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

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(This article appeared in the Canadian Journal of Disability Studies, Vol 5, No 4, 2016.)

Abstract

Social capital is emerging 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 living 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 living with a broad range of disabilities 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 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.

Key words: *disability; social capital; social support; community integration; wellbeing*

Introduction

During a 1990 presentation at the Pacific Coast Brain Injury Conference in Vancouver, BC, 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, many people with disabilities continue to be isolated and excluded from their communities, from social activities, from employment opportunities – in short, from what we would call normal life (Flaherty, 2008).

Community-based rehabilitation has encouraged a move away from managing and caring for individuals with disabilities in segregated settings towards removing barriers and providing what is necessary for their full participation in community life (Irvine, 2007). Central to this movement has been the work of rehabilitation professionals who teach individuals the functional and adaptive skills necessary for achieving a maximum level of independence. Although the field of rehabilitation has traditionally adhered to the Medical Model, viewing disability as a direct consequence of impairment and focusing primarily on attempts at fixing these impairments (Bricher, 2000; Donoghue, 2003; Hubbard, 2004), the independent living movement of the 1960s has advocated for a more integrative approach that views disability as an environmental limitation rather than a personal defect (White, Simpson, Gonda, Ravesloot, & Coble, 2010). 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).

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. Indeed, the ICF explains variations in human functioning in terms of the dynamic interplay between these factors. 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.

Calling attention to 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. 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).

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). 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 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). Indeed, research suggests that 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). 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

Intuitively, social capital is a simple concept: The number and quality of our relationships predict how happy and healthy we are. However, establishing what exactly constitutes social capital, and if and how it can be measured, continues to elude. Key terms such as "trust" and "community" are often difficult to quantify, and this makes attempts to operationalize social capital and transition away from a purely theoretical understanding a challenge (Svendsen & Sorensen, 2006). Further, unlike other forms of capital, social capital is often viewed as an intangible and has not always received equal recognition from the scientific community (Svendsen & Sorensen, 2006). Finally, social capital means different things to different people and the degree to which one wants or needs social interaction differs from person to person. Given the lack of agreement about the parameters of this construct, the task of obtaining a single and direct measure of social capital is an inherently complicated one.

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. Investigating the concept of social capital may prove difficult without recourse to qualitative measurement and there may be a need to use somewhat less precise methods in order to approach empirically such a complex social phenomenon. These difficulties are magnified when studying individuals with disabilities and may be one reason why this type of research is so scarce. Nevertheless, the beneficial influences of social capital on sustaining health and wellbeing are well known, even if the exact mechanisms by which they do so remain unclear.

Social capital and disability

Given the importance of social relationships for health and wellbeing, 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 to have fewer friends and less stable relationships (DeGeorge, 1998; Irvine, 2007).

Efforts to understand social capital among people with disabilities may be complicated by the considerable heterogeneity in disability type and severity, including cognitive and emotional functioning, as well as by individual and cultural variations. However, living with a disability of any kind clearly 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 people whose disabilities render them more dependent on others in activities of daily living, limiting their access to social capital-building opportunities and making them among the most vulnerable and socially excluded members of society (Lau, Chow, & Lo, 2006). As a result, creating a repository of diverse and meaningful social networks may be a challenge. Exploring the extent to which differences in social capital vary as a function of disability type is an important and interesting question for future research. Our aim here however is to investigate the overall existing trends in social capital among relatively dependent individuals whose disabilities are sufficiently severe to necessitate ongoing support from social services and/or associations for community living.

Present study

In 2000, Putnam and colleagues at the Harvard Kennedy School of Government undertook the first systematic attempt to measure social capital within communities across America. Putnam's findings 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. 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, who has historically experienced greater social isolation and lower social capital compared with the general population. Although professionals who work in the field have long recognized the importance of the psychosocial aspects of disability and the interaction between individuals and their environments (Kenneth, 2004), no known study 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. Based on Putnam's seminal work, the present study sought to provide empirical answers to these questions and to identify key areas in which levels of social capital are lower among people with disabilities.

2. Method

Survey data were collected by the Interdependence Network (IN), a group of six disability-based human service organizations from around the United States and Canada. The Harvard Kennedy School's (HKS) *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. The current report is based on the results of the first of three surveys comprising a longitudinal study gauging the effectiveness of intervention programs aimed at raising social capital among service recipients. The data were compared and contrasted with general population (GP) statistics.

