Somewhere to live, something to do, someone to love: Examining levels and sources of social capital among people with disabilities

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Abstract

Social capital has emerged as an important ingredient in the maintenance of physical and mental wellbeing. Although this construct has been studied within the disability community, a comparative analysis of social capital among individuals with disabilities and the general population is missing from the literature. Also sparse is an investigation into the sources from which people with disabilities draw their social capital. Building on the seminal work of political scientist Robert Putnam, a modified version of the Harvard Kennedy School's *Social Capital Community Benchmark Survey* was administered to 218 adults with high support needs living with a broad range of disabilities and currently receiving support from one of six disability organizations across the United States and Canada. Chi-squared analyses were conducted to test for differences between observed frequencies and expected frequencies obtained from general population surveys on six key measures of social capital. Results indicate that, in most areas, social capital levels among individuals with disabilities were lower when compared with those of general population respondents. In cases where social capital levels were higher than or comparable to general population respondents, an incongruity between subjective evaluations and quantitative reports, and/or support received from non-normative sources such as parents and professionals are likely explanations. Our findings support continued efforts by rehabilitation professionals to facilitate community integration for people with disabilities through the promotion of friendships and other social relationships in a variety of contexts.

Keywords

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During a 1990 presentation at the Pacific Coast Brain Injury Conference in

Vancouver, B.C., physiatrist Sheldon Berrol (as cited in Flaherty, 2008) eloquently noted

that what is most important to us all is to have somewhere to live, something to do, and

someone to love. For individuals living with disability, however, these elements are

frequently missing. Although major reform in education, housing, transportation,

vocational training, transition services and rehabilitation has greatly improved quality of

life for people with disabilities, many continue to be isolated and excluded from social

activities, from employment opportunities, and from their communities (Flaherty, 2008).

Over the past several decades, social capital has gained currency as a key

determinant of physical and mental wellbeing. As a theory, social capital offers a

conceptual measure of the instrumental value of social relationships and has significance

for social work and rehabilitation practice within the disability community. Professionals

in these fields are in a vital position to assist in the social capital building of the people

they support; however, research has yet to undertake a comparative analysis in key areas

of social capital between individuals with disabilities and the general population. There is

also little known about the sources from which people with disabilities draw their social

capital. This knowledge may be useful in better understanding the social capital needs of

this population and may assist in the development of targeted programs for this purpose.

The present study sought to address this paucity in the research literature by shedding

light on these important but understudied lines of inquiry.

Background

That people with disabilities have historically faced pervasive inaccessibility that perpetuated their exclusion from community participation is well known (Barnes & Sheldon, 2010; Galer, 2014; Isaac, Raja, & Ravanan, 2010). The response to the "problem" of disability traditionally included funneling individuals into residential or long-term care facilities and leaving them in the care of professionals and policy makers (Galer, 2014). Growing public opposition that rejected segregated models of care eventually gave way to deinstitutionalization and the development of community-based services, accommodations, and supports that centered instead on the capabilities and rights of people with disabilities. This shift challenged conventional medical model discourses of disability as inherent impairments in favour of social models that view disability largely as the result of unexamined barriers and discriminatory attitudes (Benedet & Grant, 2014). Rehabilitation professionals figured prominently in this shift, teaching individuals functional and adaptive skills and expanding opportunities for social inclusion and greater participation in community life.

Nonetheless, the goal of helping individuals better integrate into their communities through the delivery of more holistic services has not always been successful. National surveys report that people with disabilities continue to face high levels of institutionalization, unemployment and social disconnection, lower levels of life satisfaction, and that a disproportionate number socialize less often with friends, relatives and neighbours, and partake less frequently in community activities (Condeluci, Ledbetter, Ortman, Fromknecht, & DeFries, 2008; National Organization on Disability, 2010). Over the last several decades, the dynamic interplay between individual, community, and institutional level factors has gained prevalence in understanding and

explaining variations in human functioning. In 2001, the World Health Organization

developed the International Classification of Functioning, Disability and Health (ICF), a

framework for the conceptualization, classification and measurement of health and

health-related domains within disability. According to the ICF model, the health of

people with disabilities is a multidimensional experience. Aside from the exclusively

biological processes that determine disability, psychosocial and environmental influences

are also implicated in how individuals experience their disability. From the ICF

perspective, the ultimate goal for people with disabilities is not merely enhancing their

functionality but also their full inclusion and participation within the community. The

expansion of social networks, therefore, may be regarded as a central tenet of the

rehabilitation agenda.

The Role of Social Capital

The importance of social connections cannot be overstated. Humans are by nature

social creatures; our relationships are a fundamentally important aspect of our wellbeing

(Irvine, 2007; Kroll, 2011; O'Brien, 2012). Social capital theory advocates that the

support systems provided by our networks of family, friends, neighbours, coworkers,

acquaintances and other associations have value and offer benefits in concrete and

measurable ways. Political scientist Robert Putnam has written extensively on the

concept of social capital and defines it as "our relations to one another" (Putnam, 1995, p.

666); the "connections among individuals - social networks and the norms of reciprocity

and trustworthiness that arise from them" (Putnam, 2000, p. 19). Major social institutions

such as religious organizations (Stone, Cross Purvis, & Young, 2003), neighbours

(Gambrill & Paquin, 1992; Walker & Hiller, 2007; Ziersch, Baum, MacDougall, &

Putland, 2005) and employment (Potts, 2005; Walker et al., 2007; Williams, 2008) have

historically been important repositories of support and emotional wellbeing as they present opportunities for socializing and are often antecedents to the development of relationships. Work settings, for example, are the second most important social unit in many people's lives following family (Stewart, 1985) and workplace relations have traditionally been among the most common forms of civic connectedness (Putnam, 2000). Social connections also impact career mobility (Kulkarni, 2012) and it is estimated that between 40-70% of those seeking employment find their jobs through others in their social network (Parris & Granger, 2008).

