

**SOCIAL PARTICIPATION, QUALITY OF LIFE AND ATTENDANCE IN BRAIN  
INJURY DROP-IN CENTRES: AN EXPLORATORY STUDY**

by

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## ABSTRACT

### Introduction

Many individuals with traumatic brain injury (TBI) experience long term or life-long changes in social participation and quality of life, including social isolation, loneliness, reduced involvement in social and leisure activities, decreased social support networks and reduced satisfaction with life. There are few community-based interventions available to address these issues, and little research on their effectiveness. The brain injury drop-in centre (BIDC) is an innovative model of long-term support not yet addressed in the literature.

### Purpose

(a) To determine if there is a relationship between social participation and subjective quality of life (SQOL) for community-dwelling individuals with TBI.

(b) To compare social participation and SQOL for individuals with TBI who attend BIDCs with individuals who do not attend but who have been identified as potentially benefitting from attending.

### Methods

**Subjects.** Participants were 23 individuals recruited from BIDCs ('BIDC group') and 19 individuals recruited through community-based clinicians and service providers ('Comparison group'). The Comparison group was found to consist of 7 participants who stated that maybe they would attend a BIDC but for the most part were too busy to attend ('Maybe group'), and 12 participants who stated that yes they would attend but were not aware of BIDCs or experienced a contextual barrier to attendance ('Yes group').

**Design.** A cross sectional design was implemented with convenience sampling.

## **Results**

The correlational analysis (Chapter Two) showed statistically significant associations involving SQOL and the social and subjective measures of social participation. The comparison study (Chapter Three) found the BIDC group to have, on average, higher levels of SQOL and social participation than the Comparison group, in particular as compared to the Yes group.

## **Conclusions**

This exploratory study contributes to the TBI literature in showing that it is the more subjective and not objectively measured nature of participation that is associated with SQOL. Findings provide tentative support that attendance at BIDCs may benefit social participation and SQOL. This study provides a foundation for more rigorous quantitative investigation of the effectiveness and efficacy of BIDCs, as well as direction for qualitative studies to further explore social participation, SQOL and the experience of attending BIDCs.

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## LIST OF ABBREVIATIONS

AKHS	Abdel-Khalek Happiness Scale
ASAP	Adult Subjective Assessment of Participation
BIDC	brain injury drop-in centre
CIQ-SI	Community Integration Questionnaire, Social Integration Scale
FrSBe	Frontal Systems Behavior Rating Scale
ICF	International Classification of Functioning, Disability and Health
M	mean score
MoCA	Montreal Cognitive Assessment
MPAI-4	Mayo Portland Adaptability Inventory, version 4
NS	not statistically significant
SD	standard deviation
SF-36 GHQ	Short Form 36 General Health Question
SQOL	subjective quality of life
SRDS	Zung Self-Rating Depression Scale
QOL	quality of life
QOLHQ	Quality of Life and Health Questionnaire
SPS	Social Provisions Scale
TBI	traumatic brain injury
UCLA-LS	University of California at Los Angeles Loneliness Scale
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

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## CO-AUTHORSHIP STATEMENT

Chapters Two and Three will each be revised into a manuscript co-authored with Dr. Tal Jarus, Dr. Lyn Jongbloed and Dr. Anita Hubley at the University of British Columbia (UBC). As the first author of each of these manuscripts, my contributions included formulating the hypotheses/research questions, conducting the literature reviews, identifying the research design, selecting the measurements, preparing the ethics submissions, recruiting participants, collecting the data (with some assistance from a research assistant), analyzing the data, interpreting the data, and preparing the first version of each manuscript. I will be responsible for rewriting the manuscripts and submitting them for publication.

Dr. Tal Jarus provided feedback and input throughout each step of the project. All co-authors contributed to finalizing the hypotheses/research questions, research design and selection of measurement tools. In addition, Dr. Anita Hubley reviewed the submission to the UBC Behavioural Research Ethics Board and contributed to planning the statistical analyses. All co-authors reviewed the results of data analyses and contributed to the interpretation of data.

## **CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW**

### **Epidemiology and impact of traumatic brain injury**

Traumatic brain injury (TBI) is a major health issue, with potential serious long-term outcomes<sup>1</sup>. Worldwide, TBI is a leading cause of disability<sup>2</sup>. Each year in developed countries, 100 to 200 people out of 100,000 require hospitalization as a result of TBI<sup>3,4</sup>. In the USA, this represents the highest incidence rate of all injury categories<sup>5</sup>. In Canada, in 2003 to 2004, hospital admissions for TBI represented 9% of all trauma admissions<sup>6</sup>. It is estimated that 43% of those who are hospitalized with TBI go on to experience long-term disability<sup>7</sup>.

There is a significant cost of TBI and the resulting disability to society and to the individual with TBI. The cost to society includes the expense of medical care and lost productivity. A Canadian study investigated 10-year outcomes following initial hospitalization for TBI and found that, as compared to the general population, individuals with TBI had higher physician claims and more frequent and longer hospital stays<sup>8</sup>. This included that, after controlling for pre-injury mental health and other confounders, individuals with TBI had almost three times the number of hospitalizations for mental health-related issues as compared to the general population<sup>8</sup>. For all individuals hospitalized in the USA in 2000 with a TBI, the total lifetime cost for medical care has been calculated at US\$7.4 billion, including physical care only and not other services such as mental health or vocational rehabilitation<sup>5</sup>. For the same cohort, the total lifetime cost for productivity losses has been estimated at US\$51.2 billion, higher than for any other injury category<sup>5</sup>.

Individuals with TBI, in particular when the injury is moderate to severe, may experience physical, cognitive, communication, behavioural, and/or emotional impairments for many years, if not indefinitely<sup>9</sup>. These impairments may affect all aspects of a return to successful living in

the community, including for work or school, independent living, personal and social relationships, and leisure activities<sup>9-13</sup>. For example, 20 to 40% of individuals with TBI who were employed prior to injury are unable to return to work in any capacity<sup>11, 14-16</sup>, despite provision of vocational rehabilitation services<sup>17</sup>. A high proportion of individuals with TBI experiences reduced involvement in social and leisure activities<sup>11, 18-20</sup>, as well as reduced social networks and increased social isolation<sup>20-22</sup>. This includes disruption in family relationships<sup>14, 20, 23, 24</sup>. In addition, many individuals with TBI experience low quality of life such as measured by subjective well-being and life satisfaction<sup>21, 25, 26</sup>.

### **Participation and quality of life**

For individuals with TBI, it has been suggested that the primary goals for rehabilitation include a return to active and purposeful roles and activities at home and in the community<sup>27-29</sup>, or, more succinctly, community integration<sup>30</sup> or participation<sup>27, 31</sup>. Another primary goal is enhanced quality of life<sup>30, 32-35</sup>. Following are findings from the literature relating to these goal areas.

#### **Community integration or participation**

For individuals with TBI, an early conceptualization of community integration was level of functional independence for social, productive, and home activities, as constituted by the three subscales of the Community Integration Questionnaire (CIQ)<sup>36</sup>. This understanding was broadened by McColl and colleagues<sup>34, 37</sup> who identified that, for individuals with TBI, community integration includes not only social, productive and home activities, described by McColl as occupation (referring to leisure and productivity) and independent living, but also social support. Other researchers have also recognized that successful independent living is measured not only by level of involvement in an activity, but also the individual's subjective

experience of integration into a community<sup>38</sup>. More recently in the rehabilitation sciences literature in general<sup>39</sup>, and TBI rehabilitation literature more specifically<sup>13, 27, 40-43</sup>, community integration has been seen as closely related and perhaps analogous to participation. Both community integration and participation involve consideration of preferences and interests<sup>44</sup>, satisfaction with performance<sup>44-46</sup>, enjoyment<sup>44</sup>, frequency and intensity of involvement in activities<sup>44, 45</sup>, motivation to change level of engagement in activities<sup>40</sup>, feelings of belonging and sense of community<sup>42</sup>, and availability of support and opportunities to participate<sup>47</sup>.

The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), one of the best known models of disability<sup>48</sup>, defines participation as involvement in a life situation<sup>49</sup>. This model's proposed definition of involvement includes '...taking part, being included or engaged in an area of life, being accepted, or having access to needed resources...' (p. 15). The ICF indicates that an individual's level of participation is the result of an interaction between their health condition, personal and environmental contextual factors, body structures and functions, and performance of activities (execution of a task or action). The nine domains of activity and participation are learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life<sup>49</sup>.

Social participation is another term found in the literature. This is considered by some as interchangeable with community integration and participation<sup>27, 43</sup>. However, others see community integration and participation as broader constructs, and social integration or social participation as only one dimension<sup>36</sup>. This study takes the latter perspective. For this study, social participation is operationalized as involvement in leisure activities, social interactions and a social network. This study recognizes that, in assessing social participation, there needs to be

consideration not only of diversity, frequency and intensity of social and leisure activities and roles, but also to the individual's subjective experience, including satisfaction with performance, enjoyment, and availability of social supports.

**Social participation outcomes.** More than 35 outcome studies have addressed social participation outcomes for individuals with TBI. A common finding is that reduced participation in leisure and social activities is a major concern, including for many individuals with TBI who have been successful in returning to work in some capacity<sup>19, 36, 50</sup>. One of the early landmark TBI outcome studies<sup>51</sup> found that, for individuals with TBI, including those who were successful in returning to work, there was a significant change in leisure and social participation. At two years post injury, half of the sample participated in fewer leisure activities than prior to injury, with the more severely injured having the fewest social encounters and social outings. Subsequent outcome studies, whether at 6 months or 24 years post TBI, have reported similar findings. Individuals with TBI have fewer hobbies, pastimes, recreation and interests than prior to injury<sup>11, 14, 20, 52-54</sup> and compared to individuals without TBI<sup>40, 55</sup>. There is a greater reduction in participation in active pursuits and activities outside of the home or involving others than for passive and solitary activities<sup>11, 18, 40</sup>. Not only are individuals with TBI participating less in leisure and social activities, but they also have low satisfaction in these areas<sup>56</sup>. A number of studies have reported a large proportion (40 to 45%) of individuals responding that they would like to find places and opportunities to socialize with others, participate in physical leisure activity, and/or do more activities outside of the home<sup>18, 57, 58</sup>.

Individuals with TBI report fewer friends<sup>21, 23, 54</sup> and less social interaction with others, in particular outside of their home and family<sup>20, 55</sup>. Although some of these individuals may not want any relationships, many of them report wanting friends and a partner<sup>54</sup>. Not only do

individuals with TBI experience smaller social networks than individuals without TBI<sup>22</sup>, but they also have low satisfaction with their interpersonal relationships<sup>16, 26, 56</sup>. In one qualitative study<sup>19</sup>, a major theme was loss of friends, with one participant describing this as ‘...an enormous source of sorrow...’ (p. 44). In another qualitative study, individuals with TBI described a strong need for services to foster human connectedness and social belonging<sup>59</sup>. Even though the size of social networks overall tends to decrease, the extent of contact with, and support from, family members may increase<sup>21, 60, 61</sup>. This may relate to the need to move back with parents and become financially dependent on family<sup>20, 21, 59, 62</sup>. However, there is evidence of persistent and long term problems with marital and other family relationships<sup>14, 20, 23, 24</sup>, and family members may experience a high sense of burden<sup>23</sup>.

It may be that perceived support (quality of support) is more critical than the actual number of individuals in a person’s support network (quantity of support). Stronger associations have been found between health outcomes and measures of perceived support, than measures of received supports<sup>22, 63</sup>. Measures of perceived available supports have also been found to not be related to measures of received support and support networks<sup>64</sup>. A recent study involving individuals with TBI found that, despite the size of their support networks remaining similar to pre-injury, their satisfaction with support tended to be decreased<sup>22</sup>.

Social participation outcomes do not appear to improve over the long term and may worsen<sup>11, 22, 65</sup>. One study found that, at 10 to 20 years post injury, 31.1% of respondents had no friends outside of their family, and 8.2% of respondents had no social support at all<sup>23</sup>. Another study found that, at 20 years post TBI, 42% of respondents had no interests, many of the remainder had only one interest, and 61% of respondents had no friends or acquaintances although they did have contact with one or more family members<sup>54</sup>.

**Predictors of social participation.** There are a number of factors associated with low levels of community integration or social participation. These include more severe TBI<sup>13</sup>, more challenging behaviours such as disinhibition, impulsivity, frequent mood changes and irritability<sup>13, 61</sup>, lack of insight<sup>54</sup>, and other personality changes and executive impairment, such as lack of initiative and difficulty carrying out plans<sup>11, 54</sup>. Inappropriate behaviours may lead to rejection from peers, and individuals with TBI lack the strength, durability, reciprocity, and commitment required of more enduring relationships<sup>61</sup>. Of note is that cognitive and behavioural changes, as well as fatigue, depression, and anxiety, are stronger predictors than physical impairment of reduced social participation<sup>66</sup>.

### **Quality of life**

Despite the term ‘quality of life’ having evolved over time<sup>67</sup>, there is no consensus or clarity as to a conceptual model or operational definition<sup>68</sup>. There is agreement, however, that quality of life is multi-dimensional in nature, and that there is a strong subjective component<sup>25, 68, 69</sup>. The WHO<sup>69</sup> defines quality of life as an ‘...individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns...’ (p. 1405). The WHO gives six broad dimensions or domains: the individual’s physical state, cognitive and affective state, level of independence, social relationships, environment and spirituality/religion/personal beliefs, with the latter relating to the person’s perception of meaning in life<sup>69</sup>.

Quality of life is often viewed as having two distinct components: objective, that is, external to the individual’s perspective, and subjective, involving the individual’s emotional evaluation and cognitive perception of their life experience<sup>25, 70, 71</sup>. Subjective quality of life (SQOL) is defined by the person<sup>72</sup>. SQOL may involve or be synonymous with life satisfaction,

subjective well-being<sup>25, 65, 73</sup>, happiness<sup>74</sup> and ‘the good life’<sup>75</sup>. Subjective quality of life or subjective well-being reflects an individual’s evaluation of their life<sup>76</sup>. It reflects their perspective of the match or mismatch between their current life status and achievements on the one hand and, on the other hand, their expectations, priorities and how they would like their life to be, including as it relates to goals, aspirations, values, standards, desires, wants, and needs<sup>25, 70</sup>. Subjective well-being is defined in simple terms as how an individual thinks (cognitive component) and feels (affective component) about his or her life<sup>77</sup>. Life satisfaction has been identified as representing the cognitive and global appraisal of one’s life as a whole<sup>78, 79</sup>, based on information relevant to the individual<sup>80</sup>. This may be broken down into specific domains, such as satisfaction with work life, transportation, health care, public health, social services, parks and recreation, families and environment<sup>81</sup>. The affective perspective of subjective well-being includes presence of positive affect, such as contentment or joy, and absence of negative affect, such as anger, sadness, anxiety, worry, guilt, shame, loneliness or helplessness<sup>81</sup>.

A review of the TBI literature indicates that, to date, the primary dimension of SQOL that has been addressed is life satisfaction<sup>82-84</sup>. Few, if any, studies have considered the affective perspective of SQOL for individuals with TBI. For this study, SQOL will be operationalized in terms of an individual’s overall appraisal of their quality of life, as well as their self-perceived levels of happiness and feelings of loneliness. Happiness was selected to represent the individual’s appraisal of presence of positive affect, because it is the best recognized component of pleasant affect described in the literature and is often used interchangeably with subjective well-being<sup>76, 84, 85</sup>. Loneliness was selected because feelings of loneliness have been found to predict lower levels of life satisfaction<sup>86</sup> and SQOL<sup>87</sup>. Furthermore, by anecdotal reports,

happiness and loneliness are the components of affect that may be most strongly influenced by attendance at a brain injury drop-in centre (BIDC), a primary focus of this study.

**Quality of life outcomes and predictors.** Individuals with TBI have been found, on average, to have low subjective well-being or life satisfaction as compared to their pre-injury status<sup>25</sup> and as compared to adults without disability<sup>21, 25, 26, 83</sup>. Much research has explored factors associated with, and predictors of, subjective well-being. For the general population, variables such as income, education, age, gender, and social class have been found to have no or low correlation with subjective well-being, whereas number of close friends and recreational activities are amongst those factors with moderate correlations<sup>75</sup>. It is suggested that, for individuals with acquired physical disability, connections to other people such as socializing with others and helping others are among those actions that promote the good life or subjective well-being<sup>75</sup>. For individuals with TBI, there is some evidence that severity of injury predicts quality of life<sup>88</sup>. Other and perhaps stronger predictors include multiple losses in the areas of work, income, friendships and other relationships, opportunity to help and encourage others, active and passive recreation, understanding and expressing oneself, physical and mental health, and sense of a future<sup>25</sup>.

### **Association between participation and quality of life**

For individuals with TBI, a relationship has been found between participation and quality of life, although this relationship is not yet clear and there is mixed evidence as to which aspect of participation is more strongly associated with quality of life<sup>89</sup>. Studies have found life satisfaction and global quality of life to be associated with general community integration<sup>21, 70, 88</sup>, social integration<sup>26, 65</sup>, the ability to engage in leisure activities<sup>71</sup>, and emotional and social

support<sup>21, 71</sup>. However, one study found that, even though perceived social support was a predictor of life satisfaction, the degree of involvement in community activities was not<sup>90</sup>.

### **Community-based TBI rehabilitation interventions**

For many individuals with TBI, rehabilitation is long-term, and for some, life-long. There are three phases to TBI rehabilitation: acute, post-acute, and community. The acute and post-acute phases focus on medical stabilization, remediation of cognitive, physical and behavioural impairments, and restoration of function such as for self-care, mobility and communication. Restoration of function may continue in the community phase, but the primary focus shifts to reintegration into the community. Much research has focused on identifying best practice for rehabilitation in the acute and post-acute stages<sup>91, 92</sup>. However, although it has been identified that long-term rehabilitation and support service interventions are required for individuals with TBI<sup>11, 59</sup>, there has been little empirical research addressing community-based interventions. Studies on the effectiveness of rehabilitation have only just begun to address the areas of social participation and quality of life<sup>27</sup>. This includes that there are very few reports of interventions addressing the social network and support needs of individuals following TBI<sup>93</sup>. Further studies aimed at interventions for improving community integration<sup>30</sup> and to better define the contributors to quality of life for people with TBI<sup>88, 92</sup> are required.

A number of different community-based therapies, programs, services and supports (to be referred to collectively as ‘interventions’) have been developed over the past 10 years that address activity and participation for individuals with TBI, including in North America, Australia, and the UK. Many of these interventions, as shown in table 1.1, are described in the research literature, although not all of them have undergone empirical scrutiny.

For the purposes of this study, these interventions are categorized as (a) clinical interventions which are provided by health care clinicians, (b) support service interventions which are provided by paid staff but not health care clinicians, and (c) unpaid supports, which are provided by family members, friends or co-workers. Because support service interventions do not rely on costly health care professionals, they are potentially more cost effective and feasible to provide on an ongoing basis than clinical interventions. Unpaid supports are the most-cost effective of all, but they depend on the goodwill of others to be maintained, and there is a risk of caregiver distress and burn-out to family and others<sup>94, 95</sup>.

As can be seen in table 1.1, a number of these interventions specifically address social participation. Unfortunately, as is evident not only from the author's clinical experience but also from a review of the literature, many if not most of these clinical and support service interventions are not widely available. This is for a number of reasons. For example, the clinical interventions, where they exist, are typically time-limited owing to the costs involved with the clinical specialization required. Some interventions that are described in the literature were pilot studies and it is not known if they continued past that point. Some of the non-clinical support services may not exist because they often do not meet the mandate of health care funders and therefore may not be funded and/or they are difficult to sustain. Because many of the paid interventions are not widely available, as noted by Kalpakjian<sup>21</sup>, '...the burden of community integration and social support often falls on the family who themselves may have limited resources and energies...' (p. 263).

It is promising that so many different and innovative social participation interventions have been described in the literature, and that those interventions that have undergone empirical investigation have shown some benefit to individuals with TBI<sup>34, 35</sup>. However, more research is

required<sup>30, 35, 91, 96</sup>, including on those interventions that do exist. In particular, the B IDC, a long term support service that does not depend on costly clinical expertise and is not yet addressed in the literature, warrants investigation.

### **The brain injury drop-in centre**

A B IDC is located in a community setting rather than a hospital or health clinic and provides formal and informal social and recreational activities, peer support and educational in-services for adults with brain injury. There are at least nine B IDCs located in British Columbia, most of which are funded in whole or in part by health authorities. Some of these B IDCs are open each weekday and others are open once or twice per week. Many B IDCs offer at least one or two meals during the week. A referral is not required from a physician or other clinician for attendance. Criteria for attendance typically include that the individual has experienced an acquired brain injury, provides his or her own attendant caregiver if one is required, and follows basic rules of conduct relating to use of appropriate behaviours, for example, no use of alcohol or drugs on the premises. No appointments are necessary, although participants may need to sign up for, and commit to, attendance in specific activities, group outings or education sessions. Individuals may attend as often or little as they choose, and for as long as they like. B IDCs may be cost effective not only in comparison to clinical interventions, but also to support services that provide one-to-one support. B IDCs have a low staff to client ratio; for example, there may be one to two staff members for a dozen or more attendees in a day.

A B IDC provides a comprehensive array of activities and supports for the long term and, by the nature of these, would appear to address social participation and quality of life. Anecdotal reports from staff, participants, family members, and caregivers indicate that individuals who attend a B IDC may experience improved social skills, reduced social isolation, improved mood,

and improved well-being. However, there is no empirical evidence to support these reports. To the best of my knowledge, to date, there has been no systematic investigation of these claimed benefits to date.

There is no description in the literature of a B IDC. There is some description of drop-in centres for individuals with mental illness<sup>97</sup>, although I am not aware of any empirical research on such drop-in centres. There are other programs described for individuals with brain injury which have some commonalities to a drop-in centre and which do have some empirical support. The Clubhouse, initially developed for individuals with mental illness<sup>98</sup>, is one such program. A Clubhouse is described in the TBI rehabilitation literature<sup>99</sup> as a ‘...consumer-directed, community-based, day program that is operated by and for its members who experience disability after brain injury...’ (p. 17). However, the primary focus of a Clubhouse is on employment skills. TBI research relating the effects of attendance at a Clubhouse has focused on return-to-work outcomes<sup>99</sup>. As determined in an extensive literature search on TBI community-based rehabilitation interventions, there are no published research findings relating the Clubhouse model and outcomes for social participation.

