with low ADL were less frequently communicating with peers over the phone or on social media. Given the

importance and high frequency of technology-based communication today, instruction and intervention need to assist adults with lower functioning to access this vital communication. Research has already demonstrated how assistive technology and technology-specific instruction may promote more frequent social media usage and more online social connections for people with IDD (Grace et al., 2014; Raghavendra et al., 2018). Future technology and social media interventions should focus on reaching people with severe to profound disabilities, to ensure that all adults have access to the friendships and social activity that occur online.

The second recommendation relates to the lack of variety of social activity for adults with low-quartile ADL. The low-quartile ADL group participated in less than half as many social activities than the high-quartile ADL group. Lacking diverse social activities, adults with low ADL may miss out on expanding their interests and exploring new interests with peers. Furthermore, new social activities offer opportunities to make new friends and develop new discussion topics about their diverse interests. As found by Wilson et al. (2017), when disability professionals organized multiple different social activities between adults with IDD, new friendships and future activities not planned by the researchers emerged organically. Interviewed participants mentioning how the structured social group has led to more social activities with peers, which they felt they lacked before the study (Wilson et al., 2017). Disability professionals and disability organizations should consider creating these structured social groups with diverse social



activities, so this population can discover new interests and find like-minded peers who enjoy these activities too.

The third practice recommendation specifically focuses on frequency of participation with disability organizations and caretakers/professionals across ADL quartiles. Across these quartiles, frequency of participation in disability organizations increased as level of functioning increased, and frequency of participation in activities with caretakers/professionals decreased. While disability organizations work hard to create social activity opportunities for adults with disabilities, the differences in disability organization involvement between adults with low ADL and high ADL emphasizes a gap in the disability organization services oriented at the low ADL group.

In response to this need, disability organizations may consider creating more inclusive programs with fewer daily living barriers to enrollment, or they may additionally consider creating separate programs that meet the strengths and needs of adults with low ADL. For example, Special Olympics offers the Motor Activity Training Program for people with disabilities who do not have the level of functioning necessary to meaningfully participate in Special Olympics sporting events (Special Olympics, 2022). While not typical sporting events, this separate program offers social and recreational activity for groups of adults with significant cognitive impairments.

An additional consideration for disability organizations is how their programs foster friendships between people with disabilities. The current study's results indicated that the connection between frequency of activity with peers with disabilities and number

of friends with disabilities was stronger for adults with high ADL compared to low ADL. Additionally, the correlation between activities with peers without disabilities and number of friends without disabilities was higher for adults with higher ADL compared to lower ADL. To tackle this issue, disability organizations and professionals should familiarize and implement the principles of the original contact hypothesis to increase friendship development between adults with low functioning levels, high functioning levels, and no disabilities. The contact hypothesis proposes that interactions between differing groups (such as adults with low ADL and neurotypical adults) may reduce prejudice and discriminatory practices (Allport, 1954). Allport (1954) additionally mentions that four important conditions, equal status, common goals, intergroup cooperation, and authority support, are necessary to promote effective intergroup bonding. Best Buddies non-profit organization models some of these relationship-building practices, including inclusive living opportunities that allow friendships to build over common goals of home-building and equal status as co-residents (“Best Buddies Living”, 2022).

Based on our results, adults with low ADL may spend vast amounts of time with caregivers/professionals and little time in disability organizations. This finding may relate to the support needs of adults with low ADL that disability organizations will not permit at their program, such as behavioral interventions or assistance using the bathroom. Given the low frequency of social activities outside of the home for adults with low ADL and the lack of support for these adults at disability events, caregivers may consider

attending disability events with their adult with low ADL. Multiple search engines are available, such as Tennessee Disability Pathfinder, that provide information on various events for people with various disabilities and their caregivers (Tennessee Disability Pathfinder, 2022).

Even if no organized activities are available, caregivers can take steps to promote spur-of-the-moment social interactions for adults with IDD. For example, Bould et al. (2018) found that, when adults with disabilities went on hour-long outings with a dog and the dog handler, they consistently had more interactions with new people in their community than the adults who went on outings with just a dog handler. While a dog may not always be appropriate, caregivers can consider their adult with IDD's interests and how they can make opportunities for the adult to talk about their interest with other community members.

### *Implications for Policy and Funding*

Although members of the disability community may advocate for an inclusive, neurodiverse approach to policy and advocacy, the current research indicates that adults with severe and profound disabilities may not be getting adequate community involvement under the current laws and policies. Certain needs may be different for adults with the lowest ADL scores, and policy makers should incorporate this knowledge as they create future policies and funding for disability and other community

organizations. To support organizations who may not yet be prepared to accept people with all levels of functioning, increased funding and training should be provided to organizations that demonstrate increased participation of adults with severe to profound disabilities.

This equitable funding concept is already common in public schools for children with lower levels of functioning. For example, a dense, urban school district reported that the schools exclusively serving students with extensive support needs had the highest spending per student (Mumpower, Bergfeld, & Potts, 2021). This equitable funding addresses that students with the most extensive support needs require the most funding, for services such as behavioral, occupational, and speech therapy, to grow socially and academically. A similar equity-based funding system should continue into adulthood, so the adults with extensive supports needs can continue to make strides towards robust social engagement and other opportunities.

A similar recommendation relates to future directions for research. As mentioned in the introduction, few social activity studies have included adults with severe to profound disabilities. Without this research, practitioners have little research to address the challenges specific to adults with lower functioning and how to increase the social activities for these adults. Furthermore, researchers have yet to directly observe or interview adults with low-functioning disabilities about their social experiences. By conducting interviews with that population or observing their social activity when the adults do not have reliable, functional communication, researchers would uncover deeper

insights into who these adults are spending time with, what social activities they are doing, and how these two groups of variables connect to their number of friends across different friendship categories. Until this information is gathered, the social lives of adults with low ADL will remain vague and offer few recommendations for practice.

### *Limitations*

This study had several limitations that must be mentioned. The most pressing limitation of this study was that caregivers, rather than the adults with disabilities, were the participants. The perspective of adults with IDD should be included to get both perspectives on the social experiences of these adults. A second limitation was that the social activity items differed from those found in previous studies; the social activities measured by Mihalia et al. (2017) did not overlap much with the social activities measured in this study. The twenty social activities of this study came from input from various members of the disability community to get a more in-depth analysis of their social lives, but this decision impaired the possibility of statistical comparisons to previous studies. Finally, our friendship variables were simply created for this study. Given the results of this broad study of social engagement and our broad exploration of friendship, a more detailed exploration is needed of friendship variables in future research.

## *Conclusion*

Still, the current research highlights many of the differing social experiences of adults with IDD. Based on our findings, adults with lowest functioning had the least frequent social activity and the lowest number of friends. Particularly concerning, adults who are lower functioning participated the least in disability organization activities and the most frequently with caregivers and professionals; these findings together indicate a restricted set of social contacts and activities for adults with the most extensive support needs. It is crucial for policy makers, practitioners, and researchers to recognize these differences in social engagement based on level of functioning to create social services and experiences that are more inclusive of these adults.

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