In 2000, Putnam and his colleagues at the Harvard Kennedy School of Government undertook the first systematic attempt to measure social capital within communities across America. Since then, Putnam's research has revealed that levels of civic engagement - how much residents trust others, socialize with others, and join groups - predict quality of life indices far better than either income or educational level. The role of community participation and its attendant benefits are central to Putnam's theorizing and the importance of social networks for both objective and subjective wellbeing has been well documented by previous research. Indeed, the literature is remarkably consistent in the conclusion that the more connections we form, the more opportunities we have, and the better able we are to deal with the stressors of life (Condeluci et al., 2008; d'Hombres, Rocco, Suhrcke, & McKee, 2011; Folland, 2007; Hawe & Shiell, 2000; Putnam, 2000; Rocco & Suhrcke, 2012; Scheffler, Brown, & Rice, 2007). However, Putnam's research has also revealed that levels of social capital have deteriorated significantly over the past several decades, leaving contemporary citizens disconnected from family, friends, neighbours, and even democratic structures. Some

researchers have suggested that this social isolation - the lack of social capital - actually

causes disease (Cohen, 2004). Social isolation has long been recognized as a major risk

factor for depression (Karp, 1994; Victor, Scambler, Bowling, & Bond, 2005) and the

higher rates of depression, suicide and general malaise among today's youth have been

attributed to more time spent alone and fewer, weaker, and more fluid relationships

(Putnam, 2000). Thus, high social capital, as considered in the present study, is viewed

as both a natural motivator of human behaviour and a mechanism of health and

wellbeing.

The Challenge of Measuring Social Capital

Social capital has been covered thoroughly by a number of scholars and continues

to be the subject of much controversy (Bordeau, 1986; Brisson, Roll, & East, 2009;

Coleman, 1988; Lin, 2001; Putnam, 2000; Schuller, 2007; Webber, Reidy, Ansari,

Stevens, & Morris 2015; Ziersch & Baum, 2004). Distinctions have been drawn between

bonding, bridging, and linking varieties of social capital (Hawkins & Maurer, 2012;

Mithen, Aitken, Ziersch, & Kavanagh, 2015), and disagreement exists over whether

social capital is a collective social resource that benefits communities, or whether its

benefits are associated with people, their personal networks, and support (Hawkins &

Maurer, 2012; Poortinga, 2006). Others still argue that such studies are not studying

social capital directly, but rather indirectly, through its causes and consequences (Appel

et al., 2014). Further, because social capital is a multidimensional concept, it is often

conflated with related constructs such as social support, social network, sense of

community, community connectedness, quality of life, and civic participation, to name a

few (Fowler, Wareham-Fowler, & Barnes, 2013; Hawkins & Maurer, 2012; Kawachi &

Berkman, 2001; Lovell, Gray, & Boucher, 2015; Merriam & Kee, 2014; Saltkjel & Malmberg-Heimonen, 2014). Key terms such as "trust" and "community" are often difficult to quantify, making attempts to operationalize social capital and transition away from a purely theoretical understanding a challenge (Svendsen & Sorensen, 2006). This has resulted in considerable conceptual confusion and a general lack of consensus over what exactly constitutes social capital and if and how it can be measured. Inconsistencies in the literature regarding the positive relationship between social capital and health have been reported (e.g., Mithen et al., 2015; Murayama, Fujiwara, & Kawachi, 2012; Ziersch & Baum, 2004) and may be a reflection of differences in conceptual understandings and measurements.

It is often the case, however, that the most interesting and important questions are also the most difficult to study. This is particularly the case when dealing with the social, emotional, and interpersonal contexts within which human social activity takes place. Given the constraints of space, we are unable to engage in the larger debate surrounding social capital and its relationship to related constructs, though we do acknowledge their importance in the literature. The present study draws on the common themes identified in the work of Putnam (1995, 2000) who analyzed levels of social trust, participation in voluntary associations, and other forms of political and civic engagement as indicators of social capital. More broadly, we conceive of and employ social capital as an umbrella term for the many advantages an individual can acquire through membership in a social community and as an important factor in health and wellbeing.

Social capital and disability

Global research has shown that people with disabilities experience poorer physical and psychological health than people without disabilities (World Health Organization and World Bank Group, 2011). Disability theorists who have studied social capital and related constructs such as social support and community engagement have demonstrated the deprivations faced by people with disabilities in these areas (Bramston, Bruggerman, & Pretty, 2002; Kampert & Goreczny, 2007; Kinne, Patrick, & Doyle, 2004; Morris, 2001). Though Putnam sampled the majority of sectors of American society, absent from his work is any mention of disability groups. Declining trends in civic engagement are especially relevant when applied to the disability community, which has historically experienced greater social isolation and lower social capital compared with the general population. Given the importance of social relationships for health and wellbeing, then, an exploration of the social lives of people with disabilities seems timely.

