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#### ORIGINAL ARTICLE

# Friendship, Quality of Life, and People with Intellectual and Developmental Disabilities

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Abstract People with intellectual and developmental disabilities (IDD) often have fewer opportunities to create and maintain friendships. In fact, it is not uncommon for people with IDD to consider their paid staff friends, which is problematic given high staff turnover and a lack of reciprocity, a key element of friendship. The aim of this study is to explore the relationships between friendship and quality of life of people with IDD. We had two main research questions: 1) what factors predict people with IDD having friends (outcomes present)?; and, 2) how does having friends (outcomes present) impact the quality of life of people with IDD? To do so, this study analyzed Personal Outcome Measures<sup>®</sup> interviews data from approximately 1300 people with IDD exploring the relationships between friendship and factors at individual, organizational, and societal levels. Findings revealed friendship predicts improved outcomes in almost every area of one's life; as such, it is critical to promote the development, maintenance, and growth of friendship of people with IDD. To do so, organizations need to make it best practice to facilitate the friendships of the people they serve. Systemic issues also need to be addressed in order to promote the friendships of people with IDD.

**Keywords** Friendship · People with intellectual and developmental disabilities · Interpersonal relationships · Organizational supports · Quality of life

Social relationships, such as friendship, have many benefits for people with and without disabilities. Social relationships can enhance ones' quality of life as general benefits

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include emotional well-being and more favorable mental health, such as lower stress, and increased sense of belonging (Lafferty et al. 2013; Fulford and Cobigo 2016; Petrina et al. 2016; Ward et al. 2013; Petrina et al. 2014). As a result of social support, friendship can result in more positive engagement, conflict resolution, and community participation (Petrina et al. 2014; Lafferty et al. 2013; Fulford and Cobigo 2016). In children in particular, friendship leads to positive gains in social, cognitive, and emotional development (Petrina et al. 2014).

Despite a desire for friendship, research indicates a number of social relationship disparities for people with intellectual and developmental disabilities (IDD) (Fulford and Cobigo 2016). Compared to nondisabled people, people with IDD experience more loneliness, have more difficulty forming and maintaining friendships, see their friends less often, and have less close relationships with their friends (Fulford and Cobigo 2016; Petrina et al. 2017; Petrina et al. 2014). Research also suggests people with autism spectrum disorder (ASD) in particular may have the fewest friends across all other disability categories (Petrina et al. 2014).

One reason for these disparities is people with IDD's "impoverished" social networks due to a lack of opportunities for fostering and maintaining friendships (Pottie and Sumarah 2004). Although people with IDD often understand friendship, even often on an age appropriate level, "the friendships they envisage [do] not always materialise" (Cuckle and Wilson 2002). Segregation is a byproduct of historical institutionalization. Although deinstitutionalization of people with IDD is at an all-time high, physical and social isolation of people with IDD is still common (Braddock et al. 2015; Rossetti et al. 2015; Fulford and Cobigo 2016). As a result, even in community-based settings, many people with IDD have fewer opportunities to meet people (Bigby 2008; Fulford and Cobigo 2016; Simplican et al. 2015). Because of limited opportunities, many people with IDD consider paid support staff their friends (Asselt-Goverts et al. 2015; Pottie and Sumarah 2004). For example, Bigby (2008) found half of the participants with disabilities in their study had no friends other than staff; this is problematic as "there was no evidence that residents stayed in touch with staff once a staff member left the house, thus given the high level of staff turnover, it is likely that friendships with staff would be short-term" (p. 151).

As a result of limited opportunities, Bogenschutz et al. (2015) proclaims, "focusing on the benefits of social inclusion for both people with IDD and for people without disabilities is a necessary endeavor and important framework that emphasizes inclusion as having reciprocal benefits for the entire community" (p. 212). Indeed, more inclusion of people with IDD in schools has led to more opportunities for social inclusion, including more interaction with nondisabled peers (Webster and Carter 2007). However, physical inclusion alone does not necessarily lead to an increase in friends for people with IDD (Wong 2008; Rossetti et al. 2015).

Although friendships between people with IDD and nondisabled people do occur, and can be meaningful, reciprocity may be lacking; while nondisabled peers may find people with IDD likable and sociable, friendship requires mutual affection (Cuckle and Wilson 2002; Petrina et al. 2017; Pottie and Sumarah 2004). Friendship often depends on trust, life-sharing, fidelity, maintenance, and mutual respect (Pottie and Sumarah 2004). Reciprocity may be missing element from relationships with many nondisabled peers (Rossetti et al. 2015; Petrina et al. 2016; Webster and Carter 2007). Prejudicial disability attitudes may make cultivating reciprocity and mutual respect difficult for



people with IDD. For example, when 1200 students without disabilities were surveyed, the majority noted 'altruism' was the main reason they would be friend a person with a severe disability (Hendrickson et al. 1996; Wong 2008). As a result, pity may be a serious barrier to developing friendships.

