



# Social Capital and People with Intellectual and Developmental Disabilities

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## Abstract

Social capital is the idea that one's relationships and social networks serve as a form of capital, operating as reciprocal networks of material, financial, social, and emotional resources and support. Social capital can be a powerful concept to help increase people with intellectual and developmental disabilities' (IDD's) inclusion, social ties, wellbeing, and quality of life. Despite people with IDD being more socially isolated, less attention has been drawn to social capital in the IDD field. The aim of this study was to examine people with IDD's ( $n=5,493$ ) social capital-related outcomes— quality of life outcomes related to social capital (i.e., people have intimate relationships; people participate in the life of the community; people have friends; people are respected; people are connected to natural support networks; people live in integrated environments; people interact with other members of the community; and, people perform different social roles)— using secondary Personal Outcome Measures interview data. People with IDD had an average of 42.25% social capital-related outcomes present. Social capital-related outcomes differed based on age, primary communication method, decision-making authority, race, support needs, residence, housemates, and employment/day settings. Social capital-related outcomes increased people's quality of life. Facilitating the social capital of people with IDD with meaningful reciprocal relationships and integration is a must.

**Keywords** Social capital · People with intellectual and developmental disabilities · Quality of life · Personal outcomes

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Social capital is the idea that one's relationships and social networks often serve as a form of capital, operating as reciprocal networks of material, financial, social, and emotional resources and support (Gotto et al., 2010; Putnam, 2001; Rodgers et al., 2019; Shpigelman, 2018; Woolcock & Narayan, 2000). Social capital improves people's welfare in a wide range of ways. For example, research indicates social capital increases people's physical and mental health, especially among marginalized groups (Kim et al., 2006; Mithen et al., 2015; Poortinga, 2012; Rodgers et al., 2019; Szreter & Woolcock, 2004). In addition, social capital is associated with reduced poverty because it connects people with resources and increases resilience (Kyne & Aldrich, 2020; Mithen et al., 2015; Woolcock & Narayan, 2000). Social capital may be especially beneficial in emergency situations, such as natural disasters (Hawkins & Maurer, 2010; Kyne & Aldrich, 2020). For example, research indicates after Hurricane Katrina, people, especially marginalized ones, relied on social capital for both short-term and long-term survival (Hawkins & Maurer, 2010). Not only did social capital help connect people with food, water, and other logistics via mutual aid, it also helped people cope with the trauma they experienced as a result of Katrina (Hawkins & Maurer, 2010).

Social capital is comprised of two forms of social capital: bonding and bridging. Bonding social capital is the relationships we have with those who are similar to us and share our backgrounds, values, and identities (Gotto et al., 2010; Poortinga, 2006, 2012; Szreter & Woolcock, 2004; Wass et al., 2023). Our informal social networks, such as family members and friends, can be examples of bonding social capital. These group relationships and ties not only help strengthen our relationships but also can serve as a source of support and mutual aid, connecting us with resources that we likely would not be able to access on our own (Gotto et al., 2010).

Meanwhile, bridging social capital is the relationships we have with those who are less similar to us and do not share our identities (Poortinga, 2006; Wass et al., 2023). While bonding social capital helps support us, bridging social capital represents wider solidarity (Poortinga, 2012). For example, Gotto et al. (2010) notes that advocacy organizations for people with disabilities and those for older adults, while centering different populations, likely have similar goals and can leverage strengths together to their advantage to promote their shared values. People with dissimilar identities and social roles than ourselves may also help us gain access to resources that are not available within our bonding social capital ingroups, helping us advance (Mithen et al., 2015; Rodgers et al., 2019).

## **Social Capital and People with Intellectual and Developmental Disabilities**

Social capital can be a powerful concept to help increase people with intellectual and developmental disabilities' (IDD's) inclusion, social ties, wellbeing, and quality of life (Gotto et al., 2010; Hall & Kramer, 2009; Stainton et al., 2020; Wass et al., 2023). For example, Hall and Kramer (2009) found people with IDD developed social capital through their workplaces, and connections with coworkers and others at those workplaces. In addition, by connecting people with IDD with resources

and connections, and assisting them as they navigate social structures, social capital can increase people with IDD's opportunities, choices, and control over their lives (Gotto et al., 2010). In fact, because of the ways it connects people with resources, choices, and opportunities, and because of the benefits of relationships and integration more broadly, social capital can increase people with IDD's quality of life (Gotto et al., 2010; Stainton et al., 2020; Wass et al., 2023). Quality of life includes a range of domains, including physical, material, and emotional well-being, interpersonal relationships, personal development, social inclusion, self-determination, and rights (Schalock, 2004; Schalock et al., 2002). As a result of the benefits of social capital, Stainton et al. (2020) even suggests a key way to measure the effectiveness of social capital is how it improves people's quality of life.