The two other programs described in the literature with some similar characteristics of a B IDC are the Headway program with over 100 groups and branches located in the UK<sup>100, 101</sup> and SteppingStones, a day program located in the USA<sup>102, 103</sup>. Both are similar to a B IDC in that there is a primary focus on improving social participation and quality of life. However, by their description, SteppingStones and many of the Headway programs appear to be more structured than a B IDC, involve professional health care providers, and include a focus on providing support to caregivers. There may also be a stronger emphasis on involvement by members and

volunteers to perform infrastructure activities and run the programs, than is the case for a BIDC. Both of these programs are funded through charities.

The literature provides some qualitative information relating to social participation outcomes for the Headway and SteppingStones programs. Using qualitative research, a Headway program was found to provide a sense of purpose and a safety net, an opportunity to develop social contacts and form long-lasting relationships, emotional and social support during times of struggle with family relationships, and valuable peer support<sup>100</sup>. A survey of SteppingStones members found that members felt that their emotional, social, and quality of life needs were being met both through formal programs (an emotions group and ‘Brain Power’ group) and the informal social environment<sup>103</sup>. One member stated, ‘...My day is so much better when I come here than if I’d stayed home. If I’d stayed home, and there wasn’t a SteppingStones, I’d be so depressed...’<sup>103</sup> (p. 1275). Leisure outcomes are not discussed in the literature relating to the Clubhouse, Headway, or SteppingStones programs. However, there is some indication from other studies that positive leisure outcomes may be achieved through the type of programming offered at a BIDC. For example, in a study of 25 individuals with severe TBI who participated for six months in a funded ‘Community Group Program’ where they were assisted to participate in leisure activities, those individuals who engaged regularly in these activities over the six months reported improvements in social integration, a reduction in frequency of symptoms of depression, and increased happiness and sense of belonging<sup>104</sup>.

Findings from an investigation specific to BIDCs would assist funders, the agencies that staff them, referrers, and the individuals who attend to better understand the benefits specific to BIDCs, and perhaps ways to enhance BIDCs.

### **The hypotheses/research questions**

The aim of this research is to compare social participation and SQOL for a group of individuals who attend a BIDC, with a group who do not. Another aim is to determine if there is a relationship between social participation and SQOL for the total sample. Specific hypotheses are as follows.

1. For community-dwelling adults with TBI, there will be positive correlations between social participation and SQOL measures. This will be determined by analyzing the association between each measure of SQOL and each measure of social participation. Social participation will be measured by (a) the social integration scale of the Community Integration Questionnaire, (b) the Social Provisions Scale and (c) six of the scales of the Adult Subjective Assessment of Participation (diversity, frequency/intensity, with whom one participates, where one participates, enjoyment, and satisfaction with performance). SQOL will be measured by (a) the global rating scale of the Quality of Life and Health Questionnaire, (b) the University of California Los Angeles Inelness Scale and (c) the Abdel-Khalek Happiness Scale.
2. Community-dwelling adults with TBI and who attend a BIDC will have higher *social participation* than these who are identified as potentially benefitting from attending BIDCs but who do not attend.
3. Community-dwelling adults with TBI and who attend a BIDC will have higher *SQOL* (subjective well-being) than these who are identified as potentially benefitting from attending BIDCs but who do not attend.

### **The following chapters**

This study was conducted to fulfill the requirements of a Master of Science thesis. The results are provided in a manuscript-based format, that is, two manuscripts (chapters) suitable for submission for publication, prefaced by this introductory chapter and followed by a concluding discussion chapter. The appendices contain copies of the ethics certificates and participant consent form, detailed information about the measures used, and details relating to the statistical analyses used including management of missing data, linearity and sample size testing.

In total, there are four chapters to this thesis. Chapter 2, the first manuscript, consists of the correlational analyses, focusing on the first hypothesis. This portion of the study involved all 46 individuals who participated in the study. Chapter 3, the second manuscript, provides the methods and results of the cross-sectional comparison analyses, focusing on the second and third hypotheses. The comparisons were between the B IDC group, which consisted of 23 individuals who attend a B IDC, and the Comparison group, which was comprised of 19 of the individuals who do not attend a B IDC. Chapter 4 provides a final discussion and conclusions.

Table 1.1: Community-based rehabilitation interventions addressing activity and participation for individuals with TBI

Rehabilitation interventions	Activity and participation categories		
	Independent living	Productivity	Social Participation
Clinical interventions	-home-based programs* <sup>105-107</sup>	-supported employment, job coaching* <sup>9, 108-110</sup> -vocational case coordination + <sup>111</sup>	-clinician-led support groups* <sup>112-114</sup> -social skills training* <sup>115, 116</sup> -network of support + <sup>117</sup>
	<u>Multi-focus clinical interventions (independent living, productivity, social participation)</u>		
	-psychologist-led comprehensive (holistic) day treatment program/therapeutic milieu program* <sup>118-120</sup>		
	-modified psychologist-led comprehensive day treatment program* <sup>121, 122</sup>		
	-outpatient services (multi/inter-disciplinary)* <sup>123-125</sup>		
	-psychological counselling* <sup>126, 127</sup>		
	-residential and transitional living programs* <sup>128-130</sup>		
	-home/community-based program (multi/inter-disciplinary)* <sup>125, 131, 132</sup>		
	-community outreach team* <sup>133</sup>		
	-telephone follow-up* <sup>134, 135</sup>		
	-family education/support/empowerment program* <sup>136</sup>		
	-case management + <sup>91, 137</sup>		
	-substance abuse programs + <sup>138, 139</sup>		

Table 1.1 (continued): Community-based rehabilitation interventions addressing activity and participation for individuals with TBI

	Independent living	Productivity	Social Participation
Support service interventions	-independent living centres + <sup>140</sup> -group home ++ -family care home ++ -life skills worker ++		-community day program* <sup>103, 141</sup> -peer support* <sup>12</sup> -one-to-one volunteer <sup>142</sup> -community leisure groups* <sup>104</sup> -psychosocial support group* <sup>143</sup> -circle of support + <sup>144</sup> -life skills worker ++ -drop-in centre ++
		<u>Dual focus support service interventions (productivity and social participation)</u>	
Unpaid supports		-Clubhouse + <sup>99</sup> -employer/co-worker support and accommodations + <sup>145, 146</sup>	-family and friends as supports + <sup>61, 93, 147</sup>

\* Empirical studies are provided in the literature

+Descriptions of interventions/supports are provided in the literature, but with no empirical evidence

++No information is found in the literature, but the intervention/support is in existence as per author's clinical experience

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## CHAPTER TWO: THE CORRELATIONAL STUDY<sup>1</sup>

### **The association between social participation and subjective quality of life for non-employed, community-dwelling adults with moderate to severe traumatic brain injury**

#### **Introduction**

Worldwide, traumatic brain injury (TBI) is a leading cause of lifelong disability<sup>1-4</sup>. It is estimated that, in 2005, 3.17 million people in the USA, or 1.1% of the total US population, were living with disability resulting from TBI<sup>5</sup>. Disability is conceptualized by the World Health Organization's International Classification of Functioning, Disability and Health (ICF) as impairment, activity limitations and participation restrictions<sup>6</sup>. For many individuals with TBI, in particular when moderate to severe, long term disability is experienced in terms of physical, cognitive, behavioural and/or emotional impairment<sup>1, 3, 7</sup> and activity limitations and participation restrictions for work or school, independent living, and/or social and leisure activities<sup>8-12</sup>. In addition to disability, many individuals with TBI experience a reduced quality of life<sup>13-15</sup>.

It has been suggested that the primary goals of TBI rehabilitation are community integration or participation<sup>16-19</sup> and quality of life<sup>18, 20-23</sup>. Community integration is concerned with a person's activities and life roles, and physical and social inclusion in community life<sup>11</sup>. In the rehabilitation sciences literature, community integration has largely been replaced by the term participation<sup>16, 24, 25</sup>. The ICF defines participation as involvement in a life situation<sup>6</sup>, with the proposed definition of involvement to include '...taking part, being included or engaged in

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<sup>1</sup> A version of this chapter will be submitted for publication: McLean AM, Jarus T, Jongbloed L, Hubley AM. The association between social participation and subjective quality of life for individuals with moderate to severe traumatic brain injury.

an area of life, being accepted, or having access to needed resources...'<sup>6</sup> (p. 15). For individuals with TBI, the objective perspective of community integration or participation considers the level of functional independence for home, social and productive activities<sup>26</sup>, the frequency and intensity of involvement<sup>26-28</sup>, and having disability-needs identified and supported<sup>29</sup>. Participation also involves the subjective experience of integration into a community<sup>30</sup>, including a sense of belonging<sup>31, 32</sup>, perceived relationships or social supports<sup>31, 32</sup>, satisfaction with living arrangement<sup>31</sup>, preferences and interests<sup>27</sup>, enjoyment<sup>27</sup>, satisfaction with performance<sup>27, 28, 33</sup>, and motivation to change level of engagement in activities<sup>24</sup>.

One aspect of participation of particular concern for individuals with TBI is social participation<sup>9, 34, 35</sup>, that is, involvement in social and leisure activities and within a social network. A high proportion of individuals with TBI, including many of those individuals who have been successful in returning to work<sup>26, 36</sup>, experiences reduced involvement in social and leisure activities<sup>24, 34, 37</sup>. Reduced involvement refers to a decline in leisure and social activities<sup>38-40</sup>, low satisfaction for social and leisure activities<sup>41</sup>, and a reduction in active pursuits and activities outside of the home<sup>9, 42</sup>. Further, many individuals with TBI experience social isolation and reduced social networks<sup>35, 39, 43</sup>, including fewer friends<sup>15, 44</sup>, disruption in family relationships<sup>38, 39, 44, 45</sup>, and low satisfaction with interpersonal relationships<sup>41, 46, 47</sup>.

Quality of life, the other primary goal of TBI rehabilitation, is a multi-dimensional construct<sup>14, 48, 49</sup>. Quality of life is defined by the World Health Organization as an '...individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns...'<sup>48</sup> (p. 1405). The subjective or 'insider' dimension of quality of life is defined by the person<sup>50</sup> and involves the

individual's emotional evaluation and cognitive perspective of his or her life experience<sup>14, 51, 52</sup>. Subjective quality of life (SQOL), or subjective well-being<sup>14, 53-55</sup>, has a cognitive component and an affective component<sup>14, 51, 52, 56</sup>. The cognitive component may be represented by life satisfaction or a global appraisal of one's life as a whole<sup>14, 57</sup>. The affective component includes presence of positive affect, such as happiness, and absence of negative affect, such as sadness or loneliness<sup>14, 58, 59</sup>.

An individual's SQOL needs to be understood to broaden our understanding of his or her experience and overall quality of life<sup>50, 52, 60</sup> and better guide our rehabilitation interventions<sup>50, 52, 61</sup>. For individuals with TBI, more is known about the life satisfaction aspect of SQOL than about the affective dimensions such as happiness<sup>14</sup>. For example, researchers have learned that people with TBI experience lower levels of life satisfaction than individuals with spinal cord injury<sup>60</sup> and without disability<sup>14, 15, 47, 62-64</sup>. For individuals with TBI, many studies have found life satisfaction to be most strongly associated with the participation dimension of disability, less strongly related to activity, and weakly if at all related to impairment<sup>61, 65</sup>, although some studies have found severity of TBI to have some contribution in predicting life satisfaction or overall SQOL<sup>62, 66</sup>. Being employed may be the aspect of participation that is most strongly associated with higher levels of life satisfaction<sup>63, 67-69</sup>. For this population, life satisfaction is also associated with social participation, specifically with social integration as measured by the Community Integration Questionnaire<sup>47, 53, 63</sup>.

There is still much to be learned about social participation and SQOL for individuals with TBI, including further examination of the association between social participation and SQOL. The aim of this research study was to test the hypothesis that, for community-dwelling individuals with moderate to severe TBI, there is a positive correlation between measures of

social participation (involvement in social and leisure activities and a social network) and measures of SQOL (cognitive and affective appraisal of subjective well-being).

## **Methods**

### **Participants**

The sample consisted of 46 community-dwelling and unemployed adults with TBI. Participants were recruited throughout urban and suburban areas within the southwest region of mainland British Columbia, Canada. Participants were recruited through community-based case managers, health care clinicians, brain injury service providers and brain injury drop-in centres. Information was provided to potential participants through information posters, letters of initial contact and presentations at drop-in centres. Individuals interested in participating were invited to contact the researchers directly or through their service providers.

Participants needed to meet the following inclusion criteria: age 19 to 65 years, moderate to severe TBI that had occurred at least one year prior, living in the community, fluent in English, and able to provide informed consent. Moderate to severe TBI (which relates to initial severity of injury) was determined by information provided by the participant or his/her clinician demonstrating at least one of the following<sup>70</sup>: an initial Glasgow Coma Scale of 12 or less, post traumatic amnesia of 1 hour or more, and/or loss of consciousness of more than 15 minutes. If no information was available for these measures, then hospitalization of at least 48 hours as related to the TBI<sup>71</sup> was sufficient evidence for the purposes of this study. Individuals were excluded if they had aphasia or were otherwise unable to complete questionnaires, were currently working (paid or unpaid) unless doing volunteer work for only a few hours per week, were currently involved in a formal rehabilitation program, or they had an Axis 1 psychiatric

diagnosis<sup>72</sup> other than mild to moderate depression (for depression, they were excluded if their index score was 0.70 or greater on the Zung Self-Rating Depression Scale).

### **Study design**

A cross-sectional design was used in this study of the association between social participation and SQOL. Each participant met with a researcher (the first author) or the research assistant (the ‘assessors’), both registered occupational therapists, to complete the consent form and all of the measures. The research assistant was otherwise not involved in the research project. Prior, each participant was advised that they were welcome to have a friend, family member or caregiver present. 13 out of the 46 participants chose to have someone present (8 participants from the BIDC group, 5 participants from the Comparison group). An assessor met with each participant to administer all of the measures; this included reading the instructions out loud for each measure and ensuring that the participant understood the instructions prior to proceeding. For the self-report questionnaires, participants were then provided with the option of reading the items on their own or having the items read out loud by the assessor.

Questionnaires were presented in the same order for every participant. The assessor ensured that all of the questions were answered and, in the event of any missing responses, confirmed that this was because the participant had chosen not to provide a response and had not just overlooked the item. Quality of data was further enhanced by asking the attending friend, family member or caregiver to verify objective information (such as history of injury and rehabilitation) as well as participant responses to the Frontal Systems Behavior Rating Scale (FrSBe), a measure of frontal lobe functions (apathy, executive function and disinhibition).

Three participants (1 from the BIDC group and 2 from the Comparison group) who were not accompanied by a family member provided permission for the assessor to telephone a family

member or caregiver for details relating to their injury and history of rehabilitation therapies and support services. Some participants, on their own initiative or at the suggestion of the assessor, made use of a day timers or calendar to verify details about their social participation, in particular frequency/intensity of their social and leisure activities.

Short breaks were provided as requested by the participant or if the assessor observed the participant to show signs of physical discomfort or fatigue including onset of difficulties with concentration; for some individuals, the session was terminated altogether and completed on another day, with all sessions completed within a 2-week period for each participant.

Participants required an average of 2.78 hours (ranging from 1.75 to 4.67 hours) to complete all of the measures, with no single session lasting more than 3.25 hours (including at least one 10 to 15-minute break). 33 participants (71.7%) completed all measures in one session, 11 individuals (23.9%) required two sessions, and 2 participants (4.3%) required three sessions.

Inter-rater reliability and procedural consistency were enhanced by the assessors meeting together, prior to any data collection, to review all of the questionnaires, procedures, and the scoring of the performance-based measure (Montreal Cognitive Assessment). Then, for the first 2 participants, one assessor administrated all of the measures and the other assessor observed (alternating between the two sessions), so that any issues relating to procedure could be discussed afterwards. For all participants, the assessor recorded information relating to duration of session(s) and frequency and duration of breaks taken, whether or not someone else was present, the measures completed during each session, the general presentation of the participant and, in the event that more than one session was required, the reasons for this.

Ethical approval was provided by the Behavioural Research Ethics Board of the University of British Columbia and the relevant health authorities. Copies of the Ethics

certificates are provided as Appendix A. Written information about the study was provided to, and written consent obtained from, all participants. A copy of the consent form is provided as Appendix B. Participants were provided with a small monetary compensation for their participation in the study.

## **Measures**

The measures used are summarized in Table 2.1. More details about each measure are provided in Appendix C. A copy of the study-specific questionnaire relating to participant characteristics is provided in Appendix D.

**Participant characteristics.** A short questionnaire was used to collect information about demographics and injury characteristics, including gender, age, cause of TBI, time post injury, rehabilitation interventions, education, employment, living situation and income. Formal measures were used to obtain information about health status and physical, cognitive and neurobehavioural impairment. A measure of *perceived general health* was obtained using the General Health Question from the Short Form-36 Health Survey (SF-36 GHQ)<sup>73</sup>. The full SF-36 has been found to have good concurrent validity for individuals with TBI<sup>74</sup>. Two measures were used to characterize participants in terms of their *cognitive function*: (a) the performance-based Montreal Cognitive Assessment (MoCA)<sup>75</sup> and (b) the self-report Frontal Systems Behavior Rating Scale (FrSBe)<sup>76</sup>. The MoCA, which screens for a number of different cognitive functions, has been found to have good internal consistency and high test-retest reliability<sup>75</sup>, and validation studies are underway with an acquired brain injury population<sup>77</sup>. The FrSBe was used to provide a more in-depth assessment of frontal lobe functions, has demonstrated high internal consistency, good test-retest reliability and good construct validity (convergent and discriminant)<sup>76, 78, 79</sup>. The Zung Self-Rating Depression Scale (SRDS)<sup>80</sup> provides a screen of

*depressive symptoms*. Most individuals with depression have an index score between 0.50 and 0.60; an index score of 0.70 or greater indicates severe depressive symptoms<sup>81</sup>. The SRDS has demonstrated high test-retest reliability<sup>82</sup>, fair internal consistency<sup>83,84</sup> and good convergent validity with other depression measures<sup>83</sup>. The Mayo Portland Adaptability Inventory, version 4, (MPAI-4)<sup>85</sup> was used to collect additional information about the participants' level of *physical, cognitive and communication impairment* using the abilities subscale, and their level of *pain, fatigue, emotional and interpersonal adjustment* using the adjustment subscale. For individuals with acquired brain injury, there is acceptable internal consistency for the measure as a whole and each of the subscales, acceptable item agreement (between individuals with brain injury, significant others and rehabilitation staff), moderate convergent validity, and some predictive validity (in terms of long term vocational and independent living outcomes<sup>86-88</sup>..

**Social participation.** Social participation was operationalized as involvement in social and leisure activities and a social network. Three measures were used: (a) the social integration scale of the Community Integration Questionnaire (CIQ-SI)<sup>26</sup>, (b) the Social Provisions Scale (SPS)<sup>89</sup> and (c) the Adult Subjective Assessment of Participation (ASAP)<sup>90</sup>. The Community Integration Questionnaire is one of the most widely used and recommended measures of outcome following TBI<sup>91,92</sup>. The CIQ-SI, considered a measure of general social integration, focuses on frequency of participation in social and leisure activities and, to some degree, the nature of a person's social supports. Modest inter-correlations between subscales, moderate inter-rater reliability (between individuals with TBI and their caregivers), and high face validity have been found for the TBI population<sup>19, 26, 93-96</sup>. The SPS, which focuses on the degree to which a person perceives his/her social relationships as providing different dimensions of social support, has been low internal consistency for subscales (and therefore this study considers only

the total score), and adequate construct validity (discriminant and convergent)<sup>89</sup> including for individuals with TBI<sup>15</sup>. The ASAP examines level of participation in different life occupations or situations beyond basic self-care activities and outside of paid or unpaid work. This study used the scales relating to participation in social and leisure activities. There is a score for each scale: diversity of activities, frequency/intensity of participation, enjoyment, satisfaction with performance, with whom the individual participates and where the individual participates. The ASAP has demonstrated good test-retest reliability and construct (discriminant) validity<sup>90</sup>.

**Subjective quality of life.** SQOL refers to the cognitive and affective appraisal of one's subjective well being<sup>58</sup>. Three self-report measures of SQOL were used in this study: (a) the Quality of Life and Health Questionnaire (QOLHQ)<sup>97 98</sup>, (b) the Abdel-Khalek Happiness Scale (AKHS)<sup>99</sup> and (c) the University of California at Los Angeles Loneliness Scale (UCLA-LS)<sup>100</sup>. The QOLHQ includes a single item, numerical scale used for appraising global quality of life, ranging from 0, 'worse possible quality of life', to 10, 'best possible quality of life'. Fair to moderate construct (convergent) validity of this scale has been found for individuals with cancer<sup>97</sup> and individuals with TBI<sup>101</sup>. The AKHS is another numerical scale, ranging from 0 (minimum happiness) to 10 (maximum happiness). It has good test-retest reliability, and construct (adequate discriminant and good convergent) validity<sup>99</sup>. The UCLA-LS, which is considered to focus on intimate and interpersonal loneliness<sup>102</sup>, has high internal consistency, high test-retest reliability, high face validity, and good convergent validity<sup>100</sup>. We used a 10-item version<sup>103</sup>.

### **Statistical analysis**

Data analyses were conducted using descriptive and correlation statistics, using SPSS for Windows version 17.0. Descriptive statistics (means, standard deviations, ranges and

proportions) were used to describe the group in terms of participant characteristics and measures of social participation and SQOL. Correlational analyses were used to examine the bivariate associations between the measures of social participation and SQOL.

Data were missing on three of the measures of participant characteristics (FrSBe, SRDS and income), but not from any of the measures of social participation or SQOL. Missing data were handled based on directions provided in the instruction manual for the FrSBe<sup>104</sup> and on directions provided by Shrive et al. for the SRDS<sup>105</sup>. Details are provided as Appendix E. Missing data had no influence on the correlational analyses.