A common assumption is that social relationships are immaterial to individuals with disabilities either because they lack the ability to understand them or because they have too little in common with their nondisabled peers to develop meaningful relationships (O'Brien & O'Brien, 1993). However, people with disabilities who have friends are more likely to have a positive self-concept, better communication skills, healthier emotional functioning, more positive coping strategies and a better grasp of life skills (DeGeorge, 1998; Geisthardt, Brotherson, & Cook, 2002; Heiman, 2000; Schleien, Heyne, Rynders, & McAvoy, 1990; Stainback & Stainback, 1987). Although it is generally accepted that making friends is a simple and natural process, individuals with

disabilities often do not make friends as easily and effortlessly as their non-disabled peers and tend, as a result, to have fewer friends and less stable relationships (DeGeorge, 1998; Irvine, 2007).

We acknowledge at the outset that efforts to understand social capital among people with disabilities may be complicated by the considerable heterogeneity in disability type, including cause, course, and severity, as well as the wide range of different rehabilitation needs and objectives. In addition, co-occurring individual and structural factors such as gender, age, race/ethnicity, and socioeconomic status may act interactively to enhance or constrain access to social capital (Webber, 2005) and have considerable implications for people's wellbeing. Nevertheless, living with a disability of any kind has a profound impact on the physical, psychological, and social domains of everyday life and, accordingly, on one's social capital. This is especially true for individuals with high support needs whose disabilities necessitate greater support in activities of daily living and for whom creating a repository of diverse and meaningful social networks may be a challenge. Disaggregation of data by impairment type is important and future research should assess how the experience of disability is moderated by this and other co-occurring variables, and to what extent these variables can predict levels of social capital. Our aim here, however, is to investigate the overall existing trends in social capital among a diverse group of individuals whose disabilities are sufficiently severe to necessitate ongoing support from social services and/or associations for community living.

Present study

Professionals who work in the field of rehabilitation have long recognized the importance of the psychosocial aspects of disability and the interaction between individuals and their environments (Kenneth, 2004). However, no known study to date has attempted a comparative analysis of social capital levels between people with disabilities and the general population. In addition, little previous research has examined the sources from which many people with disabilities draw their social capital. Guided by Putnam's seminal work, the present study sought to provide empirical answers to these questions by exploring broad areas of convergence and difference between the general population and people with disabilities who have high support needs and to provide an assessment of whether and in what ways these two groups differ.

In light of the existing literature on social capital and disability, we expect participants with disabilities to demonstrate greater deficits in their social capital levels compared with the general population. If on the other hand findings reveal that social capital levels are higher or comparable among participants with disabilities, this may be a reflection of the effectiveness of community-based organizations in providing the support and optimism needed to achieve community integration for this population. In addition, we hypothesize that the sources of social capital among people with disabilities, i.e., access to social capital building opportunities, will be primarily family members and/or rehabilitation professionals or other individuals in paid positions of care and support, rather than natural friendships.

Method

Participants

Participants were drawn from a sample of convenience consisting of 218 individuals between the ages of 18 and 80 who have a variety of disabilities and high support needs. All participants were ongoing recipients of programs and/or services including residential, day support, social and recreational, and community support from the Interdependence Network, a group of six disability-based organizations from around the United States and Canada[1]. Participant demographics are provided in Table 1.

Table 1

Participant characteristics (N = 218)

	Frequency	Percent
Gender		
Male	135	62
Female	83	38
Age		
18-25	30	13.8
25-29	17	7.8
30-39	39	17.9
40-49	58	26.6
50-59	38	17.4
60-69	6	2.8
70-79	2	0.9
80+	1	0.5
Missing	27	12.4
Disability Type (more than one may apply)		
Intellectual	132	61

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[1] The Interdependence Network affiliate agencies include: Community Living Mississauga (Mississauga, Ontario, Canada); communityworks, Inc. (Kansas City, Missouri, USA); Connect Communities (Vancouver, British Columbia, Canada); Hope Services (San Jose, California, USA); John F. Murphy Homes (Portland, Maine, USA); and United Cerebral Palsy/CLASS (Pittsburgh, Pennsylvania, USA)

Physical	72	33
Other mental health	55	25
Autism	24	11
Hard of hearing	4	2
Blind	4	2
Cerebral Palsy	6	3

Questionnaire Development

The Harvard Kennedy School's (HKS; 2006) *Social Capital Community Benchmark Survey* was used as a proxy to develop the *Social Capital Inventory*, the first tool created to examine social capital levels among individuals with disabilities (see Appendix A). The *Social Capital Community Benchmark Survey* was modified in a number of ways in order to facilitate its administration and make it more appropriate for our sample. First, questions with significant overlap were removed to reduce interview time and respondent fatigue. For example, of the 10 questions pertaining to social trust in specific situations and towards specific people, only the general question of whether most people can be trusted was adapted for the present study. Second, questions not relevant to the objectives of the study were also removed (e.g., "Would you like to see spending for public schools increased or decreased?"). Finally, some questions were added in order to better understand the social capital needs of our sample (e.g., "How many of your close friends are paid staff or support professionals?"). The final questionnaire consisted of 65 items relating to six key indicators of social capital as outlined by the *Social Capital Community Benchmark Survey*: Social Trust, Social Support, Diversity of Friendships, Conventional Politics Participation, Civic/Community Leadership, and Informal Socializing (see Table 2 for a sample of items used from each index). An additional

index, Associational Involvement, was excluded from our analysis due to a large portion

of missing data.

Response options included 4- or 5-point scales (e.g., *For each of the following*

statements, please tell me whether you strongly agree, agree somewhat, disagree

somewhat or strongly disagree); dichotomous responses (e.g., *yes* or *no*); and quantitative

questions (e.g., *How many siblings do you have?*).