While social capital can have widespread benefits, people with disabilities have less social capital than people without disabilities, both for bonding and bridging social capital (Dimakos et al., 2016; Mithen et al., 2015). In fact, people with IDD face disparities in many of the areas and outcomes which contribute to their social capital—the mediating factors that can produce and foster social capital, henceforth called 'social capital-related outcomes.' For example, people with IDD are significantly more social isolated (i.e., having a lack of social connections) and lonely (i.e., being unhappy about unmet social needs) than people without disabilities (Darragh et al., 2017; Mooney et al., 2019; Robinson & Idle, 2022; Tilly, 2019; Wormald et al., 2019). Social exclusion and isolation have a profoundly negative impact on people's health and wellbeing (Emerson et al., 2021; Heinze et al., 2021; Ipsen & Repke, 2022; Pagan, 2020). For example, lonely people are more likely to have cardiovascular issues, have high blood pressure and hypertension, experience strokes, and have increased mortality rates (Heinze et al., 2021; Pagan, 2020, 2021; Tama & Astutik, 2020; Wormald et al., 2019). Lonely people are also more likely to have anxiety and depression, and participate in self-injurious behaviors (Greig et al., 2022; Pagan, 2020; Tama & Astutik, 2020). In addition to this impact on health and wellbeing, without these social connections, people with IDD will have difficulty developing and, by extension, leveraging social capital.

The increased social isolation of people with IDD is largely due to social exclusion and social participation barriers, such as a lack of accessible environments, transportation, assistive technology, and social supports (Clarke et al., 2019; Dobransky & Hargittai, 2021; Jaiswal et al., 2020; Koutsogeorgou, 2020; Tarvainen, 2021; Wormald et al., 2019). Due to ableist structures and systems, sometimes people with IDD are physically segregated from social connections and opportunities, while other times, biased attitudinal barriers alienate people with IDD (Wormald et al., 2019). Yet, it is these very social ties, networks, and relationships that are a critical foundation for developing social capital (Gotto et al., 2010; Hall & Kramer, 2009; Hoyle, 2023; Nelon, 2020). As such, attention to these social capital related areas of people with IDD's lives is critically important to expand their social capital, especially to remove barriers to social capital.

## Purpose

Social capital as a concept can help us understand people's social ties and connectivity (Hawkins & Maurer, 2010). Despite people with IDD facing many disparities in areas that both help create social capital and that would benefit from additional social capital, less attention has been drawn to social capital in the IDD field and in Disability Studies than other fields (Gotto et al., 2010). In addition, many of the studies that have been conducted related to social capital and people with IDD have had small sample sizes of less than 50 people and some have used proxies instead of information from people with IDD themselves (Hoyle, 2023). For these reasons, the aim of this study was to examine social capital-related outcomes of people with IDD. The secondary aim of this study was to examine the benefits of social capital-related outcomes on other areas of people with IDD's quality of life. To meet these aims, we had the following research questions:

1. How many social capital outcomes do people with IDD have present, and which areas of social capital-related outcomes do people with IDD have most and least present in their lives?
2. How does the presence of social capital-related outcomes differ among people with IDD based on their sociodemographics?
3. How can social capital-related outcomes impact people with IDD's quality of life?

To examine these questions, we analyzed secondary Personal Outcome Measures® (POM) Social Capital Index data from 5,493 people with IDD.

## Methods

### Measure

While no tools currently measure every possible aspect of social capital (Hoyle, 2023), in this study, due to our focus on social capital-related outcomes, we were most interested in individual level components of social capital. Individual level components of social capital are those most informed by interpersonal relationships (Gotto et al., 2010; Hoyle, 2023). Therefore, we used data from the POM, a validated, person-centered quality of life outcome measure used in human services to examine individual, personal outcomes of people with disabilities (Friedman, 2018a; The Council on Quality and Leadership, 2017).

The POM was developed more than 30 years ago based on focus groups with people with disabilities and their families about what mattered in their lives; over time it has also been revised through Delphi testing, feedback from advisory groups, consultation with content experts, and validity and reliability testing (Friedman, 2018a; The Council on Quality and Leadership, 2017). The most recent version of the POM includes the following 21 outcome 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; people are respected; people use their environments; people live in integrated environments; people interact with other members of the community; people participate in community life; people are connected to natural support networks; people have friends; people have intimate relationships; people decide when to share personal information; people perform 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.