Seven outliers were identified for the main outcome variables (social participation and SQOL). However, none of the outliers were extreme and none had a Mahalanobis distance exceeding the critical value of 13.82 and, therefore, none of the outliers were removed from the analysis. Tests for normality were conducted, including examination of skewness and kurtosis values, the Kolmogorov-Smirnov statistic, box plots and normal and detrended probability plots. It was found that the scores were not normally distributed for the majority of the main outcome variables, including two of the three SQOL measures, and, therefore, for the majority of correlational analyses. The non-parametric Spearman rho was therefore used instead of the Pearson product-moment correlation coefficient. Linearity was confirmed for all of the statistically significant correlations through inspection of scatter plots and the fit of a quadratic line. Detailed findings are provided in Appendix F. To avoid an inflated risk of Type I errors in conducting multiple correlations, the level of significance was set at  $\alpha = 0.01$ . The strength of the correlation coefficients was interpreted according to Cohen's classification<sup>106</sup>, where a correlation coefficient ranging between 0.10 and 0.29 is considered small, between 0.30 and 0.49 is considered medium, and between 0.50 and 1.0 is considered large.

## Results

### Participant characteristics

Results are shown in table 2.2. As is typical for the TBI population<sup>107</sup>, the majority of participants were male and the largest proportion of participants had been injured in a motor vehicle accident. At the time of injury, just over half of the participants had completed grade 12 education or less, and the majority of participants had been working. At the time of assessment, about 15% of participants were living in a community-based supported living situation (group home or family care home), and, for the other participants, it was a fairly even split between living alone and with others. The majority of participants were on a fixed disability income of less than \$12,000.00 per year, which falls below the poverty line, labelled by Statistics Canada as the ‘after-tax low-income cut-off’<sup>108</sup>.

On average, participants were found to rate themselves at just above good health (i.e., just above the mid point between poor and excellent health), with almost the same SF-36 GHQ mean scores as were found by two other studies involving individuals with moderate and severe TBI<sup>51,74</sup>. A majority of participants were found to have cognitive impairment, with 84.8% of individuals scoring within the range of impairment on the MoCA and almost half of the participants falling within the range of frontal lobe impairment as measured by the FrSBe. Results of the MPAI-4 abilities scale revealed that about 40% of participants fell within the range of a moderate to severe level of current impairment, with further analyses identifying the areas rated at the highest levels of impairment to be memory, mobility, and attention/concentration. The MPAI-4 adjustment scale found about a quarter of participants to have a moderate to severe level of current adjustment limitations, with the highest scores being for

fatigue, irritability/anger/ aggression, and family stress. Nearly 60% of the group fell within the range of having depressive symptoms.

### **Social participation and SQOL**

Table 2.3 shows the results of the social participation and SQOL measures. On the ASAP, only a small percentage of participants fell within the ‘not enjoying’ range of the enjoyment scale and ‘not satisfied’ range of the satisfaction with performance scale. On average, participants were found to perform almost two thirds of their social and leisure activities outside of home and to be with others for just over half of such activities. With regard to SQOL, participants provided mean ratings that were higher than the midpoint on the global quality of life scale and the happiness scale. Only about a quarter of participants rated themselves below the midpoint between worst possible and best possible quality of life, and an even smaller proportion of participants rated themselves below the midpoint between minimum and maximum happiness. For the measure of loneliness (UCLA-LS), on average, the mean score was just above 20, with a majority of individuals scoring above this cut-off point, that is, as more lonely than is considered a normal experience.

### **Correlational analyses**

Results of the correlational analyses between measures of SQOL and measures of social participation are summarized in table 2.4. Higher levels of loneliness were associated with lower levels of perceived social support and lower levels of social integration. There were statistically significant correlations between both the global rating of quality of life and rating of happiness and three of the ASAP scores: satisfaction with performance, enjoyment and proportion of activities performed with others. That is, higher levels of global quality of life and happiness were associated with higher proportions of activities performed with others and higher levels of

satisfaction and enjoyment. In applying Cohen's classification of strength of correlations<sup>106</sup>, all of these associations were medium or large. There were no other statistically significant correlations at  $p < 0.01$ , and no correlations otherwise at  $p < 0.05$ .

### **Discussion and conclusion**

This study analyzed the association between social participation and SQOL for a group of 46 community-dwelling adults with moderate to severe TBI. Social participation was measured in terms of perceived social supports, an overall measure of social integration, and various dimensions of involvement in social and leisure activities: diversity, frequency/intensity, enjoyment, satisfaction with performance, where, and with whom. SQOL was measured in terms of an overall appraisal of quality of life, a rating of happiness, and a measure of loneliness, thus capturing dimensions of the cognitive and affective appraisal of subjective well-being. We found statistically significant associations involving all three aspects of SQOL and five out of the eight measures of social participation: a general measure of social integration, perceived social supports, enjoyment, satisfaction with performance, and proportion of activities performed alone. There were no associations found between SQOL and the measures of diversity, frequency/intensity, or proportion of activities performed outside of home. Interestingly, both global quality of life and happiness were correlated with the same measures of participation while loneliness was correlated with other measures of participation.

The strong association found between loneliness and perceived social supports was not surprising, considering that one definition of loneliness is '...an aversive state experienced when a discrepancy exists between the interpersonal relationships one wishes to have, and those that one perceives they currently have...' <sup>109</sup> (p. 698). To the best of our knowledge, there are no published studies that have investigated the association between loneliness and social supports

in individuals with TBI. There are very few studies altogether that have investigated the experience of loneliness for individuals with TBI, although a number of studies have addressed social supports<sup>110-113</sup>, with some researchers equating social isolation with loneliness<sup>45</sup>. However, the subjective state of loneliness is separate from the objective state of social isolation<sup>114</sup>, and loneliness is a multidimensional concept, with an emotional dimension in addition to a social dimension<sup>109</sup>.

Loneliness and social support have been studied to some extent in other populations. Russell<sup>115</sup> measured loneliness and perceived social support in groups of college students, nurses, teachers, and the elderly using the same perceived supports measure as our study (i.e., SPS) and a revised version of the UCLA-LS. Comparable to our results, Russell found loneliness to have a large, negative association with perceived social support. Mellor and colleagues<sup>116</sup> explored loneliness and satisfaction with personal relationships in the general population, and found that the less satisfied one is with personal relationships, the lonelier one feels.

Also not surprising, considering the subjective nature of the variables involved, was our finding of an association between each of the SQOL measures of global quality of life and happiness, and each of the social participation measures of enjoyment and satisfaction with performance. There were no associations found between these two SQOL measures and the more objective and quantitative aspects of social participation, that is, diversity and frequency/intensity. Our findings are consistent with other TBI studies that have explored SQOL. Brown et al.<sup>65</sup> tested various predictive models of SQOL for individuals with TBI and found that individuals' subjective perspective tells more about their SQOL than do objective measures. Seibert and colleagues<sup>117</sup> found global ratings of quality of life to be associated with

enjoying social and recreational activities, although only for men and not for women. Eriksson et al.'s<sup>118</sup> findings suggested that higher levels of SQOL may be associated with more participation in everyday activities only if the activities are desired by the individual. Beyond the TBI population, a study that focused on older adults found that satisfaction with accomplishment was more associated with quality of life than the performance itself<sup>119</sup>

To the best of our knowledge, no studies have investigated the experience of happiness for individuals with TBI. However, our findings are congruent with recent literature in the area of positive psychology. For example, Vella-Brodrick et al.<sup>120</sup> reported on a study of Americans and Australians where it was found that pleasure, life meaning, and engagement or 'flow' in activities are contributors to happiness and subjective well-being. Dunn and Brody<sup>59</sup> explained that 'flow' involves being involved and fully engaged in the present moment where skill and challenge are in balance, and which often occurs when pursuing creative or stimulating activities, aesthetic experiences, hobbies or sport. Dunn and Brody recommended to individuals with disability that they seek positively reinforcing experiences, as this has been found to help regulate emotional well-being and, in turn, promote subjective well-being or 'the good life'.

We also found that higher levels of happiness and global quality of life are associated with more participation in activities with others than alone. These findings are consistent with previous research involving individuals with TBI that has shown that there is an association between SQOL and emotional and social support<sup>15, 51</sup>. Beyond the TBI population, Diener and Seligman<sup>121</sup> found that college students with the highest ratings for happiness and overall quality of life spent the least amount of time alone and the most time socializing with others. Dunn and Brody<sup>59</sup> reviewed research findings that show the importance of participating in activities with others as a contributing factor to achieving happiness or 'the good life'. Reyes-Garcia et al.<sup>122</sup>

found that, for a non-clinical population, there was a negligible or negative association between solitary leisure and subjective well-being, but a positive and statistically significant association between social leisure and subjective well-being.

There were no correlations reaching statistical significance between SQOL and the other dimensions of social participation as measured by the ASAP: diversity, frequency/intensity and proportion of social participation activities performed outside of home. That is, there appears to be little or no relationship between SQOL and how varied a person's social participation activities are, how often they engage in social participation activities, and whether social participation takes place at home or elsewhere. Instead, it is the subjective and social factors that have the greatest relationship with SQOL.

An interesting finding was that loneliness was the only dimension of SQOL that was found to be associated with the CIQ-SI. Other studies have found the CIQ-SI to have a small to medium association with the Life Satisfaction Index-A<sup>53</sup>, the Quality of Life Rating<sup>47</sup>, and the Satisfaction with Life Scale<sup>63</sup>. However, the CIQ-SI measures more than one aspect of social integration (i.e., frequency of participation and social support) and the first two of these SQOL quality of life measures are multidimensional; it is not known which dimensions of the CIQ-SI are more strongly associated with which dimensions of SQOL. Of note is that Corrigan et al.<sup>123</sup> found that, although higher scores on the CIQ-SI were related to higher levels of life satisfaction (as measured by the Satisfaction with Life Scale), this did not contribute substantially to a prediction model for life satisfaction.

### **Limitations**

The study design used does not allow for determination of a cause and effect relationship between social participation and SQOL for individuals with TBI. It may be that, by enhancing

the social and subjective aspects of an individual's social participation, the individual's subjective well-being will be bolstered. Alternately, it may be that it is individuals with higher SQOL who tend to perceive higher levels of social support, engage in a higher proportion of their social participation activities with others, and have an enhanced subjective experience of social and leisure activities. However, if improved social participation can result in improved subjective well-being, then these study results can provide some direction to clinicians in terms of a focus for community-based TBI rehabilitation interventions. Another study limitation is that the group size of 46 individuals with TBI is too small to represent a broader population of community-dwelling individuals with TBI. Findings from this study can be extended only to individuals similar to the participants in the study.

### **Future research**

This study highlights the need for further study of the subjective aspects of participation and quality of life. As demonstrated in this study and also found by others<sup>24, 124, 125</sup>, there is still much to be learned about community integration and social participation for individuals with TBI, in particular the subjective factors. There is also much to be learned about SQOL, including about the experience of happiness and loneliness for individuals with TBI, and the relationship between social participation and SQOL. Larger studies, with a better representation of community-dwelling individuals post TBI, are required to confirm the results of this study. Further, as is also noted by Corrigan and Deming<sup>63</sup>, more research is needed to develop a fuller understanding of all of the factors that influence SQOL after TBI, including environmental and personal factors.

Comparison studies are needed to assess cause and effect such as by measuring the effect of social participation interventions on SQOL for individuals with TBI. Some of the social

participation interventions that have been investigated to date include one-to-one volunteers for social and recreation activity<sup>126</sup>, peer support<sup>127</sup>, circle or network of support<sup>128, 129</sup>, a supported leisure program<sup>130</sup>, community day programs<sup>131</sup>, and a Tai Chi program<sup>132</sup>. However, few studies have measured SQOL as an outcome of social participation interventions. Based on the results of our study, it is recommended that future studies include measurement of both objective and subjective dimensions of participation and quality of life.

Further, as has been recommended by others<sup>15</sup>, qualitative research methods may provide a richer understanding of SQOL and the subjective dimensions of social participation for individuals with TBI. To date, Häggström and Lund<sup>133</sup> have explored the meaning of participation and complexity of strategies that influence participation, Jumisko et al.<sup>37</sup> have explored the experiences of ‘feeling well’ after moderate to severe TBI, and Fraas and Calvert<sup>134</sup> have investigated the characteristics that lead to a meaningful or productive life following brain injury. Future studies could focus in more depth on happiness and loneliness as dimensions of SQOL for individuals with TBI.

### **Clinical implications**

The findings from this study may provide clinicians with some increased awareness of factors to consider when assisting individuals with TBI to achieve increased social participation and SQOL. It may not be possible to influence SQOL directly. However, findings from this study support Johnston et al.’s<sup>50</sup> suggestion that, if gains can be made in the areas of function most valued by a person, in this case social participation, it may be possible to maximize quality of life. Findings from our study suggest that there may be no positive influence on SQOL by simply increasing the *variety and frequency* of social and leisure activities, but instead, by increasing the opportunities for individuals to *participate with others* and by enhancing the

*subjective experience* of social and leisure activities. These findings are congruent with those of other researchers. Quality of life researchers have found that (a) connections with others and (b) the subjective experiences relating to engagement and meaning are associated with SQOL, regardless of whether SQOL is conceptualized as ‘the good life’<sup>59</sup>, happiness<sup>120</sup>, or subjective well-being<sup>135</sup>. Hemmingsson and Jonsson (2005)<sup>136</sup> discuss that the subjective experience of meaning is an important aspect of participation. Specific to individuals with TBI, Fraas et al. (2009)<sup>134</sup> found that the characteristics of a meaningful life include developing a social support network, redefining oneself through new roles, and participating in fulfilling and meaningful activities (such as activities that enable goal attainment and provide a sense of empowerment). Ylvisaker and colleagues<sup>137-139</sup> provide a role model in the approach that they describe for community-based TBI interventions, with a focus on positive relationships with others and engagement in meaningful activities.

Of course, clinicians need to also consider other factors that may influence SQOL and/or social participation, such as level of employment, health conditions (including depression), cognitive or physical impairment, and environmental factors. These factors may have a direct impact on social participation or SQOL, or may modify or mediate the relationship between social participation and SQOL. For example, depression has been found to be strongly and negatively associated with quality of life<sup>24, 41, 51, 63, 118</sup>. Other contributors to SQOL include personality, health, religion, the type and quality of personal relationships, and an individual’s economic situation and political environment<sup>135, 140</sup>.

Finally, as is also cautioned by others<sup>65, 141</sup>, clinicians must maintain an individualized approach when working with individuals with TBI. In our study, there was large variance in scores for SQOL and social participation, a reminder that the TBI population is not

homogenous, and that statistical findings that are based on mean scores do not necessarily reflect individual experiences.

### **Conclusion**

Despite its limitations, this exploratory study provides some insight into aspects of social participation and SQOL that, to date, have had very little attention in the TBI literature. If interventions that focus on the subjective and social dimensions of social participation prove to have a positive influence on SQOL, then this will provide clinicians with more effective tools to assist their clients in achieving optimal quality of life.

Table 2.1: Measures used

Category	Measurement tool	Construct measured	Subscales or scores	Interpretation of score
Participant characteristics	Study-specific questionnaire	Demographics and injury characteristics		
	SF-36 General Health Question	General health perception	Total score: 1-5	The lower the score, the higher the self-perceived health
	Montreal Cognitive Assessment (MoCA)	Cognition (visuospatial/ executive function, attention, memory, language, abstraction, orientation)	Total score: 0-30	≥26: normal
	Frontal Systems Behavior Rating Scale (FrSBe)	Cognition (apathy, disinhibition, apathy)	Age and education-corrected t-score: 0-100 (M=50, SD= 10)	<60: not clinically significant 60-64: borderline impairment ≥65: clinically significant
	Zung Self-Rating Depression Scale (SRDS)	Depressive symptoms	Total index score: 0.25-1.00	<0.50: no depression 0.50-0.69: depression ≥0.70: severe depression
Mayo Portland Adaptability Inventory (MPAI-4)	Physical, cognitive, emotional, behavioural and social abilities and difficulties	Three scales: abilities, adjustment, participation. For each, a t-score: 0-100 (M= 50, SD=10)	<30: relatively good outcomes 30-40: mild limitations 50-60: moderate limitations >60: severe limitations	

Table 2.1 (continued): Measures used

<b>Category</b>	<b>Measure</b>	<b>Construct measured</b>	<b>Subscales or scores</b>	<b>Interpretation of score</b>
Social participation	Community Integration Questionnaire, social integration scale (CIQ-SI)	Frequency of social and leisure activities; social supports	Social integration scale: 0-12	The higher the score, the higher the social integration
	Social Provisions Scale (SPS)	Dimensions of perceived social support	Total score: 24-96	The higher the score, the greater the degree of perceived support
	Adult Subjective Assessment of Participation (ASAP): social and leisure activities	Dimensions of participation in social and leisure activities	Diversity: 0-100% Frequency/intensity: 1-7 Enjoyment: 1-6 Satisfaction with performance: 1-6 With whom (others): 0-100% Where (outside of home): 0-100%	Higher scores represent: -more diversity -performed more often -higher enjoyment -more satisfaction with performance -more activities with others -more activities outside of home
Subjective quality of life	Quality of Life and Health Questionnaire, numerical rating scale (QOLHQ)	Global rating of quality of life	Score: 0-10	The higher the score, the higher the global rating of quality of life
	Abdel-Khalek Happiness Scale (AKHS)	Overall rating of happiness	Score: 0-10	The higher the score, the higher the rating of happiness
	UCLA Loneliness Scale (UCLA-LS) (10-item version)	Loneliness	Total: 10-40	15-20: normal experience of loneliness >30: severe loneliness

Table 2.2: Participant characteristics (n=46)

<b>Characteristic</b>	<b>Mean (SD) and range</b>	<b>Proportion (number of participants)</b>
Gender - male		67.4% (31)
Age - years	44.17 (10.87) range 23-63	
Cause of injury (5 participants had 2 TBIs):		
Motor vehicle accident		69.6% (32)
Fall		17.4% (8)
Sports injury		8.7% (4)
Gunshot		6.5% (3)
Other (assault, explosion)		4.4% (2)
Years post injury	15.66 (10.56) range 2-44	
Education status prior to injury:		
Less than grade 12		39.2% (18)
Grade 12		13% (6)
Some post secondary		13% (6)
Post secondary completed		34.8% (16)
Employment status prior to injury:		
Student or trainee		8.7% (4)
Employed		73.9% (34)
Unemployed		17.4% (8)
Current living situation		
Living alone		43.5% (20)
Living with family or roommate		41.3% (19)
Supported living		15.2% (7)

Table 2.2 (continued): Participant characteristics (n=46)

<b>Characteristic</b>	<b>Mean (SD) and range</b>	<b>Proportion (number of participants)</b>
Annual income – CAN\$		
Less than \$12,000.00		63.0% (29)
\$13,000.00-\$20,000.00		11.1% (5)
\$21,000.00-\$40,000.00		4.4% (2)
>\$40,000.00		6.6% (3)
No information provided		15.6% (7)
General health rating (SF-36 GHQ)	2.72 (1.03) range 1-5	
General cognitive status (MoCA)	21.76 (4.28) range 4-29	84.8% (39) with general cognitive impairment (score<26)
Frontal systems cognitive/behavioural impairment (FrSBe) (n=45)	57.62 (18.80) range 24-98	46.7% (21) with frontal systems impairment (t-score $\geq 65$ )
Depression symptoms (SRDS)	0.48 (0.98) range 0.29-0.69	58.7% (27) with depression symptoms (score $\geq 0.50$ )
Impairment (MPAI-4 abilities scale)	45.8 (8.82) range 7-58	39.1% (18) with moderate to severe impairment limitations (t-score $\geq 50$ )
Adjustment (MPAI-4 adjustment scale)	42.24 (10.53) range 12-64	23.9% (11) with moderate to severe adjustment limitations (t-score $\geq 50$ )

SD=standard deviation; TBI=traumatic brain injury; CAN\$ = Canadian dollars; SF-36 GHQ=general health question from the Short Form-36 Health Survey; MoCA=Montreal Cognitive Assessment; FrSBe=Frontal Systems Behaviour Rating Scale; SRDS=Zung Self-Rating Depression Scale; MPAI-4=Mayo Portland Adaptability Inventory, version 4.

Table 2.3: Outcome variables (n=46)

<b>Outcome variable</b>	<b>Maximum score possible</b>	<b>Obtained score: mean (SD) and range</b>
Social Participation:		
General social integration (CIQ-SI)	12	8.24 (2.17) range 3-12
Perceived social supports (SPS)	96	78.28 (9.49) range 60-95
ASAP social participation scores:		
Diversity of activities	100%	40.31% (11.51%) range 16.22%-56.76%
Frequency/intensity	7	4.27 (0.56) range 2.8-5.81
Enjoyment	6	5.14 (0.64) range 3.11-6
Satisfaction with performance	6	5.11 (0.74) range 2.76-6
Where: proportion of activities performed outside of home	100%	64.81% (13.46%) range 37.5%-90%
With whom: proportion of activities performed with others	100%	56.08% (18.84%) range 0%-100%
Subjective quality of life:		
Global rating of quality of life (QOLHQ numerical scale)	10	6.43 (2.25) range 2-10
Happiness (AKHS)	10	7.05 (2.16) range 1-10
Loneliness (UCLA-LS)	40	22.11 (7.10) range 10-37

SD=standard deviation; CIQ-SI=Community Integration Questionnaire, social integration scale; SPS=Social Provisions Scale; ASAP=Adult Subjective Assessment of Participation; QOLHQ=Quality of Life and Health Questionnaire; AKHS=Abdel-Khalek Happiness Scale; UCLA-LS=University of California at Los Angeles Loneliness Scale.

Table 2.4: Intercorrelations between social participation and subjective quality of life (n=46)

Social participation	Subjective quality of life		
	Global rating of QOL (QOLHQ)	Happiness (AKHS)	Loneliness (UCLA-LS)
General social integration (CIQ-SI)	0.218 p=0.146	-0.004 p=0.980	-0.393* p=0.007
Perceived social supports (SPS)	0.220 p=0.143	0.211 p=0.159	-0.516* p< 0.001
Diversity of activities (ASAP)	0.145 p=0.338	0.130 p=0.389	-.0211 p=0.159
Frequency/ intensity (ASAP)	0.100 p=0.509	0.223 p=0.136	-0.051 p=0.736
Enjoyment (ASAP)	0.452* p=0.002	0.525* p<0.001	-0.232 p=0.121
Satisfaction with performance (ASAP)	0.431* p=0.003	0.585* p< 0.001	-0.254 p=0.089
Where: proportion of activities outside of home (ASAP)	0.151 p=0.316	0.291 p= 0.050	0.027 p=0.857
With whom: proportion of activities with others (ASAP)	0.399* p=0.006	0.508* p<0.001	0.068 p=0.656

\*p< 0.01

QOL=quality of life; QOLHQ=Quality of Life and Health Questionnaire; AKHS=Abdel-Khalek Happiness Scale; UCLA-LS=University of California at Los Angeles Loneliness Scale; CIQ-SI=Community Integration Questionnaire, social integration scale; SPS=Social Provisions Scale; ASAP=Adult Subjective Assessment of Participation.