Table 2

Social Capital Index Measures

Social Capital Index	Index Description	Sample Questionnaire Items
Social Trust	How much one trusts others	• Generally speaking, would you say that most people can be trusted or cannot be trusted? • Would you say that most people try to be helpful or do you think that they are mostly looking out for themselves?
Social Support	The availability of social support systems and where people turn for help	• Do you currently have a partner or spouse? • Besides your parents, siblings, and children, how many other relatives do you have that you feel close to?
Diversity of Friendships	The extent to which social networks are broad and diverse	• Would you say that all of your friends know each? • Can you count on anyone to provide you with emotional support?
Conventional Politics Participation	Involvement in the political process	• Are you currently registered to vote? • Did you vote in the most recent election?
Civic/Community	Involvement in organized groups,	• Are you a member of the

Leadership	such as sports teams, hobby groups, and religious associations	following groups? • Would you say you attend religious services regularly, often, seldom, almost never, or never?
Informal Socializing	Connections developed through informal relationships, such as community activities, employment, and volunteerism	• Please tell us how many times in the past 12 months have you participated in these types of activities? • How do you typically spend your time during the day?

Questionnaire Administration

Questionnaire items were administered in a conversation-style format by trained

agency staff who recorded participants' responses. To ensure consistency, staff members

were provided with interview guidelines that included response wait times and suggested

prompts. Where necessary, assistance was provided in explaining the meaning of

questions and/or breaking them down into smaller segments. However, because

participants represented a range of disabilities and levels of ability, it was not possible to

completely control the amount of assistance provided by administrators. For example,

some terms, such as *friend,* were defined while others, such as *community,* were left open

to interpretation, possibly influencing participant responses. Interviews took between 45

and 60 minutes to complete. Before the interview, each participant was informed of the

purpose of the questionnaire and consent was obtained.

Data Analysis

Pearson's chi-square goodness of fit tests were performed to test for differences between

observed frequencies obtained from the present study and expected frequencies found in

the HKS survey. Because some of the questionnaire items were modified as mentioned

earlier, direct comparison of questions between the present and HKS surveys was not always possible. In such cases, responses were compared with other general population statistics obtained from large, widely recognized, published surveys conducted by Statistics Canada (2008), the Berkeley Longitudinal Study (1972-2010), Pew Research Center (2005, 2007, 2009, 2011), and Roper Center for Public Opinion Research (2005). These surveys gather ongoing data and monitor changes in social trends to better understand the attitudes, values, and behaviours of the general public, and to inform research and social policy issues. Data are collected through random, nationally representative cross-sections of adults aged 18 years or older (except Statistics Canada, whose samples include individuals 15 years and older). Participants are selected through Random Digital Dialing, a process that generates phone numbers randomly based on in-use area codes. Computer-Assisted Telephone Interviewing or face-to-face interviews are employed. Weighting factors are used to ensure the samples are accurately representative of the population. Although little information is provided about sample demographics, there is a possibility that people with disabilities were included to some extent in these samples.

In some cases, questionnaire items were not found in general population surveys and thus could not be compared. Further, statistical data such as means and standard deviations were not always provided by general population surveys, making it impossible to conduct tests of significance. This necessitated some methodological compromise such as omitting a number of questions from our analysis and/or comparing responses from questions that were similar but not matched verbatim. In addition, because the questionnaire was developed for program evaluation purposes, it did include a number of

qualitative items. Although we eliminated the majority of such questions from our analysis, some important items were retained and treated descriptively. These comparisons are not offered as evidence of statistical rigor; they do, however, permit exploration of broad areas of convergence and difference between the two sample groups and provide an assessment of the social capital of people with disabilities and whether this differs in any remarkable way from the general population.

Questions corresponded to one or more of the six indices. Responses to questions with 4- and 5-point response options were often combined for better clarity. For example, where values for both *strongly agree* and *agree* were high, they were united as a single *agree* response. Collapsing Likert responses into condensed categories has been cited as appropriate for analysis, particularly when wider scales are used (Brill, 2008). Of the 65 questions, 16 were excluded from our analysis due to significant overlap. An additional 23 questions were removed as these were qualitative and not subject to statistical analysis. Others still could not be matched with general population statistics, as mentioned earlier. Therefore, our final data analysis was based on 26 items.

Presentation of results is organized in accordance with the six social capital indices.

Results

Social Trust

Overall, people with disabilities were significantly more likely to report higher levels of social trust. Seventy-eight percent agreed that most people can be trusted compared with 44% of general population respondents (HKS, 2006), $\chi^2(1, N = 199) = 92.76, p < .001,$ and 71% agreed that most people are helpful compared with 62% of general population

respondents (Pew Research Centre, 2007), $\chi^2(1, N = 211) = 6.38, p < .05$. Perceptions of

group acceptance were also higher with 80% of people with disabilities agreeing that

their neighbourhood is accepting of people with disabilities compared with only 31% of

general population respondents who reported feeling there is little or no discrimination

against people with disabilities (Roper Centre for Public Opinion Research, 2005).

People with disabilities also provided higher neighbourhood ratings with 60% rating their

neighbourhood as excellent or very good compared with 39% of general population

respondents (HKS, 2006), $\chi^2(3, N = 218) = 46.26, p < .001$. However, 39% of people with

disabilities reported feeling they have little or no impact on making their community a

better place to live, compared with 21% of general population respondents (HKS, 2006),

$\chi^2(3, N = 218) = 60.83, p < .001$.