These disparities and the lack of opportunities people with IDD face may be particularly problematic as friendship can be especially fruitful for people with disabilities compared to nondisabled people. For example, research by Chernomas et al. (2008) with people with psychiatric disabilities found friendship with other peers with disabilities can produce increases in self-acceptance and camaraderie, and decreases in internalized stigma. Intimate relationships with peers with disabilities can also help people with disabilities navigate an inaccessible world – one which prioritizes nondisabled people; friends with disabilities "in a similar situation to oneself can result in sharing information with others who can understand and negotiate the 'system,' whether it is formal...services, social services, and self-help groups, or other networks" (Chernomas et al. 2008).

In the *National Research Goals for and with People with Intellectual and Developmental Disabilities*, Bogenschutz et al. (2015) calls "social inclusion... an important 'next frontier' in research, policy, and practice for people with IDD" (p. 211). As a result of the benefits of having friends for people with IDD, as well as the disparities people with IDD often face in cultivating friendships, the aim of this study is to explore the relationships between friendship and quality of life of people with IDD. We had two main research questions: 1) what factors predict people with IDD having friends (outcomes present)?; and, 2) how does having friends (outcomes present) impact the quality of life of people with IDD? To examine these questions, this study analyzed secondary Personal Outcome Measures<sup>®</sup> survey data from approximately 1300 people with IDD exploring the relationships between friendship and factors at individual, organizational, and societal levels.

#### Methods

#### Data

The secondary survey data utilized in this survey were transferred to the researchers with no identifiers; as such the author's institutional research board (IRB) determined it was exempt from full review. Participants for the dataset were originally recruited over approximately two years (January 2015 – December 2016) through organizations in the United States that provide services to people with disabilities, including: service coordination; case management; family and individual supports; behavioral health care; employment and other work services; residential services; non-traditional supports (micro-boards and co-ops); and, human services systems. 1341 people with IDD volunteered to participate. While age, gender, and guardianship status were relatively evenly distributed across demographic groups (Table 1), the majority of participants were White (74.4%), used verbal/spoken language as their primary communication method (82.2%), and lived in provider owned or operated homes (50.5%). While daily support needs, which was used as a proxy for severity of disability, ranged from support as needed (on call) for those with less severe disabilities to around the clock support



(24/7) for those with more severe disabilities, most participants (61.1%) had high support needs, needing 24/7 around the clock support. Table 1 details participant demographics.

#### Measure

The instrument used in this study was the Personal Outcome Measures® (The Council on Quality and Leadership 2017a), developed by the international non-profit disability organization the Council on Quality and Leadership (CQL). The Personal Outcome Measures<sup>®</sup> is designed to determine people with disabilities' quality of life, including self-determination, choice, self-advocacy, and supports, in a person-centered manner. The Personal Outcome Measures<sup>®</sup> includes 21 indicators divided into five factors: my human security; my community; my relationships; my choices; and, my goals. My human security includes the following indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people experience continuity and security; people exercise rights; people are treated fairly; and, people are respected. My community includes the following indicators: people use their environments; people live in integrated environments; people interact with other members of the community; and, people participate in the life of the community. My relationships includes the following indicators: people are connected to natural support networks; people have friends; people have intimate relationships; people decide when to share personal information; and, people perform different social roles. My choices includes the following indicators: people choose where and with whom to live; people choose where to work; and, people choose services. My goals includes the following indicators: people choose personal goals; and, people realize personal goals.

For every participant, the Personal Outcome Measures<sup>®</sup> administration occurs in three stages. In the first stage, a trained Personal Outcome Measures<sup>®</sup> interviewer has in-depth conversations with the participant with disabilities about each of the indicators (approximately one to 2 h). For these conversations, the interviewer follows specific open-ended prompts. During the second stage of the Personal Outcome Measures<sup>®</sup> interview, the interviewer speaks with someone who knows the participant with disabilities best, and knows about organizational supports, such as a case manager or direct support professional, and asks them questions about individualized supports and outcomes to fill in any gaps (approximately one to 2 h). During the final stage, the interviewer observes the participant in various settings and then completes the indicator questions about personal outcomes and individualized supports based on the information gathered in the three stages. Individual record reviews are also conducted as needed. As the measure is person-centered, if there are any discrepancies across stages, the person with IDD's answers are the ones used.