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## **CHAPTER THREE: THE COMPARISON STUDY<sup>2</sup>**

### **Differences in social participation and subjective quality of life between individuals with traumatic brain injury who do and do not attend brain injury drop-in centres**

#### **Introduction**

Traumatic brain injury (TBI) is a major health issue<sup>1</sup>. It is estimated that 43 percent of individuals who are hospitalized with TBI go on to experience long-term disability<sup>2</sup>. Disability may be experienced in terms of physical, cognitive, communication, behavioural, and/or emotional impairment<sup>3</sup>, as well as reduced participation for work, school, independent living, leisure and social activities<sup>3-7</sup>. As few as 30% of individuals who were employed prior to TBI are successful in returning to work following TBI<sup>8,9</sup>. Leisure and social activities therefore become an important aspect of everyday life for individuals with TBI. However, a high proportion of individuals with TBI experiences a decline in participation in social and leisure activities<sup>6,10-12</sup>. Other areas of concern include social isolation<sup>13,14</sup> with fewer friends<sup>15-17</sup> and less social interaction outside of the home and family<sup>12,18</sup>. Many individuals with TBI also experience low quality of life as measured in terms of health-related quality of life<sup>19,20</sup> and subjective well-being, including life satisfaction<sup>16,21-25</sup>.

It has been suggested that the primary goals of TBI rehabilitation are to improve participation or re-integration into the community<sup>26</sup> and restore quality of life<sup>27,28</sup>. Inpatient

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<sup>2</sup> A version of this chapter will be submitted for publication. McLean AM, Jarus T, Hubley AM, Jongbloed L. Differences in social participation and subjective quality of life between individuals with traumatic brain injury who do and do not attend brain injury drop-in centres.

rehabilitation alone is not sufficient for achieving successful, long-term community integration<sup>5,29</sup>. Social participation, defined for this study as involvement in social and leisure activities and within a social network, does not appear to improve simply by passage of time alone<sup>17, 30, 31</sup> and may worsen<sup>6, 13, 32</sup>. It appears, therefore, that long term rehabilitation therapies and support services are required to assist individuals with TBI in achieving these goals<sup>14, 15</sup>. It may be that, by focusing on social participation, such services can also improve an individual's subjective quality of life (SQOL) or subjective well-being, considering that some studies have found a positive relationship between participation or community integration and SQOL including life satisfaction<sup>16, 22, 24, 33, 34</sup>.

There are a number of community interventions and programs described in the research literature which aim to enhance social participation for individuals with TBI, including support groups<sup>35-37</sup>, peer support<sup>7</sup>, case management<sup>29, 38</sup>, circles or networks of support<sup>39, 40</sup>, community day programs<sup>41, 42</sup>, one-to-one volunteer support<sup>43</sup>, community leisure groups<sup>44</sup>, and community outreach teams<sup>45</sup>. However, the research evidence base for the effectiveness and efficacy of such programs is in its infancy<sup>46</sup>. More research is required to focus on community-based programs and services to meet the long term needs of individuals with TBI<sup>29, 44, 47, 48</sup>, including for social participation and quality of life<sup>49, 50</sup>.

One type of support service that has the potential to be both effective and feasible in addressing social participation and quality of life over the long term is the brain injury drop-in centre (BIDC). A search of the research literature and Internet reveals that BIDCs may exist only in British Columbia, Canada, and in the UK. A BIDC, located in a community setting and not a hospital or health centre, provides formal and informal social and recreational activities, peer support and educational in-services for adults with brain injury. Some BIDCs are open each

weekday and others are open two or three times per week. A physician's referral is not required and no appointments are necessary. Individuals may attend as often or little as they choose, and for as long as they like. The expertise of a health care professional is not required for operating a BIDD. A BIDD typically has a staff to client ratio of about one to two staff for a dozen or more attendees in a day.

By the nature of the activities and supports provided by BIDDs, it may be that, by attending BIDDs, individuals with TBI experience improved social participation and SQOL. Furthermore, BIDDs may provide a more comprehensive array of services than other long term support services, and BIDDs may be more cost effective than other rehabilitation interventions, certainly as compared to individual or group programs staffed by health care clinicians. However, we are unaware of any systematic investigation of outcomes for individuals attending BIDDs and, to the best of our knowledge, there is no published research specific to BIDDs. It is important to understand the unique contribution of BIDDs in meeting the ongoing needs of individuals with TBI, in particular as relates to the primary rehabilitation goals of improving participation and quality of life. The value of such information for service providers and funders includes not only justifying the existence of current BIDDs but also in deciding whether or not to set up a BIDD in other communities.

### **The research question**

The focus of this study was on the potential benefits of BIDDs as they relate to social participation and SQOL for individuals with moderate to severe TBI. The aim of this study was to understand the level of importance of a BIDD for individuals who attend, and to compare two groups, individuals who do and do not attend a BIDD. For the comparison, it was hypothesized that individuals who attend a BIDD have higher levels of social participation and SQOL than

individuals who do not attend but who have been identified as potentially benefitting from attending.

## **Methods**

### **Participants**

We recruited 46 participants, 23 for each of two groups: individuals attending a BIDC and individuals not attending a BIDC but who may benefit from attending. Reasons for not attending may include not knowing about BIDCs or there being a barrier to attendance such as the person lacking transportation or living too far from a BIDC. Details regarding sample size testing are provided as Appendix G. Participants were recruited through BIDCs for the BIDC group, and through community-based case managers, health care clinicians and service providers for the Comparison group. Participants needed to meet the following inclusion criteria: age 19 to 65 years, sustained a moderate to severe TBI (which relates to initial severity of injury) that had occurred at least one year prior, living in the community, fluent in English, and able to provide informed consent. Moderate to severe TBI (which relates to severity of initial injury) was determined by information provided by the participant or his/her clinician demonstrating at least one of the following<sup>51</sup>: an initial Glasgow Coma Scale of 12 or less, post traumatic amnesia of 1 hour or more, and/or loss of consciousness of more than 15 minutes. If no information was available for these measures, then hospitalization of at least 48 hours as related to the TBI<sup>52</sup> provided sufficient evidence for the purposes of this study. Individuals were excluded if they had aphasia or were otherwise unable to complete questionnaires, were currently working (paid or unpaid) unless doing volunteer work for only a few hours per week, were currently involved in a formal rehabilitation program, or they had an Axis 1 psychiatric diagnosis<sup>53</sup> (other than mild to moderate depression). For depression, they were excluded if

their index score was 0.70 or greater on the Zung Self-Rating Depression Scale. Individuals for the B IDC group were included if they had been attending a B IDC on average at least once per week over the previous three months. Individuals in the comparison group were deemed ineligible if they had made more than three visits to a B IDC over the previous six months.

### **Study design**

A cross-sectional design was used in this study of the association between social participation and SQOL. Each participant met with either the researcher (the first author) or the research assistant (the ‘assessors’), both registered occupational therapists, to complete the consent form and all of the measures. The research assistant was otherwise not involved in the research project. Prior, each participant was advised that they were welcome to have a friend, family member or caregiver present. 13 out of the 46 participants chose to have someone present. An assessor met with each participant to administer all of the measures; this included reading the instructions out loud for each measure and ensuring that the participant understood the instructions prior to proceeding. For the self-report questionnaires, participants were then provided with the option of reading the items on their own or having the items read out loud by the assessor. Questionnaires were presented in the same order for every participant. The assessor ensured that all of the questions were answered and, in the event of any missing responses, confirmed that this was because the participant had chosen not to provide a response and had not just overlooked the item. Quality of data was further enhanced by asking the attending friend, family member or caregiver to verify information such as history of injury and rehabilitation as well as participant responses to the Frontal Systems Behavior Rating Scale (FrSBe), a measure of frontal lobe functions (apathy, executive function and disinhibition). Three participants provided permission for the assessor to telephone a family member or caregiver to confirm

information relating to their injury and history of rehabilitation services. Some participants, on their own initiative or at the suggestion of the assessor, made use of their day timers/calendars to verify details about their social participation, in particular frequency/intensity of their social and leisure activities.

Short breaks were provided as requested by the participant or if the assessor observed the participant to show signs of physical discomfort or fatigue including onset of difficulties with concentration; for some individuals, the session was terminated altogether and completed on another day, with all sessions completed within a 2-week period for each participant.

Participants required an average of 2.78 hours (ranging from 1.75 to 4.67 hours) to complete all of the measures, with no single session lasting more than 3.25 hours (including at least one 10 to 15-minute break). 33 participants (71.7%) completed all measures in one session, 11 individuals (23.9%) required two sessions, and 2 participants (4.3%) required three sessions.

Inter-rater reliability and procedural consistency were enhanced by the assessors meeting together, prior to any data collection, to review all of the questionnaires, procedures, and the scoring of the performance-based measure (Montreal Cognitive Assessment). Then, for the first 2 participants, one assessor administrated all of the measures and the other assessor observed (alternating between the two sessions), so that any issues relating to procedure could be discussed afterwards. For all participants, the assessor recorded information relating to duration of session(s) and frequency and duration of breaks taken, whether or not someone else was present, the measures completed during each session, the general presentation of the participant and, in the event that more than one session was required, the reasons for this.

Ethical approval was provided by the Behavioural Research Ethics Board of the University of British Columbia and the relevant health authorities. Written information about

the study was provided to, and written consent obtained from, all participants. Participants were provided with a small monetary compensation for their participation in the study.

## **Measures**

A summary of the measures used, with one exception, are listed in Table 2.1. The exception is a questionnaire relating to involvement (BIDC group) or potential involvement (Comparison group) in a BIDC. More details about each measure are provided in Appendix C. A copy of each of the study-specific questionnaires (relating to *participant characteristics* and *involvement in a BIDC*) is provided as Appendix D.

**Participant characteristics.** A short questionnaire collected information about the participants including gender, age, cause of TBI, time post injury, education, employment, living situation and income. In response to the General Health Question from the Short Form-36 Health Survey (SF-36 GHQ)<sup>54</sup>, individuals rated their *overall health* on a 5-point scale from ‘poor’ (rated 5) to ‘excellent’ (rated 1). The GHQ has good test-retest reliability<sup>55,56</sup>, and the full SF-36 has been found to have good concurrent validity for individuals with TBI<sup>19</sup>. Two measures were used to characterize participants in terms of their *cognitive function*: (a) the performance-based Montreal Cognitive Assessment (MoCA)<sup>57</sup> and (b) the self-report Frontal Systems Behavior Rating Scale (FrSBe)<sup>58</sup>. The MoCA, which screens for a number of different cognitive functions, has been found to have good internal consistency and high test-retest reliability<sup>57</sup>, and validation studies are underway with an acquired brain injury population<sup>59</sup>. The FrSBe, which provided more in-depth assessment of frontal lobe functions, has demonstrated high internal consistency, good test-retest reliability and good construct validity (convergent and discriminant)<sup>58, 60, 61</sup>. The Zung Self-Rating Depression Scale (SRDS)<sup>62</sup> provides a screen of *depressive symptoms*. Most individuals with depression have an index score between 0.50 and

0.60; an index score of 0.70 or greater indicates severe depressive symptoms<sup>63</sup>. The SRDS has demonstrated high test-retest reliability<sup>64</sup>, fair internal consistency<sup>65, 66</sup>, and good convergent validity with other depression measures<sup>65</sup>. The Mayo Portland Adaptability Inventory, version 4, (MPAI-4)<sup>67</sup> was used to collect additional information about the participants' level of *physical, cognitive, and communication impairment* using the abilities subscale, and their level of *pain, fatigue, emotional, and interpersonal adjustment* using the adjustment subscale. For individuals with acquired brain injury, there is acceptable internal consistency for the measure as a whole and each of the subscales, acceptable item agreement (between individuals with brain injury, significant others and rehabilitation staff), moderate convergent validity, and some predictive validity (in terms of long term vocational and independent living outcomes)<sup>68-70</sup>.

**Involvement in a B IDC.** Individuals in the B IDC group were asked about their current involvement in a B IDC including frequency of attendance, barriers to attendance, and the importance of a B IDC in their lives. This included one open-ended question, 'How would life look if you were not attending at a brain injury drop-in centre?'. Participants either wrote down their own responses, or their responses were recorded in writing by the assessor. Individuals in the Comparison group were asked if they would like to attend a B IDC and, if so, why they were not currently attending.

**Social participation.** Social participation was operationalized as involvement in social and leisure activities and a social network. Three measures were used: (a) the social integration scale of the Community Integration Questionnaire (CIQ-SI)<sup>71</sup>, (b) the Social Provisions Scale (SPS)<sup>72</sup> and (c) the Adult Subjective Assessment of Participation (ASAP)<sup>73</sup>. The Community Integration Questionnaire is one of the most widely used and recommended measures of outcome following TBI. The CIQ-SI, a measure of general social integration, focuses on

frequency of participation in social and leisure activities and, to some degree, the nature of a person's social supports. Modest inter-correlations between subscales, moderate inter-rater reliability (between individuals with TBI and their caregivers), and high face validity have been found for the TBI population<sup>71, 74-78</sup>. The SPS, which focuses on the degree to which a person perceives his/her social relationships as providing different dimensions of social support, has been found to have low internal consistency for subscales (and therefore this study considers only the total score), and adequate construct validity (discriminant and convergent)<sup>72</sup> including for individuals with TBI<sup>16, 79</sup>. The ASAP examines level of participation in different life occupations or situations beyond basic self-care activities and outside of paid or unpaid work. This study used the scales relating to participation in social and leisure activities. There is a score for each scale: diversity of activities, frequency/intensity of participation, enjoyment, satisfaction with performance, with whom the individual participates and where the individual participates. The ASAP has demonstrated good test-retest reliability and construct (discriminant) validity<sup>73</sup>.

**Subjective quality of life.** SQOL refers to the cognitive and affective appraisal of one's subjective well being<sup>80</sup>. We used three self-report measures of SQOL: (a) the Quality of Life and Health Questionnaire (QOLHQ)<sup>81</sup>, (b) the Abdel-Khalek Happiness Scale (AKHS)<sup>82</sup> and (c) the University of California at Los Angeles Loneliness Scale (UCLA-LS)<sup>83</sup>. The QOLHQ includes a single item numerical scale used for appraising global quality of life, ranging from 0, 'worst possible quality of life', to 10, 'best possible quality of life'. Fair to moderate construct (convergent) validity of this scale has been found for individuals with cancer<sup>84</sup> and individuals with TBI<sup>85</sup>. The AKHS is another numerical scale, ranging from 0 (minimum happiness) to 10 (maximum happiness). It has good test-retest reliability, and construct (adequate discriminant

and good convergent) validity<sup>82</sup>. The UCLA-LS, which is considered to focus on intimate and interpersonal loneliness<sup>83,86</sup>, has high internal consistency, high test-retest reliability, high face validity, and good convergent validity<sup>83</sup>. We used a 10-item version<sup>87</sup>.

### **Statistical analysis**

Data analyses were conducted using descriptive and comparison statistics using SPSS for Windows version 17.0. Descriptive statistics (means, standard deviations, ranges and proportions) were used to describe the group in terms of participant characteristics, the dependent variables of social participation and SQOL and, for the B IDC group, the importance ratings of attending a B IDC. Comparison statistics revealed whether or not there were any statistically significant differences between the groups for participant characteristics and the dependent variables. Multiple univariate analyses were used and not multivariate analyses, following Huberty and Morris<sup>88</sup>. This study matches three situations for which Huberty and Morris suggest use of multiple univariate analyses: (a) the research project is exploratory in nature, (b) the outcome variables are conceptually independent (for example, for social participation, *involvement in a social network* and *frequency/intensity of social and leisure activities*), and (c) some of the dependent variables have been previously studied in a univariate context (which, for this study, applies to all of the main outcome variables). In comparing the groups, normally distributed data were analyzed using independent samples t-tests, and effect sizes for differences in mean scores were calculated using eta-squared<sup>89</sup>. When results indicated that the groups were not normally distributed, the non-parametric Mann-Whitney U test was used, and effect sizes were calculated using the approximate value of  $r$ <sup>89</sup>. Where participants could be categorized into dichotomous groupings based on the dependent variable, the chi-square test for independence was used to analyze differences in proportional representation

between groups, and effect sizes were determined using the phi coefficient value<sup>89</sup>. Criteria for effect sizes (small, medium or large) were taken from Cohen 1988<sup>90</sup>. To avoid inflated risk of Type I errors in conducting multiple comparisons, the level of significance for all comparison analyses was set at  $\alpha = 0.01$ , although, considering the exploratory nature of this study, results that fall within the level of significance of  $\alpha = 0.05$  are also reported.

There were no missing data for the dependent variables of social participation and SQOL. Missing data were as a result of participants choosing not to answer a response. Data were missing for 13 out of 840 responses on the SRDS, managed as per Shrive<sup>91</sup>, six out of 1,932 responses on the FrSBe, managed by following directions provided in the instruction manual<sup>92</sup>, and for 7 participants for level of income. Further details are provided in Appendix E.

## **Results**

An unexpected finding was that the Comparison group was found to be comprised of three distinct subgroups based on their response to the question, 'Would you like to attend a BIDC?' The first subgroup (n=12) was comprised of individuals who replied that yes, they would attend a BIDC. The primary reasons for not currently attending were that the individuals were not aware of BIDCs or there were barriers to attendance, for example, the BIDC was too far away, they had difficulties accessing transportation to get to a BIDC, or they did not have the necessary caregiver support. Four participants reported that they planned to attend a BIDC but had not yet started. One individual reported being too busy with other activities and one person stated that they were focused on trying to get back to working, but on learning about BIDCs and the activities offered, both of these individuals stated that they would consider changing their schedule or priorities to attend a BIDC. This subgroup will be referred to as the Yes group. The second subgroup (n=7) was comprised of participants who responded that maybe they would

attend a B IDC. All but one of these individuals explained that they were interested in attending at B IDC, but that they were too busy to do so; the other individual expressed concerns that he or she might not relate to anyone at a B IDC. This subgroup will be referred to as the Maybe group. The third subgroup was comprised of 4 individuals who stated that they would definitely not attend a B IDC, with the primary reason given that they were busy focusing on getting back to work and driving and two participants stating that they had no interest in doing things with other people with brain injuries. This group will be referred to as the No group. There was no indication (based on their responses to questionnaires, observed behaviours, and information from their community service providers) that any of these 4 individuals lacked insight into their needs. While these individuals did meet the study's inclusion criteria, the No group was too small to be considered as a separate group in the analyses.

### **Participant characteristics**

As can be seen in table 3.1, most of the participant characteristics were found to be similar across the B IDC, Maybe and Yes groups. The most notable differences, at  $p < 0.01$ , were as follows: the participants in the Maybe and Yes groups were found to have more current involvement with rehabilitation therapies than individuals in the B IDC group. It was determined that this was for physiotherapy, acupuncture treatment, and/or intermittent psychological counselling. These group differences included the mean scores for frequency of attendance as well as the proportions of individuals in each group in receipt of rehabilitation therapies.

The B IDC group was found to have a higher proportion of individuals currently receiving support services than the Yes group ( $p < 0.01$ ). The Maybe group also had a higher proportion of individuals currently receiving support services than the Yes group, but this did not reach statistical significance. All members of the B IDC and Maybe groups were in receipt of

support services, whereas only two-thirds of the Yes group were in receipt of support services. For the BIDD group, it was found that the support services consisted primarily of BIDDs, with one person also in receipt of help from a life skills worker and one person also attending an adapted fitness program. For both the Yes group and Maybe group, the support services consisted of support from a one-to-one life skills worker, attendance at an adapted fitness program, and/or involvement of a circle of support, and for the Maybe group, services also included support from a one-to-one volunteer and/or attendance at an adapted art program.

The only other differences between groups ( $p < 0.01$ ) were for the MPAI-4 adjustment scale. The Comparison group as a whole, and more specifically the Yes group, was found, on average, to have more adjustment problems than the BIDD group. The Maybe group was also found to have more adjustment problems than the BIDD group, but at  $p < 0.05$ . On inspection of the specific items on the MPAI-4 adjustment scale, the greatest differences between the Yes group and BIDD group were that the Yes group had less social contact with others beyond professionals and family (i.e., a measure of social participation), and more fatigue. Of interest was that the Maybe group had the highest mean score for fatigue out of the three groups.

A few additional differences were found on subject characteristics at  $p < 0.05$ . There was a higher proportion of individuals living alone in the Comparison group as compared to the BIDD group, with the highest proportion of individuals living on their own found to be in the Maybe group. In addition, on average, individuals in the BIDD group were found to be older (although generally within the same age range) and more years post injury than the Comparison group.

### **Descriptive findings relating to attendance at a B IDC**

There were six B IDCs represented in this study. Four B IDCs were open twice per week, and the other two locations were open five days per week. On average, individuals in the B IDC group reported that they had attended at a B IDC for 5.42 years ( $SD=4.74$  years, range 4 months to 15 years). Frequency of attendance was from one to five times per week, on average about twice per week ( $M=2.22$ ,  $SD=0.84$ ). Almost half of the B IDC group (47.8%) reported that, if they could, they would attend a B IDC more often than they do currently, with the primary limiting factor being that the B IDC is not open often enough. Of interest was that the individuals in the Comparison group reported that, if they were to attend a B IDC, then they would attend on average once or twice per week ( $M=1.66$ ,  $SD=1.15$ , range once every 2 weeks to 5 times per week). On average, individuals in the B IDC group rated the importance of attending a B IDC at 4.44 out of 5 ( $SD=0.65$ ), where 1 represents ‘not at all important’ and 5 represents ‘very important’, with no-one providing a rating below 3 (‘somewhat important’). Using the ASAP, participants in the B IDC group reported that, on average, 36.9% of their current social and leisure activities take place at a B IDC ( $SD=19.2\%$ , range 13% to 82%). When selecting their five core or most important activities from the full ASAP measure, 82.6% of individuals selected as at least one of these activities attendance in general at a B IDC and/or a specific activity that they perform primarily at a B IDC.