2.1 Questionnaire Development

Questions were abstracted from the HKS survey and supplemented with additional questions formulated by the IN (see Appendix A). The final survey consisted of 65 questions relating to six key indicators of social capital: Social Trust; Social Support; Diversity of Friendships; Conventional Politics Participation; Civic/Community Leadership; and Informal Socializing (see Table 1). An additional index, Associational Involvement, was excluded from our analysis due to missing data or lack of meaningful results. 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?*).

2.2 Participants

Participants were 218 individuals (62% male) with a variety of disabilities between the ages of 18 and 80 affiliated with one of the six IN disability agencies. Participants were ongoing service recipients of programs and/or services for individuals

Table 1

Social Capital Index Measures

Social Capital Index	Index Description	Sample Survey Questions
Social Trust	How much one trusts others	• Would you say most people can be trusted? • Would you say most people try to be helpful?
Social Support	The availability of social support systems and where people turn for help	• Are you married? • How many other relatives do you feel close to?
Diversity of Friendships	The extent to which social networks are broad and diverse	• Do all your friends know each other? • Can you count on someone for emotional support?
Conventional Politics Participation	Involvement in the political process	• Are you registered to vote? • Did you vote in the last election?
Civic/Community Leadership	Involvement in organized groups, such as sports teams, hobby groups, and religious associations	• How often do you participate in the following groups? • How often do you attend religious services?
Informal Socializing	Connections developed through informal relationships, such as community activities, employment, and volunteerism	• How many times in the past 12 months have you participated in the following activities? • How do you typically spend your time during the day?

with disabilities including residential, day support, social and recreational, and community support. Participant demographics are provided in Table 2.

2.3 Questionnaire Administration

Survey questions were administered in a conversation-style format by trained agency staff who recorded participants' responses. To ensure consistency, staff was provided with interview guidelines that included response wait times and suggested prompts. Where necessary, assistance was provided in explaining the meaning of

Table 2

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

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 survey and consent was obtained.

2.4 Data Analysis

Data analysis was conducted to determine the distribution of responses for each item. Pearson's chi-square goodness of fit tests were performed to test for differences between observed (IN) and expected (GP) frequencies obtained from the HKS survey. Direct comparison of questions between the current and HKS surveys was not always possible, however, as many questions were added to the IN survey in order to be more relevant to participants with disabilities. In such cases, IN responses were compared with general population statistics found from large, widely recognized published surveys conducted by Statistics Canada (2008), the Berkeley Longitudinal Study (1972-2010), Pew Research Centre (2005, 2007, 2009, 2011), and Roper Centre for Public Opinion Research (2005). Where IN questions could not be matched with general population surveys, or where statistical data such as means and standard deviations were not provided by general population surveys, significance tests could not be conducted and these questions were omitted from our analysis.

Questions corresponded to one or more of the six IN 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. Of the 65 questions, 16 were excluded from our analysis due to significant overlap. Final data analysis was based on 27 questions that provided the most meaningful results. Presentation of results is organized in accordance with the six social capital indices:

Social Trust

Overall, IN respondents 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 (GP) respondents (HKS, 2006), $\chi^2(1, N = 199) = 92.76, p < .001$, and 71% agreed that most people are helpful compared with 62% of GP respondents (Pew Research Centre, 2007), $\chi^2(1, N = 211) = 6.38, p < .05$. Perceptions of group acceptance were also higher with 80% of IN respondents agreeing that their neighbourhood is accepting of people with disabilities compared with only 31% of GP respondents who reported feeling there is little or no discrimination against people with disabilities (Roper Centre for Public Opinion Research, 2005). IN respondents also provided higher neighbourhood ratings with 60% rating their neighbourhood as excellent or very good compared with 39% of GP respondents (HKS, 2006), $\chi^2(3, N = 218) = 46.26, p < .001$. However, 38.5% of IN respondents reported feeling they have little or no impact on making their community a better place to live, compared with 21% of GP respondents (HKS, 2006), $\chi^2(3, N = 218) = 60.83, p < .001$.

Social Support

Only 17% of IN respondents reported having a partner or spouse compared with 62% of GP respondents who reported being married (HKS, 2006), $\chi^2(1, N = 212) = 174.92, p < .001$. Only one-fifth of IN respondents reported having children compared with 71% GP respondents who reported having kids aged six and older (HKS, 2006), $\chi^2(1, N = 193) = 246.79, p < .001$. Sixty-nine percent of IN respondents agreed that parents provide help during sickness and over half (53%) agreed that parents help with household tasks and errands. Parental help in these areas was much lower for GP 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 GP 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, $\chi^2(3, N = 193) = 57.70, p < .001$. Results are reported in Table 3.