Social Support

Only 17% of people with disabilities reported having a partner or spouse compared with

62% of general population respondents who reported being married (HKS, 2006), $\chi^2(1, N$

$= 212) = 174.92, p < .001$. Only one-fifth of people with disabilities reported having

children compared with 71% general population respondents who reported having kids

aged six and older (HKS, 2006), $\chi^2(1, N = 193) = 246.79, p < .001$. Sixty-nine percent of

people with disabilities agreed that parents provide help during illness and over half

(53%) agreed that parents help with household tasks and errands. Parental help in these

areas was much lower for general population respondents with only 14% relying on

parents during illness (Smith, Marsden, & Hout, 2011) and 6% relying on parents for help

around the house (Smith et al., 2011). Instead, nearly half (48%) of general population

respondents reported relying on their spouse during illness (Smith et al., 2011) and half relied on their spouse for help with household tasks (Smith et al., 2011).

Diversity of Friendships

Significant differences were found in reported number of close friends, $\chi^2(3, N = 193) = 57.70$, $p < .001$. As reported in Table 3, a greater number of people with disabilities reported having fewer friends while a greater number of general population respondents reported having more close friends. Further, 42% of people with disabilities identified at least one close friend as being a paid staff or support professional. Significant differences were also found in reported number of friends living in the same community, $\chi^2(6, N = 184) = 136.82$, $p < .001$. Nearly three times as many people with disabilities (28%) reported having none of their friends living in the same community compared with general population respondents (10%; Statistics Canada, 2008). Results are provided in Table 4.

Table 3

Comparison of Reported Number of Close Friends Between People with Disabilities and General Population Respondents (%)

Number of close friends	People with Disabilities[a] (*n* = 193)	General Population Respondents
None	10	4
1-2	33	18
3-5	37	36
6 or more	21	43

[a]Rounded values do not add to 100.

Social networks among people with disabilities were less diverse with 38% reporting that all of their friends already know one another compared with 12% of general population respondents (Smith et al., 2011), $\chi^2(3, N = 183) = 202.63$, $p < .001$. Similarly, only 17% of people with disabilities reported finding a job through a friend, or a friend of a friend compared with 33% of general population respondents who found work through a friend or an acquaintance (Smith et al., 2011). Instead, people with disabilities were about three times more likely to rely on professional services for finding work (38%) than general population respondents (13%; Smith et al., 2011), $\chi^2(2, N = 146) = 94.11$, $p < .001$. When it comes to emotional support, 90% of people with disabilities reported having someone to count on. However, when asked who was most helpful in providing emotional support, 39% identified paid professionals over a partner, a parent, a sibling, another relative, or a friend. By contrast, only 1% of general population respondents reported turning to professionals when down or depressed (Smith et al., 2011) and 14.3% of general population respondents identified professionals as most helpful when dealing with a major life change (Statistics Canada, 2008). Parents ranked a close second with 38% of people with disabilities turning to them for emotional support, more than 3 times more likely than general population respondents (11%; Smith et al., 2011). Forty-three percent of people with disabilities identified parents as most helpful in providing financial support compared with only 20% of general population respondents who reported turning to parents to borrow a large sum of money (Smith et al., 2011), $\chi^2(2, N = 218) = 85.09$, $p < .001$. Only 8% and 1% of people with disabilities turned to a spouse or partner for emotional and financial support, respectively, compared with 32% and 14% of general population respondents, respectively (Smith et al., 2011).

Table 4

Comparison of Reported Number of Friends Living in the Same Community Between People with Disabilities and General Population Respondents (%)

Number of friends	People with Disabilities[a] (*n* = 184)	General Population Respondents
None	28	10
1	18	8
2	17	19
3	10	15
4	4	12
5	4	10
6 or more	8	26

[a]Rounded values do not add to 100.

Conventional Politics Participation

Thirty-nine percent of people with disabilities reported not being registered to vote compared with 19% of general population respondents (HKS, 2006), $\chi^2(1, N = 212) = 50.49, p < .001$. Only about one-third (36%) of people with disabilities voted in the last election compared with 74% of general population respondents who did the same (HKS, 2006), $\chi^2(1, N = 195) = 143.21, p < .001$.

Civic/Community Leadership

Participation among people with disabilities across all organized groups was low and ranged from 1-12% compared with a participation range of 10-34% among general population respondents (HKS, 2006). Religious involvement among people with

disabilities was also low. Less than one-third (29%) reported attending church services

regularly or often compared with nearly half (48%) of general population respondents

who attend services every week or more, or almost every week (HKS, 2006), $\chi^2(3, N =$

218) = 60.83 , $p < .001$. Only 11% of people with disabilities reported assuming leading

roles within their religious organization (e.g., choir membership) compared with 45% of

general population respondents who reported participating in services outside of worship

and 79% of general population respondents who reported volunteering at their place of

worship (HKS, 2006). Over half (55%) of people with disabilities reported not knowing

anyone else or only a few people at religious services.

Informal Socializing

People with disabilities were asked how many times in the past 12 months they had

participated in a list of informal activities. Participation rates were generally low and

ranged from an average of 1-7%, compared with an average range of 2-25% among

general population respondents who were asked whether they had participated in any

informal activity over the past year (HKS, 2006). Agency staff ranked comparably with

friends and other relatives or family as primary activity partner for people with

disabilities in a number of informal activities. Results are provided in Table 5.

When asked about how they spend their day, people with disabilities were less

likely to be working, with only 25% having either part- or full-time work compared with

62% of general population respondents who reported being employed (HKS, 2006), $\chi^2(2,$

$N = 218) = 368.63$, $p < .001$. Nearly two-thirds of people with disabilities (62%) reported

that they spend their day in either a part- or full-time day or supported employment

programs.