The Personal Outcome Measures® was developed over 25 years ago based on findings from focus groups with people with disabilities, their family members, and other key stakeholders about what really mattered in their lives. The Personal Outcome Measures® has been continuously refined over the past two decades through pilot testing, 25 years of administration, commission of research and content experts, a Delphi survey, and feedback from advisory groups (The Council on Quality and Leadership 2017a). The Personal Outcome Measures'® construct validity was recently confirmed using a principal components analysis, which retained all 21



**Table 1** Demographics (n = 1341)

Characteristic	n	%
Age range		
18 to 24	95	7.1%
25 to 34	250	18.6%
35 to 44	223	16.6%
45 to 54	279	20.8%
55 to 64	252	18.8%
65 to 74	122	9.1%
75+	39	2.9%
Gender		
Man	719	53.6%
Woman	613	45.7%
Race		
White	998	74.4%
Black or African American	246	18.3%
American Indian or Alaska Native	54	4.0%
Hispanic, Latinx, or Spanish Origin	29	2.2%
Other (Asian, Native Hawaiian, other Pacific Islander, or other)	16	1.2%
Primary method of communication		
Verbal/spoken language	1102	82.2%
Face/body expression	169	12.6%
Sign language	16	1.2%
Communication device	14	1.0%
Other	33	2.5%
Guardianship status		
Independent decision making	370	27.6%
Assisted decision making (supported and limited guardianship)	494	36.8%
Full/plenary guardianship	423	31.5%
Other	35	2.6%
Residence type		
Own home/apartment	284	21.2%
Family's house	213	15.9%
Host family/family foster care	24	1.8%
Provider-operated house or apartment	677	50.5%
Private ICFDD	22	1.6%
State-operated HCBS group home	43	3.2%
State-operated ICFDD	25	1.9%
Other	22	1.6%
Daily support		
On call - support as needed	28	2.1%
0 to 3 h/day	60	4.5%
3 to 6 h/day	94	7.0%
6 to 12 h/day	155	11.6%



Table 1 (con	ntinued)
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Characteristic	n	%
12 to 23 h/day	76	5.7%
24/7 - around the clock	819	61.1%
Other	46	3.4%

*ICFDD*, Intermediate care facility for people with developmental disabilities; *HCBS*, Home and community based services; *DSP*, direct support professionals

indicators and grouped them into the five factors described above (Friedman, The Personal Outcome Measures<sup>®</sup>, unpublished manuscript). The Personal Outcome Measures<sup>®</sup> also has inter-rater reliability as all interviewers are required to pass reliability tests with at least 85% before being certified (The Council on Quality and Leadership 2017b).

### Variables and Analysis

The main variables of this study were "friends outcomes present" and "friends organizational supports in place". Following the above procedure, suggested questions for information gathering with the participant for "friends outcomes present" included:

- How do you define friendship? Who are your friends?
- With whom do you like to spend time?
- What do you like to do with friends?
- How often do you see your friends?
- Do you spend enough time with them?
- Besides seeing your friends, what other kinds of things do you do to stay in contact?
- Do you have enough friends? Would you like more? (The Council on Quality and Leadership 2017a)

Then to determine if the "people have friends" outcome was present, based on the conversation participant must: (1.) have friends (staff and family excluded); (2.) be satisfied with the number of friends; and, (3.) and, be satisfied with the frequency of contact with their friends (The Council on Quality and Leadership 2017a). If all three of the answers were not yes, then the participant does not have the outcome present unless they do not have friends due to personal choice.

To decide if the "people have friends" individualized organizational supports were in place, the interviewer was provided the following suggested question to utilize during the interview with the participant with IDD's staff:

- With whom does the person choose to spend time?
- Who are the person's friends? How do you know?
- What contact does the person have with his or her friends?
- Are the interactions and contacts the person has with friends similar to typical friendships that you or people you know have? Are they voluntary, mutual, and interactive?



- How do you determine the importance of friendship to the person?
- How do you know if the person needs support to develop or maintain friendships?
- How do you determine satisfaction with the extent and frequency of contact?
- Are there any barriers that affect the outcome for the person?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person? (The Council on Quality and Leadership 2017a)

Then to determine if the "people have friends" supports were in place based on the conversation: (1.) the organization must know the person's preference and need for friends; and (2.) supports must be provided to assist the person with developing, maintaining, and enhancing friendships (The Council on Quality and Leadership 2017a). Both answers to the previous must be yes for the supports to be considered in place.

This study's first research question was: what factors predict people with IDD having friends (outcomes present)? The dependent variable (DV) was the if the outcome was present for "people have friends" (yes (1) or no (0)). We selected independent variables (IVs) after reviewing the literature on friendship, relationships, and IDD (Table 2). (Variable definitions can be found in The Council on Quality and Leadership 2017a.) Binary logistic regression models were then run using SPSS 23 with each of the IVs to determine which factors had significant relationships with the DV. Bonferroni correction (.0042) was used to counteract running multiple models. When models were statistically significant, univariate analyses were used to determine odds ratios.