Table 3

Comparison of Reported Number of Close Friends Between IN and GP Respondents (%)

Number of close friends	IN[a] (*n* = 193)	GP
None	10	4
1-2	33	18
3-5	37	36
6 or more	21	43

Note. IN = Interdependence Network respondents; GP = general population respondents.
[a]Rounded values do not add to 100.

A greater number of IN respondents reported having fewer friends while a greater number of GP respondents reported having more close friends. Further, 42% of IN respondents 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 IN respondents (28%) reported having none of their friends living in the same community compared with GP respondents (10%; Statistics Canada, 2008). Results are provided in Table 4.

Social networks among IN respondents were less diverse with 38% reporting that all of their friends already know one another compared with 12% of GP respondents (Smith et al., 2011), $\chi^2(3, N = 183) = 202.63$, $p < .001$. Similarly, only 17% of IN respondents reported finding a job through a friend, or a friend of a friend compared with 33% of GP respondents who found work through a friend or an acquaintance (Smith et al., 2011). Instead, IN respondents were about three times more likely to rely on professional services for finding work (38%) than GP respondents (13%; Smith et al., 2011), $\chi^2(2, N = 146) = 94.11, p < .001$.

When it comes to emotional support, 90% of IN respondents reported having someone to count on. However, when asked who was most helpful in providing

Table 4

Comparison of Reported Number of Friends Living in the Same Community Between IN and GP Respondents (%)

Number of friends	IN[a] (*n* = 184)	GP
None	28	10
1	18	8
2	17	19
3	10	15
4	4	12
5	4	10
6 or more	8	26

Note. IN = Interdependence Network respondents; GP = general population respondents. [a]Rounded values do not add to 100.

emotional support, 39% identified paid professionals over a partner, a parent, a sibling, another relative, or a friend. By contrast, only 1% of GP respondents reported turning to professionals when down or depressed (Smith et al., 2011) and 14.3% of GP respondents identified professionals as most helpful when dealing with a major life change (Statistics Canada, 2008). Parents ranked a close second with 38% of IN respondents turning to them for emotional support, more than 3 times more likely than GP respondents (11%; Smith et al., 2011). Forty-three percent of IN respondents identified parents as most helpful in providing financial support compared with only 20% of GP 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 IN respondents turned to a spouse or partner for emotional and financial support, respectively, compared with 32% and 14% of GP respondents, respectively (Smith et al., 2011).

Conventional Politics Participation

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

Civic/Community Leadership

Participation among IN respondents across all organized groups was low and ranged from 1-12% compared with a participation range of 10-34% among GP respondents (HKS, 2006). Religious involvement among IN respondents was also low. Less than one-third (29%) reported attending church services regularly or often compared with nearly half (48%) of GP 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 IN respondents reported assuming leading roles within their religious organization (e.g., choir membership) compared with 45% of GP respondents who reported participating in services outside of worship and 79% of GP respondents who reported volunteering at their place of worship (HKS, 2006). Over half (55%) of IN respondents reported not knowing anyone else or only a few people at religious services.

Informal Socializing

IN respondents 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 GP 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 IN respondents in a number of informal activities. Results are provided in Table 5.

When asked about how they spend their day, IN respondents were less likely to be working with only 25% having either part- or full-time work compared with 62% of GP respondents who reported being employed (HKS, 2006), $\chi^2(2, N = 218) = 368.63$, $p < .001$. Nearly two-thirds of IN respondents (62%) reported that they spend their day in either a part- or full-time day support program or a sheltered workshop.

Health and Life Satisfaction

Although not one of the indices created by the IN, health and life satisfaction are nonetheless important measures of social capital 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 IN and GP respondents, $\chi^2(3, N = 189) = 17.81$, $p < .001$ (see Table 6). A greater number of GP respondents reported their health as excellent or very good (55%; HKS, 2006) compared with IN respondents (40%), although more IN respondents rated their health as good (40%) compared with GP respondents (28%). Overall, however, combined health ratings of good or better appear to be comparable between IN (80%) and GP (83%) respondents. Life satisfaction ratings were also significantly different with 93% of IN respondents reporting they are quite happy or very happy compared with 83% of GP 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 5

Summary of Informal Activity Participation Rate and Primary Activity Partner Among IN Respondents

Activity	Number of Respondents who Engaged in Informal Activity with Primary Activity Partner (%)										
	Other Friends	Agency Staff	Other Relatives/ Family	No One	Roommates	Spouse	Co-Workers	Neighbors	Church Members	Activity Average	Response Rate
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.