Table 5
Summary of Informal Activity Participation Rate and Primary Activity Partner Among People with Disabilities

Activity	Respondents who Engaged in Informal Activity with Primary Activity Partner (%)									Activity Average	Response Rate
	Other Friends	Agency Staff	Other Relatives/ Family	No One	Roommates	Spouse	Co-Workers	Neighbours	Church Members		
Gone out to a restaurant	12.8	24.3	28	1.8	4.6	3.7	1.4	—	—	8.51	76.6
Gone to the movies	15.6	24.8	19.7	1.4	8.7	2.8	0.9	—	—	8.21	73.9
Been invited to the home of someone else	27.1	4.6	23.9	2.3	1.4	0.5	0.5	0.9	0.5	6.85	61.5
Hung out at a park, mall or another public space	15.1	22.9	10.6	3.7	6	1.8	0.9	—	—	6.77	61
Had people over to your home	22	5	23.4	1.8	1.4	1.4	—	1.4	0.9	6.36	57.3
Entertained people in your home	20.6	5.5	19.3	3.2	—	1.8	1.4	0.5	0.9	5.91	53.2
Gone bowling	12.8	20.2	4.1	1.8	6.4	—	0.9	—	0.5	5.18	46.8
Used the Internet	5.5	13.8	4.6	15.6	—	0.5	0.5	—	0.9	4.60	41.3
Played cards with others	7.8	15.6	8.3	0.9	6.9	0.5	0.9	—	—	4.54	40.8
Socialized with people outside of work	17	5.5	4.6	1.8	2.8	—	7.3	1.4	—	4.48	40.4
Gone to a health club or exercised	7.3	17.4	1.8	7.3	2.8	—	1.4	—	—	4.22	38.1
Gone to a museum	5.5	11	6.4	2.8	3.2	2.3	0.9	—	—	3.56	32.1
Played a team sport	13.3	6.9	1.4	2.3	1.4	0.9	—	0.5	—	2.96	26.6
Gone to a bar or tavern	9.6	3.7	4.1	3.2	0.5	2.3	0.5	—	—	2.65	23.9
Attended any public meetings on local issues	2.3	5.5	2.3	5	0.5	0.5	0.9	—	—	1.88	17
Average of all activities	12.95	12.44	10.83	3.66	3.10	1.26	1.22	0.31	0.24	5.11	46.03

Note. Dash (—) indicates responses where data were not reported.

Health and Life Satisfaction

Although not constituting their own index, health and life satisfaction ratings were measured as extensive research has documented a strong relationship between social capital and physical and mental health. Significant differences were found in the distribution of health ratings between people with disabilities and general population respondents, $\chi^2(3, N = 189) = 17.81, p < .001$ (see Table 6). A greater number of general population respondents reported their health as excellent or very good (55%; HKS, 2006) compared with people with disabilities (40%), although more people with disabilities rated their health as good (40%) compared with general population respondents (28%). Overall, however, combined health ratings of good or better appear to be comparable between people with disabilities (80%) and general population (83%) respondents. Life satisfaction ratings were also significantly different with 93% of people with disabilities reporting they are quite happy or very happy compared with 83% of general population respondents who reported a life satisfaction rating of 7 or higher on a 10-point scale (HKS, 2006), $\chi^2(1, N = 191) = 12.66, p < .001.$

Table 6

Comparison of Health Ratings Between People With Disabilities and General Population Respondents (%)

State of health	People With Disabilities (*n* = 189)	General Population Respondents
Excellent/Very good	40	55
Good	40	28
Fair	14	12
Poor/Very poor	6	5

Discussion

Survey comparisons indicate that (a) social capital levels among people with disabilities tend to be lower than that of general population respondents, and (b) in cases where levels of social capital are consistent with, or higher than, levels found among general population respondents, this may be reflective of (c) an incongruity between subjective evaluations and objective reports, or (d) support received from non-normative sources. This section reviews findings of particular interest, explores possible explanations and considers the clinical implications of our results.

(a) People with disabilities tend to have lower levels of social capital

Overall, people with disabilities show a marked disconnect from a number of social institutions including marriage, parenthood, religious organizations, employment and politics. Low engagement in these areas has removed such sources as important potential agents of social support and as facilitating community integration. These findings are consistent with previous research showing that people with disabilities are less likely to marry and have a family life (Beber & Biswas, 2009; Sheppard-Jones, Prout, Kleinert, & Taylor, 2005) and receive less support and companionship from family members and friends than individuals without disabilities (Rosen & Burchard, 1990). People with disabilities also tend to have fewer close friends, and are less likely to participate in both formal and informal activities. This is in line with previous work showing that people with disabilities are less involved in community groups and that leisure activities tend to be solitary (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). This lack of

involvement is particularly discouraging among religious institutions that have

historically encouraged the integration of different groups (McNair & Smith, 1998) and

that, apart from worship, often entail participation in some form of religious community

(Putnam, 2000; Stone, Cross, Purvis, & Young, 2003). Similarly, the workplace has

traditionally been viewed as providing opportunities to create and build social ties with

coworkers (Shooshtari, Naghipur, & Zhang, 2012). Respondents with disabilities,

however, are less likely to be employed and this follows a large body of evidence

showing that a disproportionate number of people with disabilities are either under- or

unemployed (Burkhauser & Stapleton, 2004; Dyda, 2008; Levy & Hernandez, 2009;

Verdonschot et al, 2009). In addition, research has shown that people with disabilities

tend to have lower labour force participation rates, devote less time to market work, and

suffer greater earnings penalties (Benoit, Jansson, Jansenberger, & Phillips, 2013; Brown

& Emery, 2010; Kelly, 2013; Pagan, 2013). Limited social connections therefore further

hinder the likelihood of employment and remove this venue as an opportunity to further

develop social capital.