Administration of the POM occurs in three stages. In the first stage, a certified reliable interviewer has an in-depth, facilitated but open-ended conversation with the person with IDD about what is important to them in their lives. If the person with IDD does not communicate with words or sign language, POM techniques to support communication include the use of visual cues, photos, augmentative alternative communication, gestures, preference testing, and observation (Overpeck, 2019). If the person with IDD wants they can also have someone, such as a family member, friend, or staff person, support them while they participate in the interview. In the second stage, the interviewer speaks with someone who knows that person with IDD well and also knows about the services and supports they receive, in order to examine the organizational supports they receive. If needed, the interviewer may also observe the person with IDD or do record reviews. In the third stage, the interviewer uses all of the information gathered to complete decision-trees to determine if each of the 21 different outcome areas are present (1) or not (0) as well as if supports are in place to facilitate these outcomes (supports data were not utilized for this study). See The Council on Quality and Leadership (2017) for decision-trees for each of the outcomes.

## Data and Participants

This study was a secondary analysis (our IRB determined it exempt from review). The data were originally collected between January 1, 2016 and December 31, 2022 by human service organizations (including local, county, and state governments) serving people with IDD and using the POM as part of person-centered planning or quality improvement initiatives. The data were de-identified and transferred to the research team. A total of 5,493 people with IDD were in the sample. The participants had a mean age of 44.8 (Table 1). The majority of participants were men (56.3%), white (74.7%) and primarily communicated through verbal/spoken language (81.9%). The most common form of decision-making authority (i.e., guardianship) was full/plenary guardianship (41.1%). Of the participants, 15.1% had complex medical support needs (12+ hours of skilled nursing care) and 23.8% had comprehensive behavior support needs (24-hour supervision due to risk of harm). Approximately half of participants lived in provider owned/operated homes (53.3%), with fewer people living in their own homes (16.8%), family homes (19.0%), host family / family foster care (3.4%), intermediate care facilities for people with developmental disabilities (ICFDD; 2.7%), state-run Home- and Community-Based Services (HCBS) group homes (1.7%), and other settings (3.1%). People lived with an average of 4.1 housemates. The most common work/activity setting was community day program

**Table 1** Demographics ( $n=5,493$ )

Characteristic	<i>n</i>	%
Age (M [SD]; $n=5,173$ )	44.8 (16.1)	
Gender ( $n=5,426$ )		
Man	3,057	56.3%
Woman	2,369	43.7%
Race ( $n=5,416$ )		
White only	4,048	74.7%
Black only	959	17.7%
Latiné only	173	3.2%
Indigenous only	94	1.7%
Asian only	44	0.8%
Other	46	0.8%
Multiracial	52	1.0%
Primary communication method ( $n=5,441$ )		
Verbal/spoken language	4,458	81.9%
Facial/body expression	771	14.2%
Sign language	65	1.2%
Communication device	47	90.0%
Other	100	1.8%
Decision-making ( $n=5,379$ )		
Independent	1,506	28.0%
Assisted decision-making	1,531	28.5%
Full/plenary guardianship	2,209	41.1%
Other	133	2.5%
Complex medical support needs ( $n=4,730$ )		
Yes	713	15.1%
No	4,017	84.9%
Comprehensive behavior support needs ( $n=4,730$ )		
Yes	1,126	23.8%
No	3,607	76.2%
Residence ( $n=5,343$ )		
Provider owned/operated home	2,848	53.3%
Family home	1,015	19.0%
Own home	897	16.8%
Host family / family foster care	182	3.4%
ICFDD	146	2.7%
State HCBS group home	90	1.7%
Other	165	3.1%
Total housemates (M [SD]; $n=5,105$ )	4.1 (3.9)	
Work/day setting ( $n=4,155$ )		
Community day program	2,569	61.8%
Segregated day program	2,233	53.7%
Supported community employment	559	13.5%
Sheltered work	495	11.9%
Competitive employment	474	11.4%
Enclave work	196	4.7%
Interview during a COVID-19 pandemic year		

**Table 1** (continued)

Characteristic	<i>n</i>	%
Yes	1,533	27.9%
No	3,960	72.1%

*Note* Participants could have more than one work/day setting

(61.8%), with fewer people working in segregated day programs (53.7%), supported community employment (13.5%), sheltered work (11.9%), competitive employment (11.4%), and enclave work (4.7%). Almost one-quarter of interviews (27.9%) were conducted during the COVID-19 pandemic (2020+). Most of the data came from the United States (96.25%,  $n=5,287$ ; 31 different states), but data also came from Canada (2.86%,  $n=157$ ), Australia (0.67%,  $n=37$ ), Ireland (0.11%,  $n=6$ ), New Zealand (0.05%,  $n=3$ ), and unidentified but one of the aforementioned countries (0.05%,  $n=3$ ).