The second research question was: how does having friends (outcomes present) impact the quality of life of people with IDD? For question two, additional binary logistic regression models were run to determine the impact of friendship outcomes present (IV) on quality of life – the other Personal Outcome Measures<sup>®</sup> outcome indicators (DVs). Bonferroni correction (.0025) was used to counteract running multiple models. Univariate analyses were used to determine odds ratios for significant models.

### Results

Although the majority of participants (84%) had friends, less were satisfied with the number of friends they had (56%), and the amount of contact they had with their friends (47%), leading the friendship outcome – all three of these things occurring – to be present with less than half of participants (43%). Descriptive statistics are presented in Table 2.

To determine the factors that facilitated or hindered people with IDD having friends, binary logistic regressions were run between the IVs and the DV, 'friends - outcome present.' The following variables produced significant models: daily hourly support; the organization knows the person's preference (number and level of contact) and need for friends; organizational supports provided to assist the person with developing, maintaining and enhancing friendships; friends - organizational supports in place; person is respected by family; person is respected by residential support staff;



Table 2 Descriptive statistics

Variable	n	%
Friends - outcome present	565	43.0%
Does the person have friends?	1019	84.0%
Person satisfied with the number of friends they have (yes)	662	56.1%
Person satisfied with this amount of contact with their friends (yes)	554	47.1%
The organization knows the person's preference (number and level of contact) and need for friends	695	57.9%
Organizational supports provided to assist the person with developing, maintaining and enhancing friendships (yes)	699	58.3%
Friends - supports in place	615	46.6%
Participant has experienced DSP turnover in last 2 years (yes)	750	62.8%
Person is respected by family (yes)	893	81.4%
Person is respected by residential support staff (yes)	796	82.1%
Employment/day setting		
Competitive employment	123	8.5%
Supported community employment	174	12.1%
Sheltered employment	295	20.4%
Enclave	87	6.0%
Day program	674	46.7%
Community day program	703	48.7%
Quality of life indicators		
Are safe	1092	82.2%
Free from abuse and neglect	883	66.7%
Best possible health	939	71.0%
Continuity and security	660	49.9%
Exercise rights	553	41.8%
Treated fairly	747	56.3%
Are respected	735	55.8%
Use environments	888	67.3%
Integrated environments	545	41.4%
Interact with others in community	809	61.3%
Participate in the life of the community	682	51.6%
Natural supports	634	47.7%
Intimate relationships	615	46.5%
Decide when to share personal information	671	50.7%
Perform different social roles	511	38.8%
Choose where and with whom to live	341	25.8%
Choose where to work	436	33.0%
Choose services	381	28.9%
Choose personal goals	596	45.1%
Realize personal goals	741	56.1%



participant has experienced DSP turnover in last two years; and, employment/day setting (Table 3).

According to the findings, people who receive the most daily support (24/7 around the clock) are two times less likely to have friend outcomes present compared to people who only receive support as needed (on call).

People with IDD who work in competitive or supported community employment have approximately two times the odds of having friend outcomes present compared to those people with IDD who do not work in these settings.

Table 3 Likelihood to have friends (Outcome Present): binary logistic regression models

Model	-2LL	df	$\chi^2$	$R^2$ (Cox & Snell)	O.R.	95% C	.I.
Hourly support (ref: as needed - on call)***	1703.10	6	29.09	0.02			
0 to 3 h/day					1.36	0.54	3.40
3 to 6 h/day					0.87	0.37	2.05
6 to 12 h/day					0.58	0.26	1.32
12 to 23 h/day					0.68	0.28	1.62
24/7 - around the clock					0.47*	0.22	1.00
Other					0.98	0.38	2.52
Employment/day setting***	1770.81	6	24.93	0.02			
Competitive employment					2.23***	1.48	3.38
Supported community employment					1.51*	1.07	2.12
Sheltered employment					1.26	0.96	1.66
Enclave					1.32	0.84	2.09
Day program					1.08	0.86	1.36
Community day program					1.11	0.88	1.40
The organization knows the person's preference (number and level of contact) and need for friends***	1244.86	1	393.07	0.28	14.75***	10.83	20.09
Organizational supports provided to assist the person with developing, maintaining and enhancing friendships***	1207.33	1	428.57	0.30	17.63***	12.76	24.35
Friends - supports in place***	1117.74	1	671.81	0.40	29.87***	22.02	40.53
Person is respected by family***	1443.79	1	56.51	0.05	3.58***	2.50	5.11
Person is respected by residential support staff***	1255.78	1	60.14	0.06	4.38***	2.90	6.62
Participant has experienced DSP turnover in last 2 years***	1592.08	1	33.07	0.03	0.50***	0.39	0.63