In response to the open-ended question about how life would look if they were not attending a B IDC, all but one participant responded that life would be lacking in some way. This one person stated that life would not be much different because they had lots of other things to do. It was found that most of the responses of the other 22 participants could be categorized under the themes of social participation and SQOL. In terms of social participation, participants

reported that a B IDC gave them something to do and, without a B IDC, they would miss the activities, would not have much to do, find it difficult to find something to do, or have less confidence trying new activities. They stated that there would be less chance to get out, and one participant responded that he would miss the volunteering that he does at the B IDC. Participants reported that attending a B IDC has helped them with meeting new friends and that the people at the B IDC feel like family. Two individuals stated that, without a B IDC, the only people they would spend time with would be caregivers or family members. Two participants responded that they would miss having the opportunity to talk with people about shared experiences relating to having a brain injury. One person reported that without having the B IDC to attend, his activities would consist primarily of eating, sleeping and smoking.

With regard to the theme of SQOL, individuals reported that, without a B IDC to attend, life would become boring, difficult, blank, ‘could be bleak’, gloomy, ‘a lot less fun’, and/or ‘not very good’. They expected that they would become lonely, frustrated or mad, unproductive or negative, or ‘lost’. One person stated that now, ‘I feel crappy when I miss a day’. A number of individuals felt that they would become depressed. One person felt that he might no longer have anyone to talk to when he feels depressed. Another person stated, ‘I wouldn’t be able to handle it out there.’ One individual reported having been quite depressed upon starting at the B IDC less than six months prior, that the B IDC had helped improve the depression, and that, without the B IDC, ‘I’d be right back to where I was before, stuck in my own corner of the world. I’d be lost...if I have nowhere to go, I stagnate...’

### **Comparison of social participation and SQOL**

Table 3.2 shows the mean scores for each group on measures of social participation and SQOL and summarizes the results of the comparison analyses. First, the B IDC group was

compared to the Comparison group as a whole. The B IDC group had a higher ASAP home score ( $p < 0.01$ ), that is, they participated in more activities outside of the home, than the Comparison group. At  $p < 0.05$ , there were a number of other statistically significant differences. The B IDC group was found to have a higher general social integration score (as measured by the CIQ-SI) than the Comparison group and, as measured by the ASAP, more frequency/intensity of social participation activities, a higher percentage of activities spent with others, and a higher score for satisfaction with performance for social and leisure activities. All effect sizes were medium or large.

The B IDC group was then compared to the Yes group, because the Yes group best represents the individuals who had been sought for the study's comparison group. At  $p < 0.01$ , statistical significance was reached on two of the measures: the B IDC group was found to have a higher rating for happiness and to engage in more social participation activities outside of the home than the Yes group. At  $p < 0.05$ , additional differences were found: the B IDC group had a higher score for overall quality of life, general social integration, frequency/intensity of social participation activities, enjoyment, and satisfaction with performance. Again, all effect sizes were medium or large.

Furthermore, as can be seen in table 3.2, a pattern is observed where, for many of the social participation and SQOL measures, the B IDC group and Maybe group are more similar to each other than to the Yes group, with more desirable scores than the Yes group. The exceptions are (a) three measures where it appears that the Maybe group is more similar to the Yes group than the B IDC group (i.e., general social integration, proportion of activities performed with others, and proportion of activities performed outside of the home) and (b) three measures

where the mean scores appear similar across groups (i.e., loneliness, perceived social supports, and diversity).

Table 3.3 shows the results of more clinically significant findings for social participation and SQOL, that is, the proportion of individuals in each group placing above a clinically significant cut-off point (where such cut-off points are available). It can be seen that, with the exception of loneliness, the BIDC and Maybe groups appear to have the highest proportions of individuals at or above the cut-off points and the Yes group appears to have the lowest proportions. For loneliness, the Maybe group appears to have the highest proportion of individuals who are lonelier than what is considered a normal experience, and the BIDC group appears to have the lowest proportion. None of these differences reached statistical significance. However, there were medium effect sizes found in comparing the BIDC group with the Comparison group for enjoyment and satisfaction with performance, and comparing the BIDC group with the Yes group for enjoyment, satisfaction with performance, and happiness.

### **Discussion and Conclusion**

This exploratory study provides the first report of brain injury drop-in centres. The hypotheses were supported in that individuals who attend BIDCs (i.e., the BIDC group) were found to have higher levels of SQOL and social participation than individuals who do not attend BIDCs but who had been identified as potentially benefitting from attending (i.e., the Comparison group). The strongest support for the study's hypotheses came after the Comparison group had been broken down into the Yes group (individuals who stated that they would like to attend a BIDC but either did not know about BIDCs or experienced a barrier to attending) and the Maybe group (individuals who might attend a BIDC but, for the most part, felt they were too busy to attend). For many of the measures of SQOL and social participation, it

was the Yes group and not the Maybe group that had lower mean scores than the B IDC group. Of interest was that the pattern of results showed that the Maybe group appeared to be more similar to the B IDC group than to the Yes group on many of the measures of social participation and SQOL.

Of most statistical significance ( $p < 0.01$ ) were the higher mean scores for the B IDC group (than the Comparison group and/or Yes group) in ratings of happiness and proportion of activities performed outside of home. Of lower statistical significance ( $p < 0.05$ ) were the B IDC group's higher mean scores (as compared to the Comparison group and/or Yes group) in global quality of life, general social integration and, for performance of social and leisure activities, frequency/intensity, proportion of activities performed with others, enjoyment and satisfaction with performance.

It may be that attendance at a B IDC contributes to higher levels of social participation and SQOL as compared to non-attendance. The cross-sectional design of the study does not allow for conclusions to be made relating to the cause and effect of attendance in a B IDC. However, in considering the nature of a B IDC (located in a community setting and providing a variety of group activities), it would not be surprising to find that attendance at a B IDC contributes to performing a higher proportion of one's social and leisure activities outside of their house and with other people. With regard to the other outcome measures, results of other TBI studies lend support to programs similar to B IDCs contributing to various dimensions of social participation and SQOL. This includes studies that have investigated participation in community-based leisure activities<sup>44</sup>, a social and leisure day program<sup>42</sup>, a leisure and pre-vocational skills program<sup>93,94</sup>, and a drop-in program offering social and leisure activities, education classes and training in communication and interpersonal skills<sup>95</sup>. Quantitative and

qualitative findings for all of these studies indicate that individuals who participated in these programs perceived themselves to benefit in many areas of social participation and SQOL. This includes improved scores for general social integration (CIQ-SI) and global quality of life (QOLHQ), over time and as compared to individuals who had not participated, as well as reports of happiness with involvement in the leisure activities, enjoyment of being with others, and making friends<sup>44</sup>. The participants in the drop-in program reported having benefited from the emotional and social support and the opportunity to develop social contacts and form long-lasting relationships<sup>95</sup>. The study of the day program found that the program met the emotional, social, recreational, and quality of life needs for the attendees<sup>42</sup>. One member reported, ‘...My day is so much better when I come here than if I’d stayed home. If I’d stayed home, and there wasn’t a SteppingStones, I’d be so depressed...’<sup>42</sup> (p. 1275). One description of the leisure and pre-vocational skills program reports an attendee having stated, ‘...I lost my social life after my car wreck...I was bored out of my mind at home...I look forward to coming here instead of sitting at home all day...’<sup>94</sup> (p. 42).

Our findings relating to involvement of the BIDD group in BIDDs provide further evidence that attendance in a BIDD may contribute to higher levels of SQOL and social supports. The participants in the BIDD group provided high ratings of the importance of a BIDD in their lives, and gave many examples of the positive influence of a BIDD on their SQOL and social participation.

It was interesting to find a pattern where, for many of the measures of SQOL and social participation, the Maybe group appeared more similar to the BIDD group than to the other individuals not attending a BIDD, the Yes group. It may be that this pattern has some relationship to current levels of support services, the only participant characteristic where we

found a similar pattern of results in comparing the three groups. The Maybe group was more similar to the B IDC group than the Yes group for support services in terms of current number of support services and percentage of participants receiving support services. It may be that the types of support services received by the Maybe group provide some similar benefits to social participation and SQOL as does attendance at a B IDC. Unfortunately, however, there are very few TBI studies that have investigated SQOL and social participation outcomes as related to the types of support services that were reported by our participants, such as one-to-one life skills support workers and volunteers, adapted fitness programs, adapted art programs, and peer support groups. However, those TBI studies that have been conducted provide some evidence of such programs contributing to improved SQOL and social participation. Such studies include investigation of an adapted Tai Chi program<sup>96</sup>, the use of one-to-one volunteers to assist individuals with TBI to increase their social contacts and become engaged in an increased variety of community activities<sup>43</sup> and peer support programs<sup>7,37</sup>. However, for many individuals with TBI and their funders, B IDCs may have a number of advantages over these other support services. These advantages may include the comprehensiveness and variety of social and leisure activities and supports offered by one support service. In addition, because the focus of B IDCs includes involving members in selecting and planning the activities, contributing by participating in members' meetings and volunteering, and learning skills to connect with other community social and leisure activities, B IDCs may be more empowering than other support services.

It is more difficult to find an explanation for our finding that there were no differences across groups for loneliness, perceived social supports, and diversity of social and leisure activities. Across groups, there were fairly high levels of loneliness and fairly low levels of

perceived supports. These findings are despite the differences between groups for other measures including happiness, global quality of life, and subjective dimensions of participation. Other researchers have also reported high levels of social isolation and loneliness for individuals following TBI<sup>30, 97-99</sup>. We are not aware of any TBI studies that have explored in any depth the experience of loneliness for individuals with TBI. We have found no TBI studies that have investigated the association between loneliness and social participation, or between loneliness and other aspects of SQOL such as life satisfaction or happiness. It may be that BIDs are unable to influence many of the personal, social and environmental factors that might contribute to loneliness and/or social isolation. For example, qualitative research has found that, for individuals at 10 years post TBI, barriers to social integration include break-up of relationships, dependence on family, disruption in living situation, and poor coping and adaptation to disability<sup>100</sup>. It would appear by the nature of a BID that these issues are unlikely to resolve through attendance at a BID.

### **Limitations**

There are a number of limitations to this study. Therefore, the results and conclusions must be considered tentative. First, the study's design does not allow claims to be made of a cause and effect relationship between BIDs and social participation and SQOL. Some or all of the statistically significant differences found in this study may represent a Type I error, considering the multiple comparisons performed; however, we reduced this risk by increasing the level of significance to 0.01. However, it may also be that there were Type II errors, in particular when considering the small sizes of the comparison subgroups. Sample size had been estimated using information from the literature on the CIQ-SI, the only one of our outcome variables used with sufficient information available on means and standard deviations for the

TBI population. With larger group sizes, there may be a greater number of statistically significant findings.

There may have been limitations relating to the measures used. For example, participants may have had differing interpretations of some of the questions asked of them, in particular in defining 'quality of life' for the numerical rating scale of the QOLHQ. Another limitation may be that lack of insight or self-awareness influenced how participants responded. However, the literature does not support this perspective, and instead, as summarized by Hawthorne et al.<sup>14</sup>, indicates that individuals with impaired cognition are able to provide meaningful insights about their own conditions and experiences. Some of the measures used may not have been sensitive enough to capture differences between groups, in particular the measures of loneliness and perceived social supports. Other researchers have also questioned the sensitivity of the UCLA-LS and have recommended development of tools to better measure feelings of loneliness and social isolation<sup>101</sup>. Some of the measures have not had reliability or validity tested with individuals with TBI. However, reliability was enhanced by using no more than two assessors, both registered occupational therapists, with every attempt made to ensure consistency between them. Furthermore, we did not depend on a single measure for each of our constructs of interest but instead, as has been recommended by others<sup>102</sup>, we used multiple measures in an attempt to most accurately capture information about social participation and SQOL.

Results from this study cannot be generalized beyond the participants involved in the study. Our group provides only a small representation of individuals with TBI who do and do not attend BIDCs, although it is comparable in many ways to much larger groups reported in TBI outcome studies. This includes the male to female ratio, primary cause of accident, and proportion of individuals with grade 12 education or less at the time of injury<sup>103-105</sup>. Another

limitation is that only individuals with TBI were recruited for this study, whereas many individuals who attend BIDs or who may potentially benefit from attending have other types of acquired brain injury, such from brain tumour, aneurysm, or stroke. It may be that these other individuals have differing experiences than individuals with TBI, and that more could be learned about the influence of a BID on SQOL and social participation by including these other individuals in future research. Despite our study's limitations, this research project provides the first exploration of BIDs and gives some indication of the potential benefits of BIDs.

Because of the very small group size, we were unable to analyze the results of the No group, that is, the 4 individuals who stated that they would definitely not attend a BID. Future studies could explore differences between individuals with TBI who are interested in and available for specific support services (such as was represented by our study's Yes group), individuals who are interested but not available (similar to our Maybe group) and individuals who are not interested in specific support services (similar to our No group), to better understand what support services can best meet the needs of what types of individuals.

### **Future research**

Despite the numerous difficulties in conducting research on rehabilitation interventions<sup>14</sup>,<sup>106</sup> and long term supports<sup>14</sup> for individuals with TBI, in particular within community settings<sup>107</sup>, the findings from our study support that further research is warranted in investigating BIDs. It may not be possible to conduct more rigorous clinical trials, considering that, for example, a lengthy period of time would be required to recruit a sufficient number of participants, and there would be a high risk of attrition. There are also many challenges to using randomized assignment in brain injury research, including ethical issues that arise in assigning some individuals to no treatment or a waitlist<sup>108</sup>. It would also be very difficult to blind individuals to

their group assignment. Instead, it may be more feasible to investigate specific aspects of a B IDC. For example, one could compare outcomes of those individuals attending more socially-oriented programming at a B IDC with those people attending more leisure-focused activities at a B IDC. A survey research design could collect information about commonalities and differences in activities and programs between B IDCs and better identify the unique features of a B IDC as compared to other support services. Qualitative research, such as involving in-depth interviews of individuals attending B IDCs, would provide rich data to better understand the personal experiences associated with attending a B IDC and the value of a B IDC in a person's life. Regardless of study design, it would be valuable to expand research efforts to include participants who have other types of acquired brain injury.

One topic in particular that warrants further investigation is the experience of loneliness for individuals with TBI. Our study failed to find differences across groups using the UCLA-LS, and yet individuals in the B IDC group reported that, in the event they were no longer able to attend a B IDC, they would become lonely and lose friends and social contacts. It may be that what we measured as loneliness (using the UCLA-LS) does not measure what individuals with TBI experience as loneliness. Our review of the TBI literature reveals that there has been very little if any investigation of the experience of loneliness for individuals with TBI, other than to equate it with social isolation<sup>30</sup>.

Also of interest would be investigation of the experiences of family members and caregivers, (e.g., burden of care), and the experiences of individuals who staff the B IDCs. Such information could be collected using quantitative and/or qualitative research designs. Findings from this study also indicate that, beyond further investigation of B IDCs, more research is needed to better understand other community-based support services. Research to date has

identified a number of different types of community-based support services that benefit individuals with TBI<sup>26, 109</sup>, but there has been little attention so far in identifying the common characteristics of these support services that contribute to meeting the long-term needs of individuals with TBI. One review of post-acute programs for individuals with acquired brain injury concluded that early intervention, social support and individualized, contextualised programming are important features<sup>109</sup>, but there is little information on long-term supports.

### **Clinical implications**

It may be that BIDs can provide cost effective and sustainable benefits to individuals with TBI as compared to other support services such as one-to-one life skills worker or volunteer supports, in addition to a wide variety of social and leisure opportunities within one program. However, despite any advantages that a BID might offer, including for social participation and SQOL, this type of support service is not necessarily the best match for every person with a TBI, for example, may not contribute to meeting his/her personal goals. This was certainly demonstrated by the 4 No group participants in our study: despite a clinician or service provider having identified each of these individuals as potentially benefitting from attending a BID, the individuals themselves felt that they were not a good match.

Results of this study, similar to previous findings<sup>44, 110</sup>, also provide a reminder that attention needs to be paid to addressing the barriers to accessing support services. This may be as simple as ensuring that individuals are provided with information about existing programs and supports. Contextual barriers (e.g., lack of transportation, too far to travel or unavailability of an accompanying caregiver) may be more difficult to address.

## **Conclusion**

Studies have found there to be a large proportion of individuals with TBI who have the need to find places and opportunities to socialize with others, participate in physical leisure activity, and/or do more activities outside of the home<sup>10,110,111</sup>. This current study, despite its limitations, provides evidence to suggest that such needs might be met by attending a B IDC. One benefit of attendance at a B IDC may be to social participation and SQOL. The findings from our study will assist clinicians to better understand the potential benefits of attendance at a B IDC for their clients. Further research will help to improve the knowledge of the benefits specifically of B IDCs and also, in general, of other long-term support services for individuals with TBI.

Table 3.1: Participant characteristics: mean scores (standard deviations) or proportions (n), and comparison results

Characteristic	BIDC group, n=23	Comparison group			Statistically significant differences	Effect size
		Comparison group, n=19	Maybe group, n=7	Yes group, n=12		
Gender : male	65.2% (15)	68.4% (13)	85.7% (6)	58.3% (7)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.03 <sup>S</sup> Phi=0.19 <sup>S</sup> Phi=0.07 <sup>S</sup>
Age	48.61 (10.76) range: 28-63	41.58 (8.66) range: 28-57	40.43 (9.50) age: 29-57	42.25 (8.49) range: 28-51	*BIDC & C: t(40)=2.30, p=0.027 BIDC & M: NS BIDC & Y: NS	$\eta^2=0.12^M$ $\eta^2=0.10^M$ r=0.33 <sup>M</sup>
Cause of TBI: MVA	73.9% (17)	68.4% (13)	85.7% (6)	58.3% (7)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.06 <sup>S</sup> Phi=0.12 <sup>S</sup> Phi=0.16 <sup>S</sup>
Years post injury	20.02 (12.30) range: 2-44	12.63 (5.82) range: 4-25	13.0 (5.77) range: 5-19	12.42 (6.09) range: 4-25	*BIDC & C: t(40)=2.40, p=0.021 BIDC & M: NS BIDC & Y: NS	$\eta^2=0.13^M$ $\eta^2=0.17^L$ $\eta^2=0.15^L$
Pre-TBI education: grade 12 or less	56.5% (13)	47.4% (9)	57.1% (4)	41.7% (5)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.09 <sup>S</sup> Phi=0.01 <sup>S</sup> Phi=0.14 <sup>S</sup>
Pre-TBI employment: student/working	78.3% (18)	84.2% (16)	85.7% (6)	83.3% (10)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.08 <sup>S</sup> Phi=0.08 <sup>S</sup> Phi=0.06 <sup>S</sup>
Currently doing volunteer work	21.7% (5)	31.6% (6)	42.9% (3)	25% (3)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.11 <sup>S</sup> Phi=0.20 <sup>S</sup> Phi=0.04 <sup>S</sup>

Table 3.1 (continued): Participant characteristics: mean scores (standard deviations) or proportions (n), and comparison results

Characteristic	BIDC group, n=23	Comparison group			Statistically significant differences	Effect size
		Comparison group, n=19	Maybe group, n=7	Yes group, n=12		
Current living situation: alone	26.1% (6)	63.2% (12)	85.7% (6)	50.0% (6)	*BIDC & C: $\chi^2=5.84$ , p=0.016 *BIDC & M: $\chi^2=5.66$ , p=0.017 BIDC & Y: NS	Phi=0.37 <sup>M</sup> Phi=0.52 <sup>L</sup> Phi=0.24 <sup>S</sup>
Personal care: support required	17.4% (4)	26.3% (5)	28.6% (2)	25% (3)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.11 <sup>S</sup> Phi=0.12 <sup>S</sup> Phi=0.09 <sup>S</sup>
Therapies:						
Number of therapies since TBI	3.09 (1.56) range: 0-6	3.84 (1.95) range: 0-6	5.14 (1.21) range: 3-6	3.08 (1.93) range: 0-6	BIDC & C: NS **BIDC & M: U=24.5, p=0.005 BIDC & Y: NS	r=0.51 <sup>L</sup> r=0.51 <sup>L</sup> r=0.02 <sup>S</sup>
Current number of therapies	0.30 (0.56) range: 0-2	0.84 (1.07) range: 0-3	1.0 (1.16) range: 0-3	0.75 (1.06) range: 0-3	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	r=0.03 <sup>S</sup> r=0.32 <sup>M</sup> r=0.20 <sup>S</sup>
Participants now receiving therapies	4.3% (1)	47.4% (9)	57.1% (4)	41.7% (5)	**BIDC & C: $\chi^2=8.38$ , p=0.004 **BIDC & M: $\chi^2=7.30$ , p=0.007 *BIDC & Y: $\chi^2=5.33$ , p=0.021	Phi=0.50 <sup>L</sup> Phi=0.60 <sup>L</sup> Phi=0.47 <sup>M</sup>
Current frequency per week	0.04 (0.21) range: 0-1	0.48 (0.68) range: 0-2	0.48 (0.73) range: 0-2	0.48 (0.68) range: 0-2	**BIDC & C: U=125, p=0.002 **BIDC & M: U=39, p=0.002 **BIDC&Y: U=86, p=0.006	r=0.49 <sup>M</sup> r =0.57 <sup>L</sup> r=0.46 <sup>M</sup>
Support services:						
Number of support services since TBI	2.04 (0.98) range: 1-4	1.58 (1.07) range: 0-1	2.29 (1.11) range: 1-4	1.17 (0.84) range: 0-3	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	r=0.23 <sup>S</sup> r=0.10 <sup>S</sup> r=0.42 <sup>M</sup>

Table 3.1 (continued): Participant characteristics: mean scores (standard deviations) or proportions (n), and comparison results