Participation in the political process is another important measure of how

involved we are in our communities. Political engagement provides an opportunity for

individuals with disabilities to not only endorse candidates who are sympathetic to their

cause, but also to form connections through their affiliation with political parties. People

with disabilities, however, tend not to be politically involved. An under-representation of

individuals with disabilities at the polls is not uncommon and may be due to a number of

factors including a lack of understanding of the political process, difficulty accessing the

polls or participating in door-to-door campaigning, or a general disinterest in politics

(Bell, McKay, & Phillips, 2001; Keeley, Redley, Holland, & Clare, 2008; Pavey, 2003).

(b) In few cases, people with disabilities report higher than expected levels of social capital

Other findings, however, are encouraging and point to higher than expected levels

of social capital among people with disabilities. Neighbourhood ratings along with

perceptions of group acceptance are higher among people with disabilities and the

majority report having at least one close friend. Most indicate they have someone to rely

on for emotional, financial, and instrumental support and also report comparable ratings

of general life satisfaction and overall health. Comparable health ratings are particularly

noteworthy as we would expect such evaluations to be much lower among our sample.

Research has found disability status to be highly influential in how people think about

and construct their health and health-related quality of life with poorer self-rated physical

and mental health often reported by people with disabilities (Drum, Horner-Johnson, &

Krahn, 2008).

Equally interesting is the finding of higher social trust among people with

disabilities. Given the systemic maltreatment individuals with disabilities have

historically experienced, particularly by those in positions of power or authority (Rossiter

& Clarkson, 2013; Simpson, 2007; Sobsey, 1994; Stewart & Russell, 2001; Stroman,

2002), we expected participants to report lower levels of social trust. However,

institutions where such treatment took place have now been replaced by community-

based organizations geared towards social justice and inclusion, and can be viewed as

safe, alternative settings that differentiate themselves from larger society's values,

attitudes and behaviour towards disability.

(c) However, in such cases, results are likely explained by an incongruity between subjective evaluations and objective reports

Although people with disabilities report having fewer close friends and are far more

likely to have none of their close friends living in the same community, in many areas

they nonetheless report higher than expected subjective evaluations of social capital. This

may be explained by the particular settings in which many participants spend their time.

Nearly two-thirds report attending part- or full-time day support or supported

employment programs and this is likely where many of their relationships are formed,

primarily with peers and agency staff. Therefore, for many, their psychological sense of

community corresponds to and extends from such settings and/or groups of individuals

that have proven to be trustworthy, and thus may not represent an accurate depiction of

broader society. Relatedly, the concept of naïve optimism may help explain higher than

expected ratings of life satisfaction and general health. Naïve optimism refers to an

overly simplistic and trusting view of the world that often results in a biased

interpretation of reality (Epstein & Meier, 1989). Because individuals with cognitive

impairments were overrepresented in our sample, comparable ratings here may be the

result of naïve optimism and stem from participants not being fully aware of the long-

term health and social complexities associated with their conditions.

(d) or, non-normative sources of support

Survey results also make clear that, compared with general population respondents, the

sources from which people with disabilities derive their social support are non-normative.

General population respondents are most likely to locate emotional, financial and instrumental support in marriage and partnership. Indeed, as we move through life, our primary source of support is often a spouse or partner (Peters, 2008). People with disabilities, however, report lower rates of marriage and partnership and therefore lack these key providers of informal care (Ashman, Hulme, & Suttie, 1990). Instead, parents and paid professional staff appear to dominate this area of social capital. Research shows that social support for people with disabilities is most often provided by family members (Lippold & Burns, 2009) and that aging parents commonly remain the primary caregivers throughout life (Kropf, 1997; Shooshtari, 2012). Although not a variable in the present study, the role of adult siblings is also conceptualized as one of primary caregiver, particularly after parents pass on or are no longer able to provide care (Atkin & Tozer, 2014; Egan & Walsh, 2001; Heller & Arnold, 2010). However, sibling roles and relationships are varied and research has found mixed results over how these responsibilities are negotiated over time and across the life span. While some research has found a generally positive life impact of people with disabilities on their adult siblings (Heller & Arnold, 2010), other studies reveal a negative impact with nondisabled siblings reporting concerns about the expectation of future caregiving and significant stress over how to fulfill other social and family obligations alongside their sense of duty to support a brother or sister with a disability (Davys, Mitchell, & Haigh, 2011; Heller & Kramer, 2009; Tozer, Atkin, & Wenham, 2013). This may help explain why people with disabilities most frequently identify staff members as providers of emotional support and often perceive staff as central to their social support networks, and even their friendships (Antaki, Finlay, & Walton, 2007; Lippold & Burns, 2009). Indeed, according to Taylor

and Bogdan (1989), friendships among individuals with disabilities often emerge out of an earlier professional or caring relationship.

Although parents and professionals are traditionally atypical sources of support for adults, this study does make clear that these individuals fill an obvious and important gap in the lives of people with disabilities. Our findings speak to the success of social programs such as those offered by the Interdependence Network agencies that clearly account for a considerable part of the creation of social capital and its beneficial effects. Indeed, secondary supports such as these have been shown to provide a protective function even in the absence of primary ties (Syrotuik & D'Arcy, 1984) with some (West, Kregel, Hernandez, & Hock, 1997) arguing that professional support can in fact enhance one's abilities to fulfill social needs.