<sup>\*</sup>p < .05, \*\*p < .01, \*\*\*p < .001; ICFDD, Intermediate care facility for people with developmental disabilities; HCBS, Home and community based services; DSP, direct support professionals; O.R., Odds ratio; C.I., Confidence interval



When people with IDD are respected by family and/or residential support staff they are 4 times more likely to have friend outcomes present. Those people with IDD who experience DSP turnover are approximately 3 times less likely to have friend outcomes present compared to those who do not experience turnover.

When organizations know the person's preference and need for friends, people with IDD have 15 times higher odds of having friend outcomes present than when organizations do not do so. When organizations provide support to assist people with developing, maintaining, and enhancing friendships, people with IDD have 18 times higher odds of having friend outcomes present than when they do not do these things. When organizations provide both of these – when supports are in place – people with IDD are approximately 30 times more likely to have friend outcomes present.

In order to determine how friendship can impact the quality of life of people with IDD, we also ran binary logistic regression models between the IV friends - outcome present, and each of the quality of life indicators for the Personal Outcome Measures® as DVs. Findings revealed having friend outcomes present significantly increased the odds of having all the other quality of life outcomes present: people are safe; people are free from abuse and neglect; people have the best possible health; people experience continuity and security; people exercise rights; people are treated fairly; and, people are respected; people use their environments; people live in integrated environments; people interact with other members of the community; people participate in the life of the community; people are connected to natural support networks; people have intimate relationships; people decide when to share personal information; people perform different social roles; people choose where and with whom to live; people choose where to work; people choose services; people choose personal goals; and, people realize personal goals (Table 4). People with IDD with friend outcomes present were 2 to 7 times more likely to have different quality of life indicators present. For example, those people with IDD with friend outcomes present are 3 times more likely to use their environments.

## Discussion

People with IDD often have fewer opportunities to create and maintain friendships. In fact, it is not uncommon for people with IDD to consider their paid staff friends, which is problematic given high staff turnover – the loss of contact – and a common lack of reciprocity in these relationships (Asselt-Goverts et al. 2015; Hewitt and Larson 2007; Wolf-Branigin et al. 2007; Keesler 2016; Hewitt 2014; Hewitt and Lakin 2001; Micke 2015; American Network of Community Options and Resources 2014; Hewitt et al. 2008; Bigby 2008). As friendship can promote self-acceptance and camaraderie, and less internalized stigma (Chernomas et al. 2008), the purpose of this study was to examine the relationships between friendship of people with IDD and quality of life. To our knowledge it is one of the first to specifically examine the relationship between friendship and quality of life.

Our study found significant relationships between having the outcome present for friendship and quality of life. For example, when people with IDD have friends, and are satisfied with the quality of those friendships, they are five times more likely to participate in the community. They are also approximately four times more likely to



Table 4 Impact of friends on quality of life: binary logistic regression models

Model	-2LL	df	$\chi^2$	R <sup>2</sup> (Cox & Snell)	O.R.	95%	C.I.
Are safe***	1209.94	1	17.36	0.01	1.87***	1.39	2.54
Free from abuse and neglect***	1623.88	1	40.06	0.03	2.16***	1.69	2.75
Best possible health***	1525.71	1	49.36	0.04	2.45***	1.90	3.18
Continuity and security***	1733.04	1	81.56	0.06	2.79***	2.22	3.50
Exercise rights***	1675.54	1	101.90	0.08	3.19***	2.54	4.01
Treated fairly***	1675.37	1	121.88	0.09	3.63***	2.86	4.59
Are respected***	1626.20	1	173.09	0.12	4.72***	3.71	6.02
Use environments***	1593.96	1	59.05	0.04	2.58***	2.01	3.31
Integrated environments***	1696.20	1	76.38	0.06	2.72***	2.17	3.41
Interact with others in community***	1583.65	1	160.16	0.12	4.69***	3.64	6.04
Participate in life of the community***	1567.97	1	250.83	0.17	6.62***	5.10	8.35
Natural supports***	1695.15	1	118.65	0.09	3.47***	2.76	4.36
Intimate relationships***	1611.33	1	194.76	0.14	5.06***	3.99	6.42
Decide when to share personal information***	1785.59	1	28.97	0.02	1.83***	1.47	2.28
Perform different social roles***	1533.24	1	213.31	0.15	5.66***	4.44	7.21
Choose where and with whom to live***	1442.19	1	58.91	0.04	2.66***	2.07	3.43
Choose where to work***	1594.63	1	67.11	0.05	2.66***	2.10	3.36
Choose services***	1517.54	1	54.19	0.04	2.48***	1.94	3.17
Choose personal goals***	1763.44	1	43.26	0.03	2.10***	1.68	2.62
Realize personal goals***	1776.62	1	20.33	0.02	1.67***	1.33	2.08