Characteristic	BIDC group, n=23	Comparison group			Statistically significant differences	Effect size
		Comparison group, n=19	Maybe group, n=7	Yes group, n=12		
Current number of support services	1.35 (0.49) range: 1-2	0.95 (0.62) range: 0-2	1.29 (0.49) range: 1-2	0.75 (0.62) range: 0-2	*BIDC & C: U=147, p=0.033 BIDC & M: NS **BIDC&Y: U=71.5, p=0.007	r=0.33 <sup>M</sup> r=0.05 <sup>S</sup> r=0.46 <sup>M</sup>
Participants now receiving support services	100% (23)	78.9% (15)	100% (7)	66.7% (8)	BIDC & C: NS (BIDC & M: no difference) *BIDC & Y: $\chi^2=5.68$ , p=0.017	Phi=0.36 <sup>M</sup> (no effect) Phi=0.50 <sup>L</sup>
Homemaking (CIQ-HI)	5.03 (3.41) range: 0-10	6.00 (2.88) range: 0-10	6.71 (1.19) range: 5-8.75	5.58 (3.51) range: 0-10	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	$\eta^2=0.09^M$ $\eta^2=0.13^M$ $\eta^2=0.01^S$
Transportation: driving	26.1% (6)	15.8% (3)	14.3% (1)	16.7% (2)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.13 <sup>S</sup> Phi=0.12 <sup>S</sup> Phi=0.11 <sup>S</sup>
Annual income < \$12,000.00	60.9% (14)	63.2% (12)	57.1% (4)	66.7% (8)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	Phi=0.02 <sup>S</sup> Phi=0.07 <sup>S</sup> Phi=0.07 <sup>S</sup>
General health rating (SF-36 GHQ)	2.41 (0.89) range: 1-4	3.03 (1.16) range: 1-5	2.79 (1.52) range: 1-5	3.17 (0.94) range: 2-5	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	$\eta^2=0.07^M$ $\eta^2=0.02^S$ $\eta^2=0.17^L$
General cognitive impairment (MoCA)	21.26 (4.59) range: 4-27	21.95 (4.03) range: 15-29	20.43 (2.82) range: 16-23	22.83 (4.47) range: 15-27	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	r=0.04 <sup>S</sup> r=0.17 <sup>S</sup> r=0.17 <sup>S</sup>
Frontal systems cognitive impairment (FrSBe)	58.87 (19.27) range: 26-94	58.56 (18.02) range: 24-98 n=18	46.50 (14.56) range: 24-67 n=6	64.58 (16.93) range: 44-98	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	$\eta^2<.001^S$ $\eta^2=0.07^S$ r=0.11 <sup>S</sup>

Table 3.1 (continued): Participant characteristics: mean scores (standard deviations) or proportions (n), and comparison results

Characteristic	BIDC group, n=23	Comparison group			Statistically significant differences	Effect size
		Comparison group, n=19	Maybe group, n=7	Yes group, n=12		
Depression symptoms (SRDS)	0.46 (0.09) range: 0.29- 0.69	0.51 (0.10) range: 0.35- 0.68	0.52 (0.13) range: 0.36- 0.68	0.50 (0.08) range: 0.35- 0.65	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	$\eta^2=0.08^M$ $\eta^2=0.05^S$ $\eta^2=0.03^S$
Participants with depression symptoms	30.4% (7)	57.9% (11)	57.1% (4)	58.3% (7)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	$\Phi=0.28^S$ $\Phi=0.23^S$ $\Phi=0.27^S$
Mobility aid required outside home	34.8% (8)	52.6% (10)	71.4% (5)	33.3% (4)	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	$\Phi=0.13^S$ $\Phi=0.31^M$ $\Phi=0.01^S$
MPAI-4 abilities scale	44.26 (11.08) range: 7-58	48.47 (5.08) range: 32-55	48.0 (2.31) range: 45-51	48.75 (6.25) range: 32-55	BIDC & C: NS BIDC & M: NS BIDC & Y: NS	$r=0.20^S$ $r=0.13^S$ $r=0.22^S$
MPAI-4 adjustment scale	38.96 (10.71) range: 12-54	47.21 (8.53) range: 23-64	45.00 (10.28) range: 23-55	48.50 (7.51) range: 35-64	**BIDC & C: U=91.5, p=0.001 *BIDC & M: U=37, p=0.033 **BIDC & Y: U=54.5, p=0.004	$r=0.50^L$ $r=0.39^M$ $r=0.49^M$

BIDC=brain injury drop-in centre; NS=not statistically significant; C=Comparison group; M=Maybe group; Y=Yes group; TBI=traumatic brain injury; MVA=motor vehicle accident; CIQ-HS=Community Integration Questionnaire, home integration scale; SF-36 GHQ= Short Form-36 Health Survey general health question; MoCA=Montreal Cognitive Assessment; FrSBe=Frontal Systems Behaviour Rating Scale; SRDS=Zung Self-Rating Depression Scale; MPAI-4=Mayo Portland Adaptability Inventory, version 4.

\*  $p < 0.05$ , \*\*  $p < 0.01$

<sup>S</sup> small effect size; <sup>M</sup> medium effect size; <sup>L</sup> large effect size

Table 3.2: Social participation and SQOL: mean scores (standard deviations) and comparison results

Dependent variable	BIDC group, n=23	Comparison group			Statistically significant differences	Effect size
		Comparison group, n=19	Maybe group, n=7	Yes group, n=12		
Social participation						
General social integration (CIQ- SI)	8.83 (1.88)	7.16 (2.17)	7.43 (1.27)	7.00 (2.59)	*BIDC & C: t(40)=2.68, p=0.011 *BIDC & Y: t(33)=2.395, p=.046	$\eta^2=0.15^L$ $\eta^2=0.15^L$
Perceived social supports (SPS)	79.70 (8.58)	76.53 (10.94)	76.57 (9.59)	76.50 (12.06)	BIDC & C: NS BIDC & Y: NS	$\eta^2=0.03^S$ $r=0.06^S$
ASAP diversity	40.78 (10.43)	39.98 (13.88)	40.15 (16.17)	38.29 (13.08)	BIDC & C: NS BIDC & Y: NS	$\eta^2=0.01^S$ $r=0.10^S$
ASAP frequency/intensity	4.38 (0.57)	4.06 (0.45)	4.30 (0.33)	3.93 (0.47)	*BIDC & C: U=134, p=0.034 *BIDC & Y: U=68.5, p=0.014	$r=0.33^M$ $r=0.41^M$
ASAP activities with others	63.27 (16.99)	48.67 (19.98)	47.35 (19.23)	49.44 (21.21)	*BIDC & C: t (40)=2.56, p=0.014 BIDC & Y: NS	$\eta^2=0.14^L$ $r=0.27^S$
ASAP activities outside of home	71.20 (12.11)	59.35 (11.90)	62.82 (12.45)	57.32 (11.62)	**BIDC & C: U=98.5, p=0.002 **BIDC & Y: U=50.5, p=0.002	$r =0.47^M$ $r=0.51^L$
ASAP enjoyment	5.25 (0.52)	4.93 (0.76)	5.35 (0.51)	4.68 (0.78)	BIDC & C: NS *BIDC & Y: t(33)=2.57, p=0.015	$\eta^2=0.06^M$ $\eta^2=0.17^L$
ASAP satisfaction with performance	5.31 (0.58)	4.77 (0.86)	5.09 (0.65)	4.59 (0.94)	*BIDC & C: U=138, p=0.042 *BIDC & Y: U=75, p=0.038	$r=0.31^M$ $r=0.37^M$

Table 3.2 (continued): Social participation and SQOL: mean scores (standard deviations) and comparison results

Dependent variable	BIDC group, n=23	Comparison group			Statistically significant differences	Effect size
		Comparison group, n=19	Maybe group, n=7	Yes group, n=12		
SQOL						
Global quality of life (QOLHQ)	6.83 (2.48)	5.71 (1.97)	6.71 (1.70)	5.12 (1.93)	BIDC & C: NS *BIDC & Y: $t(33)=2.07$ , $p=0.046$	$\eta^2=0.06^M$ $\eta^2=0.12^M$
Happiness (AKHS)	7.43 (2.27)	6.39 (2.05)	8.00 (1.53)	5.46 (1.72)	BIDC & C: NS **BIDC & Y: $U = 61$ , $p=0.007$	$r=0.27^S$ $r=0.46^M$
Loneliness (UCLA-3)	21.39 (7.44)	22.95 (6.76)	23.86 (7.31)	22.42 (6.69)	BIDC & C: NS BIDC & Y: NS	$\eta^2=0.01^S$ $r=0.12^S$

NS=not statistically significant; BIDC=brain injury drop-in centre group; C=Comparison group; Y=Yes group; CIQ-SI=Community Integration Questionnaire, social integration scale; SPS=Social Provisions Scale; ASAP=Adult Subjective Assessment of Participation; SQOL=subjective quality of life; QOLHQ=Quality of Life and Health Questionnaire; AKHS=Abdel-Khalek Happiness Questionnaire; UCLA-LS=UCLA Loneliness Scale.

\*  $p < .05$ , \*\*  $p < .01$

<sup>S</sup> small effect size; <sup>M</sup> medium effect size; <sup>L</sup> large effect size

Table 3.3: Social participation and SQOL: percentages representing clinical significance, and comparison results

Dependent variable	BIDC group, n=23	Comparison group			Statistically significant differences	Effect size
		Comparison group, n=19	Maybe group, n=7	Yes group, n=12		
Social participation						
ASAP enjoyment: participants with a rating at or greater than 'somewhat enjoying' ( $\geq 4$ )	100%	89.5%	100%	83.3%	BIDC & C: NS BIDC & Y: NS	Phi=0.25 <sup>M</sup> Phi=0.34 <sup>M</sup>
ASAP satisfaction: participants with a rating at or greater than 'somewhat satisfied' ( $\geq 4$ )	100%	84.2%	100%	75%	BIDC & C: NS BIDC & Y: NS	Phi=0.31 <sup>M</sup> Phi=0.42 <sup>M</sup>
SQOL						
Global quality of life (QOLHQ): participants with a rating at or greater than the midpoint ( $\geq 5$ )	73.9%	73.7%	85.7%	66.7%	BIDC & C: NS BIDC & Y: NS	Phi=0.003 <sup>S</sup> Phi=0.08 <sup>S</sup>
Happiness (AKHS): participants with a rating at or greater than the midpoint ( $\geq 5$ )	91.3%	78.9%	100%	66.7%	BIDC & C: NS BIDC & Y: NS	Phi=0.18 <sup>S</sup> Phi=0.31 <sup>M</sup>
Loneliness (UCLA-LS): participants with higher loneliness than the cut-off for 'normal experience of loneliness' ( $> 20$ )	52.2%	68.4%	71.4%	66.7%	BIDC & C: NS BIDC & Y: NS	Phi=0.17 <sup>S</sup> Phi=0.14 <sup>S</sup>

NS=not statistically significant; ASAP=Adult Subjective Assessment of Participation; SQOL=subjective quality of life; QOLHQ=Quality of Life and Health Questionnaire; AKHS=Abdel-Khalek Happiness Questionnaire; UCLA-LS=UCLA Loneliness Scale.

<sup>S</sup> small effect size; <sup>M</sup> medium effect size; <sup>L</sup> large effect size

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## **CHAPTER FOUR: FINAL DISCUSSION AND CONCLUSIONS**

### **Overview**

As reported in many outcome studies and summarized in a recent systematic review<sup>1</sup>, TBI has been found to have long-term, adverse effects on community integration or participation and quality of life. This includes two areas of particular concern for individuals with TBI: social participation and SQOL. It is, therefore, important not only to better understand which interventions might assist in improving social participation and SQOL, but also to better understand the nature of the relationship between social participation and SQOL. Our review of the literature revealed that, to date, the majority of TBI intervention studies have been concerned with the acute and inpatient rehabilitation stages of TBI rehabilitation. Furthermore, a number of studies have investigated clinical interventions for the community phase of rehabilitation<sup>2</sup>. However, we found that only a few researchers have investigated non-clinical support service interventions. We also found that only a few studies have explored the relationship between social participation and SQOL for individuals with TBI.

This thesis reported on an exploratory study of social participation, SQOL, and attendance at brain injury drop-in centres (BIDCs) for community-dwelling adults with moderate to severe TBI. The correlational study (Chapter Two) examined the association between social participation and SQOL. The comparison study (Chapter Three) investigated differences in social participation and SQOL between a group of individuals who attended BIDCs and a group of individuals who did not attend BIDCs but who had been assessed as potentially benefitting from attending. Social participation was measured in terms of general social integration, perceived social supports, and dimensions of participation in social and leisure activity (diversity, frequency/intensity, proportion of activities performed outside of the

home, proportion of activities performed with others, satisfaction with performance and enjoyment). SQOL was measured in terms of global quality of life, presence of happiness, and absence of loneliness. Each of the study's three hypotheses were generally supported, although, considering the exploratory nature of this research project and its limitations, the conclusions must be considered tentative. Findings are in support of, and provide direction for, further research into social participation, SQOL and BIDs for individuals with TBI.

### **Summary of Findings**

#### **Correlational study**

The results of the correlational study support the hypothesis that there is an association between SQOL and social participation for community-dwelling adults with moderate to severe TBI. Of interest was that statistically significant correlations were found between SQOL and the more qualitative (social and subjective) dimensions of social participation, and not between SQOL and the more quantitative or objective aspects of social participation. Specifically, it was found that higher levels of happiness and global quality of life are associated with higher levels of enjoyment, satisfaction with performance, and proportion of activities performed with others. Lower levels of loneliness were found to be associated with higher levels of perceived social supports and higher levels of general social integration. There were no statistically significant correlations found between SQOL and diversity, frequency/intensity, or proportion of activities performed outside of home.

We found little in the TBI literature with which to compare our correlational findings. To date, most TBI studies that have explored SQOL have focused on the cognitive appraisal of SQOL as measured by life satisfaction. There are few TBI studies that have investigated the affective appraisal of SQOL including loneliness and happiness. However, as is discussed in

Chapter Two, our correlational results are consistent with the few TBI and non-TBI studies that have measured similar constructs as our study, and add to these findings. Further, our project is one of the first TBI studies to consider the multi-faceted nature of social participation, thus investigating the association of both objective and subjective aspects of social participation and SQOL.

### **Comparison study**

The results of the comparison study provide tentative support for the hypotheses that, for community-dwelling adults with moderate to severe TBI, individuals who attend BIDs have higher social participation and higher SQOL than individuals who do not attend BIDs but who have been identified as potentially benefitting from attending. Of interest was that we found the Comparison group to be comprised of two distinct subgroups, which we termed the Yes group and the Maybe group. The Yes group were individuals who stated that yes, they would like to attend a BID, but were not attending because they had not yet heard of a BID or experienced contextual barriers to attending. The Maybe group was comprised of individuals who stated that they might attend a BID but, for the most part, reported being too busy to attend. When we broke down the Comparison group into the Maybe group and Yes group, we found that the differences between the BID group and Comparison group were mainly between the BID group and Yes group. The only measures for which there were no statistically significant differences between the BID group and Comparison group or between the BID group and Yes group were loneliness, perceived social support, and diversity of social and leisure activities.

The comparison findings suggest that attendance at a BID benefits many areas of social participation and SQOL. This suggestion is further supported by our descriptive findings

relating to involvement in a B IDC: the individuals in the B IDC group provided a high mean rating of the importance of a B IDC in their lives, reported that B IDC activities comprise a large proportion of their current social and leisure activities, and stated that they expected that they would experience a negative impact on many aspects of their social participation and SQOL if they were to no longer attend a B IDC. Furthermore, there is some consistency between our findings and reports in the literature of other types of day programs and community-based leisure programs in terms of the positive influence of attendance on various aspects of social participation and SQOL<sup>3,4</sup>.

When considering the information that we collected on participant characteristics, we found only one factor that might help explain why the Maybe group was more similar to the B IDC group than to the Yes group in terms of social participation and SQOL. This factor was current involvement in support services. The B IDC and Maybe groups had similar levels of involvement in support services, with both groups higher than the Yes group. It may be that a number of different types of support services, not just B IDCs, provide benefits in terms of social participation and SQOL. However, B IDCs may offer advantages to other types of support services in terms of cost effectiveness, comprehensiveness of the social participation activities offered, and opportunities to empower the participants through membership and volunteer activities and linkages with the community.

### **Clinical Significance**

The above summarized findings take into consideration statistical significance, which is concerned with whether or not the obtained results are simply a chance finding<sup>5</sup>. However, clinical significance is also important<sup>6</sup> and therefore warrants further discussion. Clinical significance speaks to the efficacy of a treatment, that is, the benefits of the treatment to

individuals or its ability to make a difference in peoples' lives<sup>5</sup>. One criterion for clinical significance, or practical importance, is the statistically reliable magnitude of results<sup>7</sup>. In our study, for both the correlational and comparison studies, we found the effect sizes to be medium or large. Another criterion for clinical significance is the clinical relevance of scores in comparison to the range of normal functioning, for example by considering the percentage of participants whose scores fall beyond a specific cut-off point<sup>7</sup>. These percentages can be analysed for statistically significant differences between groups or simply be used descriptively to augment the results of between-group comparisons of mean scores<sup>7</sup>. As is shown in table 3.3 in Chapter Three, we were able to identify clinically relevant cut-off points for a number of our social participation and SQOL measures. These cut-off points generally represent the division between less desirable and more desirable scores. Although we found no statistically significant differences between groups for the percentage of individuals on either side of the cut-off score for each dependent variable, the findings were of interest descriptively. With the exception of loneliness (which is similar across groups), there is a pattern of the B IDC group and Maybe group having the highest proportions of individuals with the more desirable scores, and the Yes group having the lowest proportions. This pattern is similar to our findings when examining differences in mean scores.

As another indication of clinical significance, it is interesting to compare our findings with the results of other studies. Such a comparison is possible for four of our measures.

**General community integration.** As shown in table 4.1, the mean CIQ-SI scores for the Maybe group and Yes group appear to fall within the range of mean scores for individuals with TBI<sup>8-11</sup>, whereas our B IDC group's mean score is more similar to that of individuals without disability<sup>8,10</sup>. Furthermore, when comparing our results to a study that investigated a six-month

program of community-based group leisure activities<sup>3</sup>, our B IDC group's mean CIQ-SI score is more similar to the *post-test* scores for the study's 'sustained activity' group, whereas our Maybe and Yes groups' mean scores are more similar to the *pre-test* score for the 'sustained activity' group and to both the pre- and post- test scores of the 'non sustained activity' group. Altogether, these findings suggest that the outcome of attending a B IDC may be similar to attending other programs that offer group leisure activities, and that attendance in such programs may be associated with a CIQ-SI score that is within the range of normal functioning.

**Happiness.** As shown in table 4.1, it appears that, on average, the individuals within our B IDC group and Maybe group have a similar or higher level of happiness as individuals without disabilities, as represented by groups of university undergraduates and government employees<sup>12</sup>. We also note that almost all of the individuals in our B IDC group (91.3%) and all of the individuals in our Maybe group rated themselves at or above the midpoint on the AKHS. These results appear consistent with the finding that most people, including individuals with disabilities, report being relatively happy<sup>13</sup>. In contrast, our Yes group reported a lower mean rating of happiness than the non-disabled groups, and only 66% of individuals in this group rated themselves at or above midpoint on the happiness scale. Thus, it may be that individuals who attend B IDCs have a level of happiness that is within a normal range of functioning; this might also be the case for individuals who are involved in other types of support services as represented by our Maybe group.

**Global quality of life.** As shown in table 4.1, it is clear that the mean ratings of global quality of life for our Yes group are below ratings of other groups with TBI as well as below a range of ratings for individuals without disability. Our B IDC group and Maybe group have mean ratings similar to other groups of individuals with TBI<sup>14-16</sup>, and this may also fall within

the range of ratings for individuals without disability<sup>14,15</sup>. However, using global quality of life measures other than numeric rating scales, a number of researchers have found individuals with TBI to have a lower SQOL than individuals without disability<sup>17-20</sup>.

**Perceived social supports.** Mean ratings for perceived social supports were similar across the groups in our study but it is difficult to know the clinical relevance of these ratings. There is no published, clinically-significant cut-off point for the Social Provisions Scale (SPS). As shown in table 4.1, the mean SPS scores in our study appear somewhat lower than for a group of college students, teachers and nurses<sup>21</sup> and a group of university students<sup>22</sup>, although somewhat higher than for a group of community-dwelling adults with TBI<sup>19</sup>.

**Summary.** In summary, the clinically significant findings augment the statistically significant findings of our research project. The clinically significant findings suggest that associations found between social participation and SQOL, and the differences found between groups on the dependent variables, are more than just trivial in size. Furthermore, specific to the comparison study, the clinically significant findings suggest that, for a number of social participation and SQOL measures, individuals within the BDC group, and perhaps also the Maybe group but not the Yes group, might approximate a non-disabled population.

### **Concluding discussion with future directions**

#### **Limitations**

As has been discussed in Chapters Two and Three, there are several limitations that reduce both the internal and external validity of our research project. This includes an inflated risk of Type I error with multiple analyses, although we adjusted for this by setting the level of significance at 0.01, and the possibility of Type II errors. There may also have been measurement errors despite our selection of reliable and valid instruments and use of only two

assessors who were well-qualified in administering tests and measures and who made every attempt to ensure consistency in data collection. We also used multiple measures to capture a comprehensive picture of social participation and SQOL outcomes.

External validity was compromised by the cross-sectional design and sampling bias. The participants involved in the study may not represent the larger population of individuals with TBI who attend or who do not attend BIDs. Based on information provided by the BIDs, it is estimated that our BID group was comprised of only about 13.5% of the individuals with TBI who attend a BID within the Lower Mainland and Fraser Valley. Individuals who did not participate in the study either did not meet the eligibility criteria or did not volunteer to participate. We do not have information about participant characteristics for the individuals who did not participate. Further, all of the Comparison group participants were known by a TBI service provider, and therefore we missed out on individuals who are not linked to any TBI service providers. This may not provide a good representation of individuals who may benefit from attending a BID. However, despite the limitations in generalizing our findings, the results do represent the individuals who participated and therefore may be of value specifically to them, the BIDs that they attend and the funders of these BIDs.

The comparison study failed to show differences between groups for loneliness and perceived social supports. This was surprising considering the descriptive finding that many individuals in the BID group reported that, if they did not attend a BID, they would lose friends and social contacts and they would become lonely. It may be that the instruments that we selected did not adequately measure loneliness and perceived social supports, at least not in terms of how loneliness or perceived social supports may be influenced by attendance at a BID.