## Variables

The main variables in this study regarding social capital-related outcomes were derived from the validated Social Capital Index, which uses content from the POM. In 2005, a factor analysis was conducted using POM to examine social capital-related outcomes, including the shared variance among variables and determine the underlying structure of the Social Capital Index (Cade et al., 2006; The Council on Quality and Leadership, 2005). The results revealed the Social Capital Index includes the following outcomes: People have intimate relationships (close meaningful personal relationships); people participate in the life of the community (integrate into their community through activities, interests, community resources, etc.); people have friends (reciprocal friendships); people are respected (respected by all the people in their lives [including family, housemates, coworkers, professionals, etc.], including interactions that reflect concern for person's opinions, feelings, and preferences, and challenging and interesting opportunities); people are connected to natural support networks (unpaid reciprocal relationships that serve as support, connection, and safety net); people live in integrated environments (use the same environments [living, work, school, community, etc.] as people without disabilities); people interact with other members of the community (direct and meaningful interaction with other people in the community); and, people perform different social roles (fulfilling life roles important to them [e.g., volunteer, social clubs, church choir member, coach, civic groups, etc.]). According to the factor analysis, the former five outcomes represent *bonding* social capital, while the latter three represent *bridging* social capital. For each participant, the total number of outcomes present (out of the possible 8) represents their Social Capital Index score, that is how many social capital-related outcomes they have present in their lives. The higher the score on the Social Capital Index, the better.

The remaining 13 outcomes from the POM (i.e., those not in the Social Capital Index) were also used as variables in this study, representing other areas of people's quality of life. In addition to POM outcome data, participants' sociodemographics were also used as variables in the study.

## Analyses

Data were analyzed using SPSS 27. Missing data was removed listwise in the analyses. All assumptions were examined prior to analyses. To explore our first research question, we utilized descriptive statistics to determine the presence of social capital-related outcomes among people with IDD. To examine our second research question, we used a linear regression model to explore differences in social capital-related outcomes aggregated via the Social Capital Index (dependent variable [DV]) based on participants' sociodemographics (independent variables [IVs]). Finally, to examine our third research question, we utilized a series of binary logistic regression models to examine the relationship between social capital-related outcomes aggregated via the Social Capital Index (IV) and the 13 other areas of quality of life measured in the POM (DVs in each model); while doing so, we controlled for all participant sociodemographics.

## Results

### The Presence of Social Capital-Related Outcomes Among People with IDD

People with IDD in our study had an average Social Capital Index score of 3.38 (out of 8;  $SD=2.37$ ), which is the equivalent of 42.25% social capital-related outcomes present (Fig. 1). People with IDD had a slightly lower percentage of bridging social capital-related outcomes present (41.48% [2.07 out of 5,  $SD=1.60$ ]) than bonding social capital-related outcomes (43.50% [1.31 out of 3,  $SD=1.08$ ]). People with IDD were most likely to have the outcomes 'people are respected' (51.71% of people) and

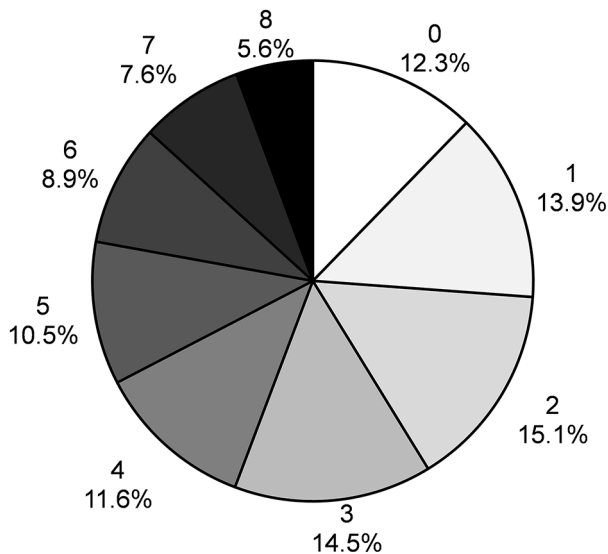


Fig. 1 Number of social capital index outcomes present



‘people interact with other members of the community’ (51.47% of people) present (Table 2). Meanwhile, people with IDD were least likely to have the outcomes ‘people perform different social roles’ (33.94% of people) and ‘people have friends’ (35.22% of people) present.