Table 6

Comparison of Health Ratings Between IN and GP Respondents (%)

State of health	IN (*n* = 189)	GP
Excellent/Very good	40	55
Good	40	28
Fair	14	12
Poor/Very poor	6	5

Note. IN = Interdependence Network respondents; GP = general population respondents.

Discussion

Survey comparisons indicate that (a) social capital levels among individuals 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 GP 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) IN respondents tend to have lower levels of social capital

Overall, IN respondents 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). IN respondents 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). IN respondents, 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). Due to limited physical abilities or cognitive impairments that often result in lower levels of education, many people with disabilities tend to have few job options available to them (Parris & Granger, 2008). 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. IN respondents, 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). Given that a large number of IN respondents have cognitive impairments, their disability may be helpful in explaining their low political involvement.

(b) In few cases, IN respondents report higher than expected levels of social capital

Other findings however are encouraging and point to higher than expected levels of social capital among IN respondents. Subjective ratings of social trust as well as perceptions of group acceptance are higher among IN respondents. The majority report having at least one close friend and are more likely to provide high neighbourhood ratings. Most IN respondents report they have someone to rely on for emotional, financial, and instrumental support and also report comparable ratings of general life satisfaction and overall health. Taken together, these results suggest that for some composite measures, levels of social capital may indeed be higher than expected among IN respondents.

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

High ratings of social trust among IN respondents must be understood in relation to the particular settings in which many of these individuals spend their time. Nearly two-thirds report attending part- or full-time day support programs or sheltered workshops and this is likely where many of their relationships are formed, primarily with peers and agency staff. Given that IN respondents report having fewer close friends and are far more likely to have none of their close friends living in the same community, their psychological sense of community may correspond to and extend from a particular setting and/or group of individuals that have proven to be trusting, and thus may not represent an accurate depiction of broader society. Alternately, this incongruity may be due in part to Naïve Optimism, an overly simplistic and trusting view of the world that often results in a biased interpretation of reality (Epstein & Meier, 1989). Because the majority of IN participants have cognitive impairments, it is unclear whether they were able to accurately evaluate risk and this may explain their high willingness to trust others. The concept of Naïve Optimism may further explain higher than expected ratings of life satisfaction and general health. Since IN respondents have a variety of disabilities and other related conditions, we would expect evaluations of these constructs to be much lower. Comparable ratings provided by IN respondents in these areas may stem from them 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 GP respondents, the sources from which IN respondents 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). IN respondents 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). Previous research has also shown that 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 IN 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 IN respondents 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 programs and sheltered workshops where many IN respondents spend their time tend to be highly homogeneous and are designed almost exclusively for people with certain types of disabilities. Thus opportunities for establishing diverse social connections may be limited to the peers and support staff they meet in these programs. Indeed, IN respondents 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). Further, although the majority of IN respondents do report having close friends, nearly half identify at least one close friend as a paid staff and support professional and the remainder, as suggested by their limited social interactions, are likely those they have met through supporting agency programs. 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 IN respondents 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). Like Putnam’s work, this study reaches 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 as well as among the sources from which their social capital is drawn.

In many ways, the results of this study were expected and validate a pattern long observed by those working in the field: People with disabilities are a population vulnerable to social isolation (Partington, 2005). For the most part, IN respondents, who represent a variety of disabilities, do not have partners or children, are unemployed, are not religiously engaged, do not lead active social lives, and have social networks that are less diverse, less reciprocal and contain more paid professionals. Moreover, they seem to rely primarily on sources of support that are atypical and temporary. Indeed, our findings strongly suggest that the task of building social capital for these individuals is left largely in the hands of social service agencies and other rehabilitation professionals.

It is important to note that the participants in this study were identified through their affiliation as service recipients of one of the six IN agencies and thus represent a small and proactive subset of all individuals living with disability. Further, they tend to live in large, urban, and progressive cities where social 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. These populations are often difficult to reach for research purposes and thus there has been little investigation among them. However, we expect their social capital levels to be even lower than those revealed by this study.

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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