Despite its limitations, this research project contributes to the literature on social participation and SQOL for individuals with TBI and provides the first systematic investigation of BIDs. This investigation represents an early stage of clinical research, considered an ‘exploratory clinical study’, with the purpose of providing a first step in investigating a treatment innovation<sup>23,24</sup>. Exploratory designs are important sources of research evidence<sup>25</sup>, and more rigorous clinical trials cannot be performed without first investigating and developing treatments using exploratory designs<sup>23</sup>.

### **Future directions for research**

The results of this investigation provide direction for future research. In following the maturational phases of neurorehabilitation research<sup>23,26</sup>, the next step in researching BIDs would be to conduct a within-subject, repeated measures experimental design, to be followed by a randomized, comparison group design. However, in considering the difficulties in TBI research in using longitudinal studies<sup>27</sup> and randomized control trials<sup>25</sup>, including challenges in creating appropriate placebo or comparison treatments<sup>26</sup> and selecting a representative sample of this highly heterogeneous population<sup>28</sup>, it is unlikely that these more rigorous designs would be feasible in studying BIDs.

Research methodologies other than randomized clinical trials may be better suited to studying community-based interventions and supports for individuals with brain injuries<sup>29</sup>. Qualitative investigation, which is much better suited to studying subjective experiences<sup>30</sup>, would be well suited to gaining an in-depth understanding of loneliness<sup>19</sup> and other aspects of SQOL, as well as the subjective dimensions of social participation. This could include exploring the meaning of time use and activity for individuals with TBI, for example, to augment recent qualitative studies that have investigated the experience of participation in daily life<sup>31</sup> and the

experience of feeling well<sup>30</sup>. Other topics of interest arising from our study are barriers to participation, and the issue of feeling ‘busy’ as reported by individuals in the Maybe group.

Quantitative and qualitative research designs would be appropriate in investigating the perspectives of family members and caregivers, for example to explore whether attendance at a B IDC by the person with TBI contributes to a reduced burden of care for others. Family members, caregivers, friends and B IDC staff members could also provide valuable information as to any changes they have observed in the person with TBI as might relate to their attendance at a B IDC. Beyond research designs that focus on individual experiences, a survey design would elicit descriptive information about B IDCs. Economic and health services research would address issues such as the cost-effectiveness of B IDCs in comparison to therapies and other support service interventions.

### **Clinical recommendations**

Considering the association that we found between social participation and SQOL, it may be that, by enhancing social participation for individuals with TBI, rehabilitation interventions can in turn benefit SQOL. Based on the findings of our correlational study, the most important aspects of social participation may be the social and subjective dimensions, including enjoyment, satisfaction with performance and performing activities with others (found to be associated with happiness and global quality of life) and perceived social supports (associated with loneliness). Based on the results of our comparison study, a B IDC may not benefit perceived social supports but may enhance enjoyment, satisfaction with performance and performing activities with others, as well as happiness and global quality of life. It may be of value to the agencies/ staff who operate B IDCs to consider that, by assisting individuals with moderate to severe TBI to perform more of their social and leisure activities with others and to

address their preferences, thereby aiming to improve enjoyment and satisfaction with performance for social and leisure activities, there may also be the potential to improve happiness and global QOL.

It may be of value to other clinicians and service providers to consider that, where there are goals of improved happiness and global quality of life, it may be more beneficial to focus on the more qualitative (social and subjective) dimensions of participation rather than just aiming to increase diversity and frequency/intensity of activities. This may include consideration of a BIDC as a support service intervention to address the social and subjective dimensions of social participation.

Findings may be of particular interest to occupational therapists, health care professionals who are concerned with promoting health and well-being through occupation<sup>32</sup>. For occupational therapists, the traditional view of occupation is in terms of the categories of work, self-care and leisure. However, it may be that these categories of occupation are not as important as the meanings of occupation, for example the meanings associated with positive experiences and engaging with others. Our participants demonstrated that even when unemployed and, for many, with little involvement in homemaking activities, they had the capacity to have high levels of SQOL and that this was associated in particular with high levels of subjective experience in social participation including participating with others. These findings resonate with other researchers who have considered the importance of occupation in terms of meaning rather than activity categories. For example, Hammell<sup>33</sup> proposed that occupation might be better described in terms of doing, being, belonging and becoming, rather than as categories of self-care, productivity and leisure. More recently, Hammell<sup>34</sup> described the ways in which individuals experience occupation ‘...as restorative, as ways to connect and

contribute, as engagement in doing, and as ways to connect the past and present to a hopeful future...’ (p. 107). Hammell reviewed that associations have been found between quality of life and personally meaningful activity<sup>34</sup>. Specific to individuals with TBI, Ylvisaker<sup>35</sup> found that participation in personally meaningful projects resulted in improved self-esteem and sense of competence and reduced anxiety.

### **Summary**

This study investigated a novel and innovative community-based support service for adults with TBI, the BIDC. Findings provide tentative support that attendance at BIDCs may benefit social participation and SQOL. This investigation also provides support for there being an association between SQOL and the more qualitative (social and subjective) dimensions of social participation. Despite this investigation being exploratory in nature, it provides a foundation for more rigorous quantitative investigation of the effectiveness and efficacy of BIDCs as well as direction for more feasible research designs including qualitative investigation. Results of our study also indicate that further research may be warranted that focuses on other long term support services interventions for individuals with TBI, considering that other support services may also benefit social participation and SQOL. Results from this study and subsequent investigations will be of value for service providers and funders, individuals with TBI, and their families and caregivers.

Table 4.1: Clinical significance in relation to other published studies: means (standard deviations)

Dependent variable	Current study	Other published studies (community samples)	
		TBI	No disability
General social integration (CIQ-SI)	BIDC group: 8.83 (1.88)	TBI model systems data <sup>8</sup> : 8.10 (NA) (n=73 men)	Willer et al., 1993 <sup>8</sup> : 8.97 (NA) (n=105 men)
	Maybe group: 7.43 (1.27)	8.95 (NA) (n=21 women)	9.39 (NA) (n=132 women)
	Yes group: 7.00 (2.59)	Willer et al., 1993 <sup>8</sup> : 6.46 (NA) (n=241 men) 7.44 (NA) (n=111 women)	Corrigan et al., 1995 <sup>10</sup> (n=104): 8.33 (2.08)
		Corrigan et al., 1995 <sup>10</sup> (n=46): 6.80 (2.01)	
		Burleigh et al. 1998 <sup>11</sup> (n=30): 7.57 (2.11)	
		Wood et al., 2008 <sup>9</sup> (n=80): 7.63 (2.62)	
		Douglas et al., 2006 <sup>3</sup> (leisure group): SA (n=6): Pre-test: 7.2 (2.6) Post-test: 9.3 (1.9)	
		NSA (n=6): Pre-test: 6.7 ( 2.7) Post-test: 7.5 ( 2.0)	

Table 4.1 (continued): Clinical significance in relation to other published studies: means (standard deviations)

Dependent variable	Current study	Other published studies (community samples)	
		TBI	No disability
Happiness (AKHS)	BIDC group: 7.43 (2.27) Maybe group: 8.00 (1.53) Yes group: 5.46 (1.72)		Abdel-Khalek, 2006 <sup>12</sup> : Government employees: 7.00 (2.01) (n=227 men) 6.34 (2.47) (n=210 women) University undergraduates: 7.36 (2.09) (n=250 men) 6.40 (2.40) (n=253 women)
Global quality of life (numeric rating scale, equivalent to a scale of 0-10)	BIDC group: 6.83 (2.48) Maybe group: 6.71(1.70) Yes group: 5.12 (1.93)	Kreuter et al., 1998 <sup>14</sup> : With partner (n=53): 6.69 (2.35) Single (n=39): 5.88 (2.46)  Dawson et al., 2000 <sup>15</sup> : Moderate TBI (n=8): 7.8 (2.0) Severe TBI (n=16): 6.2 (1.8)  Steadman-Pare et al., 2001 <sup>16</sup> (n=275): 7.1 (2.2)	Kreuter et al., 1998 <sup>14</sup> : With partner (n=155): 7.42 (1.97) Single (n=109): 6.23 (2.13)  Dawson et al., 2000 <sup>15</sup> (n=15): 7.4 (2.2)
Perceived social supports (SPS)	BIDC group: 79.70 (8.58) Maybe group: 76.57 (9.59) Yes group: 76.50 (12.06)	Kalpakjian et al., 2004 <sup>19</sup> (n=50): 72.92 ( 12.75)	Cutrona and Russell, 1987 <sup>21</sup> (n= 1,193 college students, teachers, nurses): 82.45 ( 9.89)  Dolbier and Steinhardt, 2000 <sup>22</sup> (n=120 university students): 84.8 (8.7)

CIQ-SI=Community Integration Questionnaire social integration scale; BIDC=brain injury drop-in centre; NA=information not available; TBI=traumatic brain injury; SA=sustained change in activity; NSA=no sustained change in activity; AKHS=Abdel-Khalek Happiness Scale; SPS=Social Provisions Scale

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## **Appendix A: Ethics approvals**

1. UBC Behavioural Research Ethics Board, Certificate of Approval – Full Board, March 26, 2009
2. Vancouver Coastal Health Research Institute (Vancouver Community), Certificate of Approval, May 7, 2009
3. Vancouver Coastal Health Research Institute (Coastal), Final Certificate of Approval, May 27, 2009
4. UBC Behavioural Research Ethics Board, Certificate of Approval, Minimal Risk Amendment, September 17, 2009
5. Vancouver Coastal Health Research Institute (approval to conduct research at the GF Strong Rehab Centre), Final Certificate of Approval, October 20, 2009



The University of British Columbia  
Office of Research Services  
Behavioural Research Ethics Board  
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

## CERTIFICATE OF APPROVAL - FULL BOARD

<b>PRINCIPAL INVESTIGATOR:</b> Tal Jarus	<b>INSTITUTION / DEPARTMENT:</b> UBC/Medicine, Faculty of/Occupational Science and Occupational Therapy	<b>UBC BREB NUMBER:</b> H09-00042
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
<b>Institution</b>	<b>Site</b>	
Vancouver Coastal Health (VCHRI/VCHA)	Powell River/Sunshine Coast	
Vancouver Coastal Health (VCHRI/VCHA)	North Shore Community (including Horseshoe Bay and up to Lions Bay)	
Vancouver Coastal Health (VCHRI/VCHA)	Sea to Sky Corridor (including Bella Bella, Bella Coola, Squamish, Whistler and Pemberton)	
Vancouver Coastal Health (VCHRI/VCHA)	Vancouver Community	
Other locations where the research will be conducted: Vancouver Headway brain injury drop-in centre; Coquitlam Headway brain injury drop-in centre; Semiahmoo House Surrey brain injury drop-in centre; Abbotsford brain injury drop-in centre; Chilliwack brain injury drop-in centres; subjects' homes; coffee shops; UBC Rehab Research Lab (located at the GF Strong Rehabilitation Centre).		
<b>CO-INVESTIGATOR(S):</b> Anita M. Hubley Alison May McLean		
<b>SPONSORING AGENCIES:</b> UBC College of Health Disciplines		
<b>PROJECT TITLE:</b> The effect of attendance in structured social and leisure programs on social participation and quality of life for adults with traumatic brain injury.		
<b>REB MEETING DATE:</b> March 26, 2009	<b>CERTIFICATE EXPIRY DATE:</b> March 26, 2010	
<b>DOCUMENTS INCLUDED IN THIS APPROVAL:</b>		<b>DATE APPROVED:</b> April 3, 2009
<b>Document Name</b>	<b>Version</b>	<b>Date</b>
<b>Protocol:</b>		
Research Proposal	N/A	January 27, 2009
<b>Consent Forms:</b>		
Consent form	1.0	March 11, 2009
<b>Investigator Brochures:</b>		
Recruitment poster	2.0	March 29, 2009
<b>Questionnaire, Questionnaire Cover Letter, Tests:</b>		
Subject Characteristics (study-specific questionnaire) (in development)	1.0	March 11, 2009
Quality of Life and Health Questionnaire (standardized and validated)	1.0	December 1, 1995
Mayo-Portland Adaptability Inventory (standardized and validated)	4.0	March 31, 2003
UCLA Loneliness Scale (standardized and validated)	3.0	January 1, 1980
BIDC attendance patterns, intervention group (study-specific questionnaire) (in development)	1.0	March 11, 2009
Frontal Systems Behavioral Rating (FrSBe) (standardized and validated)	1.0	January 1, 2001
General Health Question from SF-36 (standardized and validated)	2.0	January 1, 1996
Adult Subjective Assessment of Participation (ASAP) (standardized and validated)	1.0	July 29, 2008
Community Integration Questionnaire (standardized and validated)	1.0	January 1, 1991
Abdel-Khalek single-item Happiness Scale (standardized and validated)	1.0	January 1, 2006
Zung Self-Rating Depression Scale (standardized and validated)	1.0	February 1, 1997
Social Provisions Scale (standardized and validated)	1.0	January 1, 1987
BIDC attendance patterns, comparison group (study-specific questionnaire) (in	1.0	March 11, 2009

http://www.ubc.ca/~offices/ORS/UBC/BREB/FORMS/701150N005ED/FormSheet.html 4/3/2009



**Vancouver Coastal Health Research Institute (Vancouver Community)**

**Research Study**

**CERTIFICATE OF APPROVAL**

<p>INVESTIGATOR(S):  <b>JARUS, Tal - Principal Investigator</b>  <b>McLean, Alison - Co-investigator</b>  <b>UBC - Dept. of Occupational Science and Occupational Therapy</b>  <b>T-325, 2211 Wesbrook Mall, Vancouver, BC V6T 2B5</b></p>
<p>TITLE of PROJECT:  <b>The effect of attendance in structured, community-based social and leisure programs on social participation and quality of life for adults with traumatic brain injury.</b></p>
<p><b>TERM:</b> Approval has been granted until <b>March 26, 2010</b></p>
<p>APPROVAL TO CONDUCT RESEARCH AT VANCOUVER COMMUNITY SITES OF VANCOUVER COASTAL HEALTH RESEARCH INSTITUTE IS BASED ON:</p> <p><input checked="" type="checkbox"/> Research Ethics Review and Approval by (name of REB): <b>UBC - BREB</b>  Application No: <b>H09-00042</b> Approval Date (y/m/d): <b>2009-04-03</b></p> <p><input checked="" type="checkbox"/> VCH Confidentiality Acknowledgement for Access to Personal Information</p> <p><input checked="" type="checkbox"/> Funding Source: <b>UBC College of Health Disciplines</b></p> <p><input checked="" type="checkbox"/> Approval to Conduct Research at VCHRI: Approval No: <b>VC09-033</b>  Approved Sites (list):</p> <p><input checked="" type="checkbox"/> <b>AOA Programs at:</b></p> <p><input checked="" type="checkbox"/> <b>- South Community Health Office</b></p> <p><input checked="" type="checkbox"/> <b>- Raven Song Community Health Centre</b></p> <p><input checked="" type="checkbox"/> <b>- Evergreen Community Health Centre</b></p>

✓  


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**Val Munroe, RN, MS**  
Director, Vancouver Community  
Assistant Director, VCHRI – VC

Date: 2009-05-07

Copy: Principal Investigator  
Vancouver Community  
File



May 27, 2009

Dr. Tal Jarus  
Department of Occupational Science & Occupational Therapy  
T325 - 2211 Wesbrook Mall  
Vancouver, BC, V6T 2B5

**Vancouver Coastal Health Authority Research Study #CS09-070**

**FINAL CERTIFICATE OF APPROVAL**

**TITLE:** *The effect of attendance in structured social and leisure programs on social participation and quality of life for adults with traumatic brain injury.*

**Sponsor:** UBC College of Health Disciplines

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This is to inform you that your project has been approved and can start immediately. Approval has been granted until **March 26, 2010** based on the following:

1. UBC-BREB CERTIFICATE OF APPROVAL # H09-00042
2. VCHA Clinical Trials Administration Office Approval

Yours truly,

for:  
Dr. Robert McMaster  
Interim Vice-President Research



The University of British Columbia  
Office of Research Services  
Behavioural Research Ethics Board  
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

## CERTIFICATE OF APPROVAL - MINIMAL RISK AMENDMENT

<b>PRINCIPAL INVESTIGATOR:</b> Tal Jarus	<b>DEPARTMENT:</b> UBC/Medicine, Faculty of Occupational Science and Occupational Therapy	<b>UBC BREB NUMBER:</b> H09-00042
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
<small>Institution</small>	<small>Site</small>	
Vancouver Coastal Health (VCHRI/VCHA)	Powell River/Sunshine Coast	
Vancouver Coastal Health (VCHRI/VCHA)	Lions Gate Hospital	
Vancouver Coastal Health (VCHRI/VCHA)	GF Strong Rehabilitation Centre	
Vancouver Coastal Health (VCHRI/VCHA)	North Shore Community (including Horseshoe Bay and up to Lions Bay)	
Vancouver Coastal Health (VCHRI/VCHA)	Richmond Health Services	
Vancouver Coastal Health (VCHRI/VCHA)	Sea to Sky Corridor (including Bella Bella, Bella Coola, Squamish, Whistler and Pemberton)	
Vancouver Coastal Health (VCHRI/VCHA)	Vancouver Community	
<small>Other locations where the research will be conducted: Vancouver Headway brain injury drop-in centre; Coquitlam Headway brain injury drop-in centre; Semiahmoo House Surrey brain injury drop-in centre; Abbotsford brain injury drop-in centre; Chilliwack brain injury drop-in centres; subjects' homes; coffee shops; UBC Rehab Research Lab (located at the GF Strong Rehabilitation Centre). Added Aug 21, 2009: Lower Mainland Brain Injury Association drop-in centre; Hope Leisure Centre; quiet spaces in public libraries and recreation centres</small>		
<b>CO-INVESTIGATOR(S):</b> Anita M. Hubley Alison May McLean		
<b>SPONSORING AGENCIES:</b> UBC College of Health Disciplines		
<b>PROJECT TITLE:</b> The effect of attendance in structured social and leisure programs on social participation and quality of life for adults with traumatic brain injury.		

**Expiry Date - Approval of an amendment does not change the expiry date on the current UBC BREB approval of this study. An application for renewal is required on or before: March 26, 2010**

<b>AMENDMENT(S):</b>	<b>AMENDMENT APPROVAL DATE:</b> September 17, 2009	
<small>Document Name</small>	<small>Version</small>	<small>Date</small>
<b>Letter of Initial Contact:</b> Letter of Initial Contact v. 3	3.0	August 21, 2009
<b>Other:</b> (not applicable)		
The amendment(s) and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
<p>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</p> <p>Dr. M. Judith Lynam, Chair Dr. Ken Craig, Chair Dr. Jim Rupert, Associate Chair Dr. Laurie Ford, Associate Chair Dr. Anita Ho, Associate Chair</p>		



October 20, 2009

Dr. T. Jarus  
School of Rehab Sciences  
T325 – 2211 Wesbrook Mall  
Vancouver, B.C.  
V6T 2B5

**Vancouver Coastal Health Authority Research Study #V09-0299**

**FINAL CERTIFICATE OF APPROVAL**

**TITLE:** The effect of attendance in structured social and leisure programs on social participation and quality of life for adults with traumatic brain injury.

**Sponsor:** UBC College of Health Disciplines

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This is to inform you that your project has been approved and can start immediately. Approval has been granted until **March 26, 2010** based on the following:

1. UBC Ethics Committee Certificate of Approval #H09-00042
2. VCHA Clinical Trials Administration Office Approval

Yours truly,

For:  
Dr. Robert McMaster  
Interim Vice-President Research

## Appendix B: Participant consent form



THE UNIVERSITY OF BRITISH COLUMBIA

### CONSENT FORM

**The effect of attendance in structured, community-based social and leisure programs on social participation and quality of life for adults with traumatic brain injury.**

**Principal Investigator:**

Dr. Tal Jarus, PhD, OT, Dept. of Occupational Science & Occupational Therapy, UBC

**Co-Investigator:**

Alison McLean, OT, Master of Science Program in Rehabilitation Sciences, UBC

\* this study is part of the Co-Investigator's graduate thesis

**Contact number for study information and questions:** 604-822-7412

**Sponsor:** This study is funded by the Vancouver Foundation's Cedar Lodge endowment fund, through the UBC College of Health Disciplines.

**Purpose:** You are being invited to participate in this study because you are between 19 and 65 years of age, have a traumatic brain injury, and are living in the community. The purpose of this study is to investigate social participation and quality of life among individuals with traumatic brain injury.

**Who can participate in this study?**

- between 19 and 65 years of age and are living in the community
- have a moderate to severe traumatic brain injury (TBI) at least 1 year ago
- fluent in English and do not have aphasia
- able to complete questionnaires
- able to provide informed consent

**Who can not participate in this study?**

- currently involved in any formal rehabilitation programs (e.g., physiotherapy, occupational therapy, speech-language therapy, counselling)
- have a psychiatric diagnosis other than mild to moderate depression
- currently working

**Study procedures: What does the study involve?** You will complete a number of questionnaires. There will also be some assessment of your memory and other cognitive abilities. This will take about 2.5 to 3 hours total, over 2 sessions. This can be split into 3 sessions if you would prefer. You are welcome to have a friend, family member, or caregiver with you. Throughout, a researcher (who is an occupational therapist) will be with you, to explain the questionnaires. The researcher will read the first questionnaire to you. If you would like, the researcher can also read out the items from the other questionnaires.

The questionnaires will focus on the following 3 areas:

1. **General Information.** This consists of information about your age, rehabilitation supports, living situation, educational status, work status at the time of your injury, income, and some information about your knowledge of and interest in brain injury drop-in centres. There will also be 2 questionnaires about your cognitive abilities, 1 about your general mood, and 1 about your general health status.
2. **Social Participation.** This consists of information about the types of activities you participate in, your satisfaction and enjoyment of these activities, and information about the social supports (relationships) that you have in your life.
3. **Quality of Life.** This consists of information about how you feel about your well-being. This consists of well-being as it relates to your physical symptoms, your outlook on life, your daily activities, your overall rating of your quality of life, and your level of happiness and loneliness.

You can arrange to meet with the researcher at a brain injury drop-in centre, at the research lab at the GF Strong Rehab Centre, or another location where you will feel comfortable. This might be at your home or at a coffee shop, depending on what you and the researcher both agree would be safe for you both, and provide privacy for you.