### Sociodemographic Differences in the Presence of Social Capital-Related Outcomes

According to a linear regression model, there were differences in the presence of social capital-related outcomes among people with IDD based on their sociodemographics,  $F(31, 3457) = 16.65, p < 0.001, R^2 = 0.13$  (Table 3). Controlling for all other variables, for every one-year people with IDD increased in age, their social capital-related outcomes present increased by 0.007 (0.09%). For example, 20-year-old people with IDD had 3.65 (45.63%) social capital-related outcomes present, 40-year-old people with IDD 3.79 (47.38%), 60-year-old people with IDD 3.93 (49.13%), and so on. People with IDD who primarily communicated with facial/body expressions had more social capital-related outcomes present (3.78 [47.25%]) than people with IDD who primarily communicated through verbal/spoken language (3.51 [43.88%]). People with IDD with full/plenary guardianship (3.22 [40.25%]) had fewer social capital-related outcomes present than people with IDD with independent decision-making (3.51 [43.88%]). Compared to white people with IDD (3.51 [43.88%]), Latiné (2.95 [36.88%]) and multiracial (2.38 [29.75%]) people with IDD had fewer social capital-related outcomes present. People with complex medical support needs (3.18 [39.75%]) had fewer social capital-related outcomes present than those without these support needs (3.51 [43.88%]). People with comprehensive behavior support needs (3.10 [38.75%]) had fewer social capital-related outcomes present than those without these support needs (3.51 [43.88%]). People who lived in their own homes (3.83 [47.88%]), family homes (4.67 [58.38%]), and host family/family foster care (4.32 [54.00%]) had more social capital-related outcomes present than people with IDD who lived in provider owned/operated homes (3.51 [43.88%]). Meanwhile, people with IDD who lived in ICFDD (2.89 [36.13%]) had fewer social capital-related outcomes present than people with IDD who lived in provider owned/operated homes (3.51 [43.88%]). For every one-person increase in the number of housemates people with IDD lived with, the number of social capital-related outcomes they had

**Table 2** Social capital-related outcomes

Outcome	<i>n</i>	%
Intimate relationships ( <i>n</i> =5,485)	2,099	38.21%
Participate in the life of the community ( <i>n</i> =5,490)	2,162	39.38%
Friends ( <i>n</i> =5,485)	1,932	35.22%
Respected ( <i>n</i> =5,484)	2,836	51.71%
Natural support networks ( <i>n</i> =5,486)	2,350	42.84%
Live in integrated environments ( <i>n</i> =5,483)	2,464	44.94%
Interact with other members of the community ( <i>n</i> =5,483)	2,822	51.47%
Perform different social roles ( <i>n</i> =5,481)	1,860	33.94%

**Table 3** Correlates of the social capital-related outcomes

Variable	<i>t</i>	$\beta$	<i>B</i> [95% <i>CI</i> ]
Constant	18.84		3.51 [3.14, 3.87]***
Age	2.85	0.05	0.007 [0.002, 0.01]**
Woman (ref: man)	-1.48	-0.02	-0.11 [-0.26, 0.04]
Primary communication method (ref: verbal)			
Facial/body expression	2.39	0.04	0.27 [0.05, 0.48]*
Sign language	0.07	0.001	0.02 [-0.60, 0.65]
Communication device	-0.41	-0.007	-0.16 [-0.94, 0.62]
Other	1.63	0.03	0.46 [-0.09, 1.02]
Decision-making (ref: independent)			
Assisted decision-making	-1.01	-0.02	-0.11 [-0.31, 0.10]
Full/plenary guardianship	-2.92	-0.06	-0.29 [-0.49, -0.10]**
Other	-1.28	-0.02	-0.34 [-0.87, 0.18]
Race (ref: White only)			
Black only	-1.23	-0.02	-0.12 [-0.32, 0.07]
Latiné only	-2.50	-0.04	-0.56 [-0.99, -0.12]*
Indigenous only	0.24	0.004	0.07 [-0.50, 0.64]
Asian only	-0.34	-0.006	-0.15 [-1.03, 0.72]
Other	-0.92	-0.01	-0.52 [-1.65, 0.60]
Multiracial	-3.09	-0.05	-1.13 [-1.85, -0.41]**
Complex medical support needs (ref: no)	-2.98	-0.05	-0.33 [-0.54, -0.11]**
Comprehensive behavior support needs (ref: no)	-4.43	-0.08	-0.41 [-0.59, -0.23]***
Residence (ref: provider owned/operated home)			
Family home	10.27	0.19	1.16 [0.94, 1.38]***
Own home	2.83	0.05	0.32 [0.10, 0.55]**
Host family/family foster care	3.91	0.06	0.81 [0.40, 1.22]***
ICFDD	-2.38	-0.04	-0.62 [-1.13, -0.11]*
State HCBS group home	0.13	0.002	0.04 [-0.54, 0.62]
Other	3.13	0.05	0.81 [0.30, 1.32]**
Total housemates	-2.36	-0.04	-0.03 [-0.05, -0.005]*
Work setting			
Competitive employment (ref: no)	6.66	0.11	0.87 [0.61, 1.12]***
Supported community employment (ref: no)	2.91	0.05	0.34 [0.11, 0.56]**
Sheltered work (ref: no)	0.92	0.02	0.11 [-0.13, 0.36]
Enclave work (ref: no)	-0.23	-0.004	-0.04 [-0.40, 0.32]
Segregated day program (ref: no)	-2.89	-0.05	-0.24 [-0.41, -0.08]**
Community day program (ref: no)	1.89	0.03	0.16 [-0.01, 0.32]
Interviewed during pandemic year (ref: no)	-10.09	-0.16	-0.88 [-1.05, -0.71]***