Note. \*p < .05, \*\*p < .01, \*\*\*p < .001. The independent variable (IV) for each model was "friends - outcome present." O.R. = Odds ratio. C.I. = Confidence interval

perform different social roles and have intimate relationships. People with IDD are also almost four times more likely to be respected when they have the outcome present have friends. In fact, our analysis found friendship to have a significant relationship with every single Personal Outcome Measures<sup>®</sup> quality of life domain – human security, community, relationships, choices, and goals – and each of the underlying 20 indicators. Those indicators in the *community* and *relationships* factors were particularly impacted by people with IDD having friends, with significantly higher odds of being present when people have friends.

Despite these benefits, findings revealed a number of barriers need to be addressed to facilitate quality friendships for people with IDD. People with the highest support needs (presumably the most severe disabilities) –around the clock daily support (24/7) – have lower odds of having friends than people with the least support needs (presumably the least severe disabilities) – support provided only as needed. This finding suggests more needs to be done to address the barriers for people with high support needs to facilitate friendship opportunities and maintain those friendships. Those in competitive and supported employment — community based employment — also have higher odds of having friend outcomes present than those who work in more segregated settings.



One of the key contributions of our study is our finding that organizations play a key role in either facilitating friendship or serving as a barrier. Our findings revealed people with IDD have higher odds of having friendship outcomes present when they are respected by staff. Moreover, when organizations know the person's preferences for quality and quantity of friends, as well as support them to develop and maintain friendships (when organizational supports are in place), there are higher odds of people with IDD having friendship outcomes present. People's continuity and security, which is impacted by the direct support professional (DSP) crisis (American Network of Community Options and Resources 2014), also significantly impacts having friendship outcomes present. DSPs play a significant role in supporting people with IDD to foster and maintain friendships. For example, a person with IDD's ability to visit their friends may depend on the transportation and community access DSPs arrange. As the "backbone" (p. 317) of the human service industry, DSPs are an important resource, not only for facilitating opportunities for friendship of people with IDD, but their quality of life in general (Bogenschutz et al. 2014; Friedman, Direct support professionals and quality of life of people with intellectual and developmental disabilities, unpublished manuscript).

#### Limitations

A number of limitations should be noted when interpreting our results. Our data was not representative of people with IDD in the United States as the majority of the sample was White, and while 22 states were represented in the sample, the majority of data came from three states. Additionally, participants were recruited through organizations that provide long term services and supports, particularly those organizations who partner with CQL to conduct Personal Outcome Measures<sup>®</sup> interviews; therefore, this sample may not be representative of all people with IDD, or all service providers. As this was a secondary data analysis, the researcher did not have the ability to ask additional questions or add additional research variables. This study explored the relationships between friendship and quality of life; it should be noted while binary logistic regressions create models of expected odds or likelihood, causality should not be implied. We also did not explore interactions. Moreover, although Bonferroni correction was used to control for the use of multiple models, Bonferroni correction is a conservative measure.

### **Implications for Policy and Practice**

Despite an all-time high deinstitutionalization rate of people with IDD, there is still a limited community capacity for fostering social inclusion – community integration is rare (Ward et al. 2013; Braddock et al. 2015; Friedman and Spassiani 2017). Thus, it is not enough for service providers to help people with IDD make friends; organizational structures need to be changed and a lack of opportunities addressed. For example, many people with IDD are funneled into day habilitation rather than supported employment (Braddock et al. 2015). These settings are often segregated, with limited potential for community integration and with few opportunities for social interaction with those outside of staff and other attendees (Sulewski et al. 2006; Conroy et al. 2010; Lingwood 2005). In fact, these settings often violate the Americans with Disabilities Act (ADA) (1990) and *Olmstead v. LC* (1999), which require providing people with



disabilities services in the most integrated settings possible. The Centers for Medicare and Medicaid (2011) explain, "work is a fundamental part of adult life for people with and without disabilities. It provides a sense of purpose, shaping who we are and how we fit into our community" (p. 3). Yet, this infrastructure which is biased towards segregated settings is difficult to dismantle. Structural capacity for not only fostering social inclusion but also community integration needs to be greatly expanded; with attention to these systemic barriers comes not only community integration but also opportunities for autonomy, and choice making, both of which are necessary for interpersonal relationships such as friendships (Fulford and Cobigo 2016).