It is important to note, however, that the quality of relationships formed with professionals may be overestimated by individuals with disabilities and falsely perceived as true friendships (Green & Schleien, 1991). Although agency staff, attendants, and other service providers are often identified as friends, there are typically qualitative differences in the nature of these relationships as they tend to evolve out of feelings of obligation and may involve a lower level of social engagement on the part of the professional (Irvine, 2007; Lippold & Burns, 2009). In addition, agency policies are often designed to protect employees' confidentiality (Runnion & Wolfer, 2004) and may discourage social interactions between staff members and clients outside of agency settings and, in some cases, even between clients themselves. Further, these support systems tend to be fluid; continuously decreasing government funding means that professional supports are not sustainable, long-term solutions. Indeed, agency staff and

other professionals are temporary figures that often come and go over time. Parents, too, age and eventually pass on, often leaving adults with disabilities with poor informal networks (Krauss, Seltzer, & Goodman, 1992). Though no less supportive, parental and professional ties are removed from traditional sources of support and depart from the natural evolution most of us undergo as we progress through life. Our research supports this concern as over two-thirds of our sample are over the age of 30, but for the most part, have not moved on to replace parents and professionals with a life partner.

A key factor in successful social integration is the encouragement of diverse friendships between people with and without disabilities (Ager, Myers, Kerr, Myles, & Green, 2001). Day support and supported employment programs where many people with disabilities spend their time tend to be highly homogeneous and are designed almost exclusively for people with intellectual disability. Thus opportunities for establishing diverse social connections may be limited to the peers and support staff they meet in these programs. Indeed, people with disabilities report that many of their friends already know one another and this is consistent with previous research showing that participation in social activities among people with disabilities is more common with others who also have a disability (Emerson & McVilly, 2004). Agency staff also contributes significantly as an activity partner in a number of informal activities, ranking comparably alongside family and other relatives, and friends. Previous research shows that people with disabilities are often accompanied in an activity by training or therapeutic staff (Verdonschot et al., 2009) and that staff is often instrumental in organizing participation in social activities (Todd, 2000). Although there was no general population comparison for this question, it is widely accepted that the general population does not partake in

social activities with professionals but rather with family members and friends. Thus, our results support the notion that people with disabilities have restricted social networks and may be developing few relationships with nondisabled individuals who are not relatives and who are not paid to support them.

Conclusion

Social connectedness matters to our lives in the most profound way; the lack of meaningful connections with others is often a significant source of suffering (Peters, 2008). This study aimed to fill an important gap in the literature by reaching beyond anecdote to answer empirically the question of social capital among people with disabilities. Our findings point to appreciable differences in social capital among these individuals compared with the general population as well as among the sources from which their social capital is drawn.

The present study had a number of methodological challenges as addressed earlier, and was also limited by low response rates in some cases and by the retrospective nature of the questionnaire. In particular, response rates in Table 5 (informal activity participation rate and primary activity partner) varied widely and may indicate a generally low level of participation among respondents for some activities. For example, when asked about *attended any public meetings on local issues*, a response rate of 17% likely indicates that this is an activity in which most respondents simply do not partake. Although this made it difficult for us to draw significant conclusions, it does make a powerful statement about the extent to which respondents are active in their communities and engaged in common activities. Also important to note is that difficulties in response rates, response bias, reliability, and validity are not uncommon when conducting research

with people with intellectual disability (Finlay & Lyons, 2002; Heal & Sigelman, 1995) and response rates have been found to be markedly lower among participants with moderate to profound intellectual disability (Hartley & MacLean, 2006). The variability in response rates may therefore be attributed to the large number of respondents with intellectual disability in our sample (see participant demographics in Table 1). These, and others, are inherent challenges associated with conducting research with this population. Nevertheless, the results reported here are meaningful in constructing an understanding of the social capital experiences of our sample. Equally important is allowing participants with disabilities a more active role in research by capturing their own subjective views, rather than relying on informant reports and observational ratings as has been the case historically (Beart, Hardy, & Buchan, 2004; Schalock et al., 2002). Participation in research can be viewed as a form of self-advocacy as it provides opportunities for people with disabilities to speak and stand up for themselves, stand up for their rights, make choices, and be independent (People First, 1996). Engaging in self-advocacy has also been found to impact individuals with disabilities by contributing positively to their confidence and self-concept (Beart, Hardy, & Buchan, 2004).

It is important to note that the participants in this study were identified through their affiliation as service recipients of one of the six community-based disability agencies and thus represent a small and proactive subset of individuals living with disability who have successfully connected with community living organizations. Further, they tend to live in large, urban, and progressive cities where formal support services for people with disabilities have traditionally been available. Ashman, Hulme, and Suttie (1990) found notable differences in community members' access to and use of

facilities and social programs between rural and urban regions. Thus, circumstances are likely substantially different for people with disabilities who reside in more rural areas without access to services, and who likely spend the majority of their time at home with parents or other non-normative figures. Though these populations are often difficult to reach for research purposes, we expect their social capital levels to be lower than those revealed by this study, and their sources of social capital to consist primarily of family members in the absence of support gained through affiliations with community programs. In addition, because our sample was one of convenience rather than a random sample as is used in the comparative data, there is the possibility that other sociodemographic variables that were not taken into account could have influenced differences in social capital.

If it is accepted that the experience of disability rests on the relationship between the individual and the social environment, then a continued focus should be placed on rehabilitation practices that encourage and support community engagement for people with disabilities. Our findings provide a good starting point for comparative future research in this area as well as an informed direction for professionals working in the field. Our hope is that the concept of social capital will continue to appear in contemporary discourse about how best to encourage and support individuals with disabilities in their search for ways to connect meaningfully with others in their communities.

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