Note \* $p < 0.05$ . \*\* $p < 0.01$ . \*\*\* $p < 0.001$

present decreased by -0.03 (-0.38%). For example, people with IDD who lived with two people had 3.45 (43.13%) social capital-related outcomes present, four people 3.39 (42.38%), six people 3.33 (41.63%), and so on. People with IDD who worked in competitive employment (4.38 [54.75%]) had more social capital-related outcomes present than people with IDD who did not work in competitive employment (3.51 [43.88%]). People with IDD who worked in supported community employment (3.88 [48.50%]) had more social capital-related outcomes present than people with IDD

who did not work in supported community employment (3.51 [43.88%]). People with IDD who participated in segregated day programs (3.27 [40.88%]) had fewer social capital-related outcomes present than people with IDD who did not participate in segregated day programs (3.51 [43.88%]). People with IDD who were interviewed during the COVID-19 pandemic (2.63 [32.88%]) had fewer social capital-related outcomes present than people with IDD were interviewed before the pandemic (3.51 [43.88%]).

### How Social Capital-Related Outcomes Can Facilitate Other Areas of Quality of Life

According to logistic regression models, social capital-related outcomes increased the likelihood of all 13 of the other possible quality of life outcomes being present (Table 4). Controlling for all demographics, people with IDD with more social capital-related outcomes present were more likely to: be safe (OR [CI]=1.34 [1.28, 1.41]); be free from abuse and neglect (OR [CI]=1.28 [1.24, 1.33]); have the best possible health (OR [CI]=1.31 [1.26, 1.36]); experience continuity and security (OR [CI]=1.40 [1.35, 1.45]); exercise rights (OR [CI]=1.44 [1.39, 1.49]); be treated fairly (OR [CI]=1.48 [1.43, 1.54]); use their environments (OR [CI]=1.46 [1.41,

**Table 4** Impact of social capital-related outcomes on other areas of quality of life

Outcome	-2LL	X <sup>2</sup>	df	R <sup>2</sup>	OR [95% CI]
Safe	2900.88	357.55***	32	0.16	1.34*** [1.28, 1.41]
Free from abuse and neglect	4320.29	439.27***	32	0.16	1.28*** [1.24, 1.33]
Best possible health	3833.61	368.81***	32	0.14	1.31*** [1.26, 1.36]
Continuity and security	4139.64	643.61***	32	0.23	1.40*** [1.35, 1.45]
Rights	4147.75	642.44***	32	0.23	1.44*** [1.39, 1.49]
Treated fairly	4071.11	679.07***	32	0.24	1.48*** [1.43, 1.54]
Use their environments	3800.73	555.41***	32	0.21	1.46*** [1.41, 1.52]
Decide when to share personal information	4248.86	518.35***	32	0.19	1.35*** [1.30, 1.40]
Choose where and with whom to live	3170.05	950.83***	32	0.35	1.42*** [1.36, 1.48]
Choose where to work	3420.16	1008.46***	32	0.35	1.47*** [1.41, 1.53]
Choose services	3408.80	768.86***	32	0.28	1.41*** [1.36, 1.46]
Choose personal goals	4274.87	495.05***	32	0.18	1.38*** [1.33, 1.43]
Realize personal goals	4234.04	330.32***	32	0.12	1.17*** [1.13, 1.21]

Note \* $p < 0.05$ . \*\* $p < 0.01$ . \*\*\* $p < 0.001$ . All models control for all participant sociodemographics

1.52]); decide when to share personal information (OR [CI]=1.35 [1.30, 1.40]); choose where and with whom to live (OR [CI]=1.42 [1.36, 1.48]); choose where to work (OR [CI]=1.47 [1.41, 1.53]); choose services (OR [CI]=1.41 [1.36, 1.46]); choose personal goals (OR [CI]=1.38 [1.33, 1.43]); and, realize personal goals (OR [CI]=1.17 [1.13, 1.21]). For example, controlling for all other variables, the probability of people with IDD exercising their rights was 27.46% when they scored 0 (out of 8) on the Social Capital Index, 43.83% when they scored 2, 61.68% when they scored 4, 76.85% when they scored 6, and 87.26% when they scored 8.

## Discussion

The World Health Organization recognizes social capital as a critical component of health and quality of life (Rodgers et al., 2019). In this study, we examined the social capital-related outcomes of people with IDD. We found people with IDD had an average of only 42% of social capital-related outcomes present. Moreover, while strong personal relationships and social networks are core components necessary for social capital, the outcomes people with IDD least frequently had present— with only about 1 in 3 people with IDD having these outcomes— were people perform social roles, people have friends, and people have intimate relationships. Not only can these relationships be fulfilling in and of themselves, but they may be especially important for people with IDD to promote social capital.