In the meantime, while states work on "clearly defining their expected outcomes" in alignment with the advances made by people with IDD, and the rights granted to them by the ADA and Olmstead, "and then develop rates and methodologies that adequately compensate providers for achieving these goals" (Butterworth et al. 2015), organizations can alter their policies and practices as well. Given the impact of friendship, in order to increase the quality of life of people with IDD, the organizations supporting people with IDD must prioritize facilitating the friendship of people with IDD. Service policies and practices must incorporate relationships as a key part of service provision, especially in relation to community inclusion (Fulford and Cobigo 2016). While we recognize disability service organizations are currently operating in a limited fiscal landscape, creative lowcost solutions can be utilized. For example, organizations can utilize Personal Outcome Measures® interviews to determine which areas specifically need to be targeted to maximize supports in their agency. Another possible way organizations can promote not only the friendship of people with IDD but also empowerment, is to support self-advocacy groups, and encourage the people they support to join (Fulford and Cobigo 2016). Selfadvocacy is the civil rights movement of and by people with IDD. Self-advocacy serves both as a source of empowerment for people with IDD and a method for grassroots organizing. As one self-advocate describes, identifying as a self-advocate

'means knowing your rights and responsibilities. Self-advocate means standing up for your own rights. Self-advocate means speak for yourself and make your own decisions... standing on your own two feet and sticking up for your rights.' (Shapiro 1994)

In addition to being a useful method for growing identity and self-determination, because of its emphasis on interdependence — "[a] cultural value of supporting one another" (Caldwell 2011) — self-advocacy helps foster connections with other members of the disability community (Goodley 1997; Nonnemacher and Bambara 2011). Experience in the self-advocacy movement can lead to a deeper understanding of the commonalities among people with IDD, and a sense of disability pride (Caldwell 2011). In addition to being a useful tool for emancipation from ableism, the mentorship and comradery that come with self-advocacy make it a fruitful environment for fostering friendships (Goodley 1997).

## Conclusion

Quality friendships can improve every area of one's life; as such, it is critical to promote the development, maintenance, and growth of friendship of people with IDD. To do so,



organizations need to make it best practice to facilitate the friendships of the people they serve. In addition, systemic issues need to be addressed in order to promote the friendships of people with IDD. Attitudes, including issues around respect, need to be improved. The DSP turnover crisis, which also has a direct impact, needs to be addressed. Finally, deinstitutionalization and inclusion movements need to continue in order to not only promote the integration of people with disabilities, but also to help support the friendships that can significantly improve people with IDD's quality of life.

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### Compliance with Ethical Standards

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**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent 
Informed consent was obtained from all individual participants included in the study.

**Conflict of Interest** The authors declare that they have no conflicts of interest.

#### References

- American Network of Community Options and Resources (2014). Ensuring a sustainable work force for people with disabilities: Minimum wage increases can not leave direct support professionals behind. Alexandria: Author.
- 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.
- Bigby, C. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability*, 33(2), 148–157.
- Bogenschutz, M., Amado, A., Smith, C., Carter, E., Copeland, M., Dattilo, J., et al. (2015). National research goals for social inclusion of people with IDD. *Inc*, 3(4), 211–218.
- Bogenschutz, M. D., Hewitt, A., Nord, D., & Hepperlen, R. (2014). Direct support workforce supporting individuals with IDD: Current wages, benefits, and stability. *Intellectual and Developmental Disabilities*, 52(5), 317–329.
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). The state of the states in intellectual and developmental disabilities: Emerging from the great recession. Washington: The American Association on Intellectual and Developmental Disabilities.
- Butterworth, J., Winsor, J., Smith, F., Migliore, A., Domin, D., Timmons, J. C., et al. (2015). StateData: The national report on employment services and outcomes. Boston: Institute for Community Inclusion.
- Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*, 49(5), 315–326.
- Chernomas, W. M., Clarke, D. E., & Marchinko, S. (2008). Relationship-based support for women living with serious mental illness. *Issues in Mental Health Nursing*, 29(5), 437–453.
- Conroy, J. W., Ferris, C. S., & Irvine, R. (2010). Microenterprise options for people with intellectual and developmental disabilities: an outcome evaluation. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 269–277.



- Cuckle, P., & Wilson, J. (2002). Social relationships and friendships among young people with Down's syndrome in secondary schools. *British Journal of Special Education*, 29(2), 66–71.
- Friedman, C., & Spassiani, N. A. (2017). Getting out there: Community support services for people with intellectual and developmental disabilities in Medicaid Home and Community Based Services waivers. *Inclusion*, 5(1), 33–44. https://doi.org/10.1352/2326-6988-5.1.33.
- Fulford, C., & Cobigo, V. (2016). Friendships and intimate relationships among people with intellectual disabilities: a thematic synthesis. *Journal of Applied Research in Intellectual Disabilities*.
- Goodley, D. (1997). Locating self-advocacy in models of disability: Understanding disability in the support of self-advocates with learning difficulties. *Disability and Society*, 12(3), 367–379.
- Hendrickson, J. M., Shokoohi-Yekta, M., Hamre-Nietupski, S., & Gable, R. A. (1996). Middle and high school students' perceptions on being friends with peers with severe disabilities. *Exceptional Children*, 63(1), 19–28.
- Hewitt, A. (2014). Presidential address, 2014—Embracing complexity: Community inclusion, participation, and citizenship. *Intellectual and Developmental Disabilities*, 52(6), 475–495.
- Hewitt, A., & Lakin, K. C. (2001). Issues in the direct support workforce and their connections to the growth, sustainability and quality of community supports (Vol. 21). Minneapolis: University Of Minnesota, Research And Training Center On Community Living.
- Hewitt, A., & Larson, S. (2007). The direct support workforce in community supports to individuals with developmental disabilities: Issues, implications, and promising pactices. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 178–187.
- Hewitt, A., Larson, S., Edelstein, S., Seavey, D., Hoge, M., & Morris, J. (2008). A synthesis of direct service workforce demographics and challenges across intellectual/developmental disabilities, aging, physical disabilities, and behavioral health. Minneapolis: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Keesler, J. M. (2016). An evaluation of individual and organizational factors in predicting professional quality of life among direct support professionals in intellectual/developmental disability services. Buffalo: State University of New York at Buffalo.
- Lafferty, A., McConkey, R., & Taggart, L. (2013). Beyond friendship: The nature and meaning of close personal relationships as perceived by people with learning disabilities. *Disability and Society*, 28(8), 1074–1088. https://doi.org/10.1080/09687599.2012.758030.
- Lingwood, L. (2005). Modernising day services. Mental health today (Brighton, England) (Dec.), 33-36.
- Micke, H. (2015). Causes and solutions for high direct care staff turnover (Master of Social Work Clinical Research Paper). Thomas, St. Paul: St. Catherine University & University of St.
- Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, 49(5), 327–340.
- Petrina, N., Carter, M., & Stephenson, J. (2014). The nature of friendship in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 8(2), 111–126.
- Petrina, N., Carter, M., Stephenson, J., & Sweller, N. (2016). Perceived friendship quality of children with autism spectrum disorder as compared to their peers in mixed and non-mixed dyads. *Journal of Autism* and Developmental Disorders, 46(4), 1334–1343.
- Petrina, N., Carter, M., Stephenson, J., & Sweller, N. (2017). Friendship Satisfaction in Children with Autism Spectrum Disorder and Nominated Friends. *Journal of Autism and Developmental Disorders*, 47(2), 384–392.
- Pottie, C., & Sumarah, J. (2004). Friendships between persons with and without developmental disabilities. Mental Retardation, 42(1), 55–66.
- Rossetti, Z., Lehr, D., Lederer, L., Pelerin, D., & Huang, S. (2015). Parent perceptions of time spent meaningfully by young adults with pervasive support needs. Research and Practice for Persons with Severe Disabilities, 40(1), 3–19.
- Shapiro, J. (1994). No pity: People with disabilities forging a new civil rights movement. New York: Times Books.
- Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, 38, 18–29.
- Sulewski, J. S., Butterworth, J., & Gilmore, D. S. (2006). Research to practice: community-based non-work services: Findings from the national survey of day and employment programs for people with developmental disabilities.
- The Council on Quality and Leadership (2017a). Personal Outcome Measures: Measuring personal quality of life (3rd ed.). Towson, MD: Author.



- The Council on Quality and Leadership. (2017b). The Personal Outcome Measures® 2017: Measuring outcomes now and into the future. Towson: The Council on Quality and Leadership.
- Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities*, 51(1), 22–32.
- Webster, A. A., & Carter, M. (2007). Social relationships and friendships of children with developmental disabilities: Implications for inclusive settings. A systematic review. *Journal of Intellectual and Developmental Disability*, 32(3), 200–213.
- Wolf-Branigin, M., Wolf-Branigin, K., & Israel, N. (2007). Complexities in attracting and retaining direct support professionals. *Journal of Social Work in Disability & Rehabilitation*, 6(4), 15–30.
- Wong, S.-S. (2008). Judgments about knowledge importance: The roles of social referents and network structure. Human Relations, 61(11), 1565–1591.