### Social Capital and Quality of Life

While people with IDD would benefit from efforts to increase their social capital-related outcomes, our findings indicate that the impact of doing so will be widespread— in our study, social capital-related outcomes positively improved every other area of people with IDD's quality of life. For example, the more social capital-related outcomes people with IDD had present in their lives, the more likely they were to be safe, free from abuse and neglect, and have the best possible health. Not only do people with IDD face greater rates of abuse than people without disabilities, they also experience health disparities, in large part because of socio-economic disadvantages and other inequities (Baladerian et al., 2013; Emerson et al., 2011; Shapiro, 2018; Taggart & Cousins, 2014; U.S. Department of Health and Human Services et al., 2018). Social capital can connect people with resources, including those that help promote health outcomes (Kim et al., 2006; Mithen et al., 2015; Poortinga, 2012; Rodgers et al., 2019; Szepter & Woolcock, 2004).

The more social capital-related outcomes people with IDD had, the more likely they were to exercise their rights and to be treated fairly (i.e., receive adequate due process for rights restrictions). People with IDD often face barriers and gatekeepers when trying to exercise their rights. For example, many people with IDD who receive Medicaid Home- and Community-Based Service (HCBS) are not aware of the civil rights the HCBS Final Settings Rule grants them, such as access to visitors at any time, person-centered choices, and meaningful inclusion (Friedman, 2018b). In addition, guardianship is often applied in a broad, sweeping manner in the United

States, significantly restricting people with IDD's rights, and, in our study, social capital (Salzman, 2011). Having strong social ties and connections may not only help connect people with IDD with resources and education about those rights they are entitled to, but also help empower them to advocate to ensure they are treated with dignity and respect, including through alternatives to full/plenary guardianship.

Having more social capital-related outcomes were also associated with people with IDD being more likely to use their environments, choose where to work, choose their services, and choose and realize their goals. There may be a cyclical relationship here, where people with IDD with social capital-related outcomes are more likely to be supported to have and make these choices, and as a result, people with IDD make choices that are more amenable to facilitating social capital-related outcomes. For example, people with IDD are more likely to want to live in their own homes and with family members, the very settings that are associated with better outcomes, including social capital-related outcomes in our study (Friedman, 2018b, 2021; Hemp et al., 2014; Larson et al., 2013). While this cyclical relationship may be beneficial for continuing to foster and expand people with IDD's social capital, it also may result in people who are stuck outside of the cycle having difficulty entering it. That is, if people with IDD are located in segregated settings, which often have custodial, paternalistic cultures where they are not given choices and opportunities, people with IDD are going to have limited choices and social capital (American Association on Intellectual and Developmental Disabilities, 2018; Carlson, 2010; Dodds & Rempel, 2016; Spagnuolo, 2016; Trent, 1994). This was the case with outcomes in our study, with people with IDD in ICFDD, provider owned/operated homes (e.g., group homes), and in larger settings having fewer social capital-related outcomes; so too did people in segregated employment/day settings. Without social capital, people with IDD may face significant obstacles to being able to exit those socially isolating settings that limit their opportunities.

### **Additional Sociodemographic Factors in Social Capital-Related Outcomes**

To promote the social capital of people with IDD, and improve their quality of life, attention to several disparities is needed. For example, people with complex medical and/or comprehensive behavioral support needs in our study had fewer social capital-related outcomes present. People with higher support needs are more likely to live in isolated and segregated residential settings that likely limit their social capital (Claes et al., 2012). Previous research has also found these groups are less likely to receive individualized supports and, therefore, frequently face disparities in outcomes (Friedman, 2020a); this is likely also the case with social capital-related outcomes. As such, people with higher support needs would benefit from additional supports to facilitate social capital.

Increased age was associated with people with IDD having more social capital-related outcomes present and decreased age fewer social capital-related outcomes present. Both our needs for social capital and the types of social capital we value may shift over our lives (Hoyle, 2023). However, this finding contrasts some previous research which indicates older adults with IDD are more socially isolated in their neighborhoods than younger adults with IDD, in large part because they lack

person-centered supports (Boland et al., 2023). Social capital may have a mediating effect when it comes to age because social capital can help reduce the likelihood of acquiring age-related impairments (Pradana, 2022).

Latiné and multiracial people with IDD had fewer social capital-related outcomes present than white people with IDD. While more research is needed to examine these findings, and possible interactions with other sociodemographics, Wang et al. (2022) found Latiné people with disabilities experienced more disability stigma during the COVID-19 pandemic than White people with disabilities. Previous research has found stigma to be associated with social isolation and less social support (Bean et al., 2022; Brighton et al., 2022; Martins et al., 2018; Tarvainen, 2021). As such, this connection between stigma and isolation may contribute to the reduced social capital-related outcomes among Latiné and multiracial people with IDD in our study.

Finally, people with IDD who were interviewed during the COVID-19 pandemic (2020+) had fewer social capital-related outcomes present than those who were interviewed prior to the pandemic. People with IDD are at increased risk of COVID-19 infection and mortality (Centers for Disease Control, 2022). During the pandemic many people with IDD have been forced to stay home, resulting in increased isolation (ANCOR Foundation & United Cerebral Palsy, 2021; Embregts et al., 2022; Pettinichio et al., 2021). While lockdowns and formal restrictions were more common during the earlier waves of the pandemic, due to loosening restrictions and fewer precautions taken by others, many immunocompromised and high risk people with disabilities are required to continue to physically isolate, while at the same time, many of the virtual opportunities for social connection have dwindled, contributing to social isolation as well (Ryan, 2023). As COVID-19 continues, attention must be drawn to accessibility and inclusion, including via virtual opportunities for social connections for people with IDD.

## Implications

As a result of our findings about the limited social capital-related outcomes of people with IDD, concerted efforts must be made to expand people with IDD's opportunities to increase their social connections and community integration, particularly in real and meaningful ways. Community 'outings' or community 'time'—where people are shepherded as a group, often to a location that is not truly of their choosing—are not true community integration and will not lead to people making long-lasting, reciprocal connections (Friedman, 2020b; Hingsburger, 2013). Expanding people with IDD's access to technology, including smart phones and the internet, may be one such way to expand relationships and connections (Shpigelman, 2018). Many people with IDD do not have access to smart phones, computers, and/or the internet, yet, in modern society, these tools are critical to social participation and relationships, both virtual ones and in-person ones (Anderson et al., 2018; Bassey et al., 2023; Cocq & Ljuslinder, 2020; Perrin & Atske, 2021).

In addition, organizations and professionals supporting people with IDD should prioritize facilitating social ties and social capital, and these relationships should be considered a cornerstone of quality service provision. This includes learning more about what is important to people with IDD, including ensuring people with IDD

can experience a variety of different options to make informed choices about what they are interested in and what is important to them. Once professionals know what is important to people with IDD and what they want, they must support the person to do things that interest them, like clubs; these settings are likely the very same where social capital will naturally develop and grow. This also includes helping people with IDD form and maintain relationships and addressing any barriers people face related to these relationships, such as a lack of transportation or accessibility, or the need to re-establish contact with people important to the person with IDD. In addition, people with IDD should be supported to participate in self-advocacy groups. Doing so will not only empower people with IDD, but also help create bonding social capital (Fulford & Cobigo, 2016). As part of self-advocacy groups people will also likely participate in advocacy in ways that serve as natural opportunities for fostering bridging social capital.

While organizational supports to improve people with IDD's opportunities for choices, relationships, and growth, are important, they alone are not enough. There are prominent structural barriers that result in people with IDD being socially isolated and segregated. Medicaid's institutional bias, which requires institutional funding but makes funding for services in people's homes and communities optional, is one such example (Crossley, 2017). Rules, regulations, and funding need to be structured so that people are not funneled into segregated—either physically or socially—living or work settings, and instead person-centered outcomes are prioritized. Whatever methods are taken to facilitate social capital, people with IDD must be given individualized, person-centered opportunities to interact with others and develop those connections.

## Limitations

When interpreting this study's findings, several limitations should be noted. This was not a random or representative sample. For example, most participants were white, and communicated with verbal/spoken language. This was a secondary data analysis and, as such, we did not have the ability to add additional variables or ask participants follow-up questions. The data were originally collected by human service organizations; people with IDD receiving formal services may have different experiences with social capital-related outcomes than people with IDD not receiving formal services. There is a chance people may have acquiesced; however, the POM administration methodology is designed to limit this and decrease the need people may feel to do so (Finlay & Lyons, 2002). In this manuscript we focused on a specific set of individual factors and outcomes which can be related to social capital; there were other areas of social capital, especially systemic factors, that were not examined based on the aims of this study and the bounds of our data. Our study only examined one point in time, but people's social capital is always changing, likely especially during the COVID-19 pandemic. In addition, this study was cross-sectional, and we did not explore interactions. We believe these limitations also represent directions that should be pursued for future study.

## Conclusion

Social capital plays an important role in our lives, helping connect us with resources and informal and formal support. In our study, we found evidence suggesting social capital-related outcomes significantly improve the quality of life of people with IDD. Yet, many people with IDD in our study had limited or no social capital-related outcomes present. Facilitating the social capital of people with IDD with meaningful reciprocal relationships and integration is a must. People with IDD are not only passive ‘receivers’ of social capital, but valuable sources of social capital themselves; as such, when people with IDD are socially isolated, it is not just people with IDD that suffer— we *all* miss out on the social capital created in connection with people with IDD.

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## Declarations

**Ethical Approval** As it was a secondary data analysis, the study was determined exempt by our Institutional Review Board (IRB).

**Conflict of Interest** The author declares no conflicts of interest.

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