**Potential risks:** After you have filled in the questionnaire about your mood, then if the researcher is concerned about how you are feeling, the researcher will discuss this with you. If it is felt that there are concerns that your mood is so low that your safety may be at risk, then the researcher may discuss this with one of your health care providers.

There is a chance that you may become tired, or have difficulties concentrating. The researcher will watch out for this, and you can tell the researcher at any time if you feel too tired or if you are having too much difficulty concentrating. You can then take a short break, or another session can be scheduled to finish off the questionnaires.

**Potential benefits:** There is no direct benefit to you. However, you may gain some increased understanding of your current status. You may also feel you benefit in knowing that the information from this study may lead to improvements in long term supports for individuals with traumatic brain injury.

**Remuneration/Compensation:** In order to defray the costs of any inconvenience to you, and/or transportation costs, each participant will receive an honorarium of \$25.00.

### **What If you decide to participate or withdraw your consent to participate?**

- Your participation is voluntary. If you decide to take part or not take part in the study or withdraw at any time in the future, there will be no penalty or loss of benefits to which you are otherwise entitled, and your future health care will not be affected. You do not need to provide any reasons if you do not participate in the study. You may wish to discuss this consent form with others before you decide to participate.
- The study investigators may decide to discontinue the study at any time, or withdraw you from the study at any time, if they feel that it is in your best interest.
- If you choose to enter the study and then decide to withdraw at a later time, all data collected about you during your enrollment in the study will be retained for analysis. This data cannot be destroyed for a minimum of 5 years.

### **Confidentiality:**

Your confidentiality will be respected. Your identity will be kept strictly confidential. All documents will be identified only by a code number and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study. You will not be identified by name on any records kept on computer files. The computer files will be password protected. The computer will be kept in a locked room at UBC in the Department of Occupational Science and Occupational Therapy, and a back-up memory stick will be kept in a locked cabinet in this room. All data will be destroyed after 5 years. No information that discloses your identity will be released or published.

### **Contact for information:**

If you have any questions, or desire further information with respect to this study, you can contact Dr. Tal Jarus or Alison McLean at 604-822-7412.

**Contact for concerns about the rights of research subjects:** If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, contact the 'Research Subject Information Line' at the UBC Office of Research Services at 604-822-8598, or by e-mail at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

### **Consent:**

Your participation in this study is entirely voluntary and you may refuse to participate or to withdraw from the study at any time without jeopardy to your health care services.

Your signature on the next page indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study.

**CONSENT FORM – signature page**

**The effect of attendance in structured, community-based social and leisure programs on social participation and quality of life for adults with traumatic brain injury.**

Your signature below indicates that you have received a copy of this study's consent form for your own records. Your signature indicates that you consent to participate in this study.

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Printed Name of Subject	Subject Signature	Date
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Printed Name of Principal Investigator/Designated Representative	Signature of Principal Investigator/Designated Representative	Date
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### Appendix C: Measures used – details about each measure

Measure	Details
<b>Participant Characteristics</b>	
Participant characteristics questionnaire	<p><u>Time to complete:</u> 10 to 15 minutes.</p> <p><u>Description:</u> This self-report questionnaire was developed specifically for this study. It captured demographic information as well as diagnostic and rehabilitation history relating to the participant’s traumatic brain injury (TBI).</p>
<p>General Health Question from the Medical Outcomes Short Form-36 Health Survey (SF-36 GHQ)<sup>1</sup></p>	<p><u>Time to complete:</u> less than 5 minutes.</p> <p><u>Description:</u> This single question, self-report item requires the participant to rate his/her overall health on a 5-point scale: ‘excellent’ (rated 1), ‘very good’ (rated 2), ‘good’ (rated 3), ‘fair’ (rated 4) and ‘poor’ (rated 5)<sup>2</sup>.</p> <p><u>Psychometrics and use with individuals with TBI:</u> A number of studies have found good test-retest reliability for the SF-36 GHQ. For example, in a study involving two groups of individuals at a medical outpatient clinics, the test-retest reliability was <math>r=0.86</math> and <math>r=0.88</math> over an interval of one to two weeks<sup>3</sup>. Test-retest reliability for a group of individuals with stroke, with an interval of approximately three weeks, was <math>r=0.81</math><sup>4</sup>.</p> <p>The full SF-36 has been found to be able to differentiate between individuals with TBI and people without a disability<sup>5</sup>. Specific to individuals with TBI, on average, for many of the scales (including the GHQ), individuals with mild TBI reported significantly poorer health than individuals with moderate and severe TBI; however, in controlling for depression, the differences in scores between mild and moderate-severe TBI were eradicated<sup>5</sup>. For individuals with TBI, SF-36 scores were found have statistically significant correlations with other measures of health problems (e.g., a checklist of cognitive, behavioural, affective and physical symptoms, a list of medical problems, and the Beck Depression Inventory). These correlations were higher for individuals with mild TBI than for moderate-severe TBI, suggesting that the SF-36 is more sensitive to health difficulties reported by individuals with mild TBI than with moderate-severe TBI<sup>5</sup>.</p> <p>One study found a group of individuals with moderate-severe TBI (<math>n=228</math>), mean of 10.05 years (<math>SD=8.8</math>) post TBI, to have a mean GHQ score of 2.72 (<math>SD=0.96</math>)<sup>5</sup>. Another study found a group of individuals with mild, moderate and severe TBI (but mostly moderate and severe TBI) (<math>n=272</math>), mean of 14.2 years (<math>SD=4.3</math>) to have a mean GHQ score of 2.70 (<math>SD=1.0</math>)<sup>6</sup>. Thus, the mean score for both studies falls in</p>

	<p>between the rating of ‘good’ and ‘very good’.</p> <p>The same study found that higher levels of self rated health, as measured on the GHQ, were positively associated with higher levels of global quality of life, as measured using the Quality of Life and Health Questionnaire’s quality of life numerical rating scale<sup>6</sup>.</p>
<p>Montreal Cognitive Assessment (MoCA)<sup>7</sup></p>	<p><u>Time to complete:</u> 10 minutes.</p> <p><u>Description:</u> This performance measure is a fairly newly developed screen of cognitive function. The 17 items fall within the cognitive domains of attention and concentration, visuospatial/executive function, memory, language, abstraction, and orientation. The administration and scoring instructions provide the evaluator with guidelines for scoring the evaluatee’s performance on each item; these are then summed for a total score. An additional point is given if the evaluatee has 12 years or less of education. The highest score is 30; a score of 26 or higher is considered normal.</p> <p>Permission is required to use this questionnaire for research purposes. Permission was received from Dr. Ziad Nasreddine for use of the MoCA in our research study.</p> <p><u>Psychometrics and use with individuals with TBI:</u> In a sample of older adults with mild cognitive impairment or who had been diagnosed with Alzheimer’s Disease, the MoCA was found to have high test-retest reliability over a mean interval period of 35 days (SD=17.6) days (correlation coefficient = 0.92) and good internal consistency (Cronbach alpha = 0.83)<sup>7</sup>. Also with this sample of older adults, the MoCA was found to have excellent sensitivity to mild cognitive impairment, more so than the Mini Mental Status Examination (MMSE)<sup>7</sup>.</p> <p>To date, there are no reports in the literature of the MoCA having been studied with the TBI population; however, it has widespread use clinically. It has recently been studied with individuals with brain tumour<sup>8</sup>, and was found to be more sensitive to cognitive impairment than the MMSE. Validation studies are now underway with individuals with brain tumour<sup>8</sup>.</p>
<p>Frontal Systems Behavior Rating Scale (FrSBe)<sup>9</sup></p>	<p><u>Time to complete:</u> 10 minutes.</p> <p><u>Description:</u> This self-report measure complements the MoCA by providing a more in-depth assessment of executive function. The individual rates himself or herself on 46 items. Each item is a phrase that describes one aspect of behaviour, such as relating to social behaviours, organization, multi-tasking, judgment, planning, and initiative. The 5-point rating scale ranges from 1 (almost never demonstrates the specific behaviour), to 5, (almost always). The</p>

	<p>individual can provide one rating representing his/her behaviour prior to injury, and another rating representing the present time; only the latter was used for this study. The higher the score is, the greater the executive dysfunction. A raw score can be calculated for each of three subscales (apathy, disinhibition and executive dysfunction) and for the total score. These raw scores are then converted to age- and education-corrected t-scores.</p> <p><u>Psychometrics and use with individuals with TBI:</u> The FrSBe has been found to have high internal consistency. Using the normative sample (individuals without neurological conditions), Grace and Malloy<sup>10</sup> reported alpha coefficients varying from 0.72 to 0.88 for the three subscales and total score.</p> <p>Stout et al.<sup>11</sup>, using a sample of outpatients with a variety of neurological diagnoses, confirmed a factor structure consistent with the three subscales of the FrSBe. Internal consistency was found to be good using a sample of individuals with schizophrenia, with alpha values varying from 0.86 to 0.94 for the three subscales and total score<sup>12</sup>.</p> <p>Good test-retest reliability was shown for a three-month interval for a group of individuals with schizophrenia, with the correlation coefficients varying from 0.65 to 0.78 for the three subscales and total score<sup>12</sup>.</p> <p>The FrSBe has good construct validity<sup>9</sup>. For individuals with dementia, a statistically significant correlation (<math>r=0.64</math>) was found between the FrSBe total score and another measure of neurobehaviour, the Neuropsychiatric Inventory, suggesting convergent validity<sup>13</sup>. Discriminant validity has been demonstrated, including showing that apathy (one of the scales on the FrSBe) and depression are distinct syndromes<sup>14</sup>. For the non-clinical population, FrSBe scores correlate with objective measures of executive dysfunction<sup>15</sup>. For individuals with TBI, the FrSBe has been found to be predictive of community integration as measured by the Community Integration Questionnaire<sup>16</sup>.</p>
<p>Zung Self-Rating Depression Scale (SRDS)<sup>17</sup></p>	<p><u>Time to complete:</u> 10 minutes.</p> <p><u>Description:</u> This self-report measure screens for depressive symptoms, but on its own does not allow for a diagnosis of depression<sup>18</sup>. There are 20 items, each describing how a person might have felt over the past few days. The individual rates each item on a four-point response scale, from ‘A little of the time’ to ‘Most of the time’. Using the scoring key, the evaluator converts each rating to a numerical score, and sums these up to create the total score, maximum 80, converted to an index score, maximum 1.00 (representing 100%). The interpretation key indicates that most individuals with depression have an index score between 0.50</p>

and 0.69. A score of 0.70 or greater indicates severe depressive symptoms<sup>17</sup>.

Psychometrics and use with individuals with TBI: Factor analysis identified that the SRDS measures four dimensions of depression: core depressive, cognitive, anxiety and somatic (using a sample of individuals who had sought consultation from a primary care physician for whatever reason)<sup>19</sup>.

By the first author's clinical experience and as reported in the literature<sup>20, 21</sup>, the SRDS has been used with individuals with moderate and severe TBI. However, there may be some limitations to its use for measuring depression in individuals with TBI. One study discussed that the SRDS may not be sensitive enough to diagnose depression for individuals with TBI and that the somatic symptoms that are the result of TBI may overlap with diagnostic features of depression; it was recommended that a psychiatric interview was the 'gold standard' for diagnosing individuals with depression within this population<sup>20</sup>.

Another study felt that there was a confounding overlap between the cognitive/psychological symptoms of a neurological disorder such as TBI and the cognitive/ psychological symptoms associated with depression, but did not express any concerns about a potential overlap of somatic symptoms<sup>21</sup>.

To date, reliability studies have focused on internal consistency of the SRDS. The SRDS has been found to have fair internal consistency with an alpha coefficient of (a) 0.86 for a sample of individuals on an inpatient psychiatric unit<sup>22</sup>, (b) 0.75 for a group of individuals with drug addiction<sup>23</sup>, (c) 0.79 for a group of university students<sup>23</sup> and (d) 0.81 for a group of college students<sup>24</sup>. Split-half reliability was found to be  $r=0.73$  for a group of individuals on an inpatient psychiatric unit<sup>18</sup>.

One study investigated test-retest reliability of the SRDS using a group of individuals with schizophrenia (time interval not published in English), and found high reliability,  $\rho=0.87$ <sup>25</sup>.

The SRDS has been shown to be able to distinguish between individuals with depression and other psychiatric diagnoses in a group of outpatients at a psychiatric clinic<sup>17, 26</sup>, and between individuals with depression and alcohol abusers in a group of individuals referred to vocational rehabilitation services<sup>27</sup>.

A number of studies have shown convergent validity in comparing the SRDS with two other depression measures, the depression scale of the Minnesota Multiphasic Personality Inventory (MMPI-D) and the Beck Depression Inventory (BDI). For example, convergent validity was found with the MMPI-D with two groups of individuals attending a

	<p>psychiatric outpatient clinic, <math>r=0.70^{26}</math> and <math>r=0.65^{17}</math>, a group of individuals on an inpatient psychiatric unit, <math>r=0.73^{22}</math>. The SRDS is felt to cover a wider range of depressive symptoms than the MMPI-D, and therefore to be more congruent with Diagnostic and Statistical Manual of Mental Disorders (DSM) depression criteria<sup>27</sup>. Convergent validity was found with the BDI with a group of individuals on an inpatient psychiatric unit, <math>r=0.81^{22}</math>.</p>
<p>Mayo Portland Adaptability Inventory (MPAI-4)<sup>28</sup></p>	<p><u>Time to complete:</u> 15 to 20 minutes.</p> <p><u>Description:</u> This 35-item self-report questionnaire dates to 1987 with the development of the original Portland Adaptability Inventory. The MPAI-4 is the fourth version. It was designed to assist in the evaluation of physical, cognitive, emotional, behavioural and social abilities and difficulties experienced by individuals in the post-hospital period following acquired brain injury. The MPAI-4 has been recommended as part of a minimum data set for this population<sup>29</sup>.</p> <p>Each item is measured on a 5-point scale, from 0 (no problems), to 4 (severe problems). Twenty-nine of the 35 items are scored and constitute three indices or subscales.</p> <p>The Ability subscale (12 items) provides a self-report on sensory, motor and cognitive abilities; the Adjustment subscale (12 items, 3 items also contributing to the Participation subscale) on mood and interpersonal interactions; and the Participation subscale (8 items) on single items relating to social contacts, initiation, leisure, self-care, residence, transportation, employment, and money management. A raw score is calculated for each subscale and then summed to create the total raw score which ranges from 0 to 37. Each raw score subscale and the total raw score can then be converted to standard scores (t-scores) ranging from 0 to 100. The higher the score is, the more severe the limitations. A t-score below 30 represents relatively good outcomes, between 30 and 40 suggests mild limitations, between 50 and 60 in the moderate to severe range, and above 60 suggests severe limitations even as compared to other people with acquired brain injury. The final six items assess alcohol use, drug use, psychotic symptoms, law violations, other conditions causing physical impairment, and other conditions causing cognitive impairment. As these items were not directly related to the research question and are not scored, they were not administered. Only the Ability and Adjustment subscales were used in this research project.</p> <p><u>Psychometrics and use with individuals with TBI:</u> There is demonstrated reliability and validity evidence, using Rasch analysis as well as traditional psychometric analyses. Using a group of community-based individuals with moderate to severe acquired brain injury, there is acceptable internal consistency for the overall measure, Cronbach's</p>

	<p>alpha = 0.89, and for the three rating scales, with the alpha coefficients ranging from 0.76 to 0.83, average 0.79<sup>30</sup>. Inter-rater (item) agreement has been found for the three potential rating sources (individuals with brain injury, significant other, and rehabilitation staff)<sup>31</sup>.</p> <p>Convergent validity has been demonstrated for individuals with acquired brain injury in a number of studies<sup>32</sup>. This includes that moderate correlation has been found between the MPAI and the Disability Rating Scale, Rancho Scale of Cognitive Function, and a number of neuropsychological measures<sup>30</sup>. An earlier version was found to have some predictive validity in terms of long term vocational and independent living outcomes, and identification of individuals at high risk of needing more extensive community-based services and long-term supports<sup>30</sup>.</p>
<p><b>Involvement in a brain injury drop-in centre (BIDC)</b></p>	
<p>BIDC attendance questionnaire</p>	<p><u>Time to complete:</u> 10 minutes</p> <p><u>Description:</u> This self-report questionnaire was developed specifically for this research project. It captured information about attendance at a BIDC, including frequency, types of activities in which the person participates, and potential barriers to attending. There was a separate version for those who attend BIDCs and those who do not attend BIDCs.</p>
<p>Rating of importance of attending a BIDC</p>	<p><u>Time to complete:</u> less than 5 minutes</p> <p><u>Description:</u> In addition to the BIDC attendance questionnaire, individuals who attend BIDCs were asked two questions. The first was, ‘How important is attending a brain injury drop-in centre to you?’, with the following response options rated from 1 to 5: not at all important (scored 1), a little important, somewhat important, quite important, and very important (scored 5). The second question was open-ended, ‘How would life look if you were not attending a brain injury drop-in centre?’</p>
<p><b>Social Participation</b></p>	
<p>Community Integration Questionnaire (CIQ)<sup>33</sup></p>	<p><u>Time to complete:</u> 5 to 10 minutes</p> <p><u>Description:</u> This 15-item, self-report questionnaire is a measure of frequency and level of independence of participation in social and leisure activities, activities at home, and productive activities. There are six items for the social integration scale, five items for the home integration scale, and four items for the productivity scale.</p> <p>Depending on the item, there are two to five response options from which to select. Using the scoring guidelines, the evaluator converts each selection into a numerical score. A sum score can then be</p>

	<p>calculated for each of the three scales (social integration, maximum score 12; home integration, maximum score 10; productivity, maximum score 7). These, in turn, can be added to create a total score (maximum 29); the higher the score, the higher the level of community integration.</p> <p>The primary focus of the CIQ for this study was the social integration scale, although the full measure was administered. The CIQ social integration scale (CIQ-SI) has three questions relating to frequency of participation in social and leisure activities, one question asking if the person has a best friend, one question asking if the person participates in leisure activities alone or with others, and one question about level of independence for managing personal finances.</p> <p>The CIQ is one of the most widely used and recommended measures of outcome following TBI<sup>34,35</sup>. It was developed to be included in a minimum data set used in ongoing follow-up of individuals with TBI within the TBI Model Systems Database in the USA and, as such, to be fairly brief and reliable for use in telephone follow-up. The developers acknowledge that they therefore had to eliminate any questions relating to satisfaction or psychological well-being as related to community integration<sup>33</sup>.</p> <p>However, there are limitations to the CIQ. The CIQ has a narrow scope<sup>36,37</sup> and has been criticized for not including subjective measures of community integration, such as satisfaction with participation<sup>38,39</sup>. There is a potential ceiling effect for individuals with TBI living in the community<sup>40</sup>. It may not be sensitive enough to gains made in a post acute rehabilitation program<sup>37</sup>.</p> <p>There are some concerns relating to concurrent validity with other measures of social integration/social participation, such as the Social Integration scale of the Craig Handicap Assessment and Reporting Technique (CHART)<sup>33</sup> and the Social Interaction component of the Functional Independence Measure (FIM)<sup>35</sup>.</p> <p>This may suggest that these different tools measure different aspects of social integration. The division of items between the three scales was questioned, and following factor analysis with a much larger sample size than had been used in the initial development of the CIQ, it was recommended that two items be eliminated and two others be moved from one subscale to another<sup>35</sup>. However, many researchers continue to use the original version, and it is the original version that is posted on website of the Center for Outcomes in Measurement in Brain Injury<sup>41</sup>, for use by clinicians and researchers. Some recent studies have used the original version<sup>36,42</sup>, whereas other studies have used a revised version<sup>37,43</sup>, although these studies did not make clear as to what exactly this</p>
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	<p>version consisted of. This study used the original version.</p> <p>For this research study, the CIQ was not used as the primary measure of social participation. However, to allow for results to be compared with those of other studies, it was determined that a consistent measurement tool needed to be used.</p> <p>Permission is required to use this questionnaire for research purposes, and was provided by Dr. Barry Willer for our research project.</p> <p><u>Psychometrics and use with individuals with TBI:</u> The CIQ has demonstrated modest inter-correlations between subscales<sup>44, 45</sup>, moderate inter-rater reliability between individuals with TBI and their caregivers<sup>46</sup>, face validity<sup>47</sup> and concurrent validity with other TBI measures of functional outcome<sup>33, 47, 48</sup>. The CIQ has been found to be sensitive to issues experienced by individuals with TBI<sup>35</sup>.</p>
<p>Social Provisions Scale (SPS)<sup>49</sup></p>	<p><u>Time to complete:</u> 5 to 10 minutes.</p> <p><u>Description:</u> This self-report questionnaire focuses on the degree to which a person perceives his/her social relationships as providing different dimensions of social support. The focus of the SPS is on perceived support and not the actual numbers of individuals in a person's support network. The SPS has 24 items. Half of the items describe the presence of a type of support, and the other items describe the absence of a type of support<sup>49</sup>. Each item is rated on a scale of 1 (strongly disagree) to 4 (strongly agree). A total score is calculated by first reversing the negatively worded items, and summing all items. The total score ranges from 24 to 96; the higher the score, the greater degree of perceived support.</p> <p><u>Psychometrics and use with individuals with TBI:</u> A confirmatory factor analysis was conducted on a sample of college students, teachers and nurses and confirmed that the measures of individual social provisions form separate but highly correlated factors<sup>49</sup>. The items adequately represented the five constructs they were designed to assess (attachment, social integration, reassurance of worth, reliable alliance, guidance and opportunity for nurturance), with item loadings ranging from 0.39 to 0.79<sup>49</sup>. The inter-correlations between each of the factors ranged from <math>r=0.55</math> to <math>r=0.99</math><sup>49</sup>. Confirmatory factor analysis was also conducted on a group of community residents aged 65 or older, and found four (and not five) scales: intimacy, social integration, reassurance of worth, and opportunity for nurturance, with alphas ranging from 0.93 to 0.94<sup>50</sup>. In a study of individuals with TBI (former rehabilitation inpatients), the Cronbach's alpha was 0.81<sup>43</sup>.</p>

	<p>For a study involving individuals with TBI, internal consistency was found to be generally low, ranging from 0.20 to 0.75, and therefore subscale scores were not used in that study's analysis<sup>43</sup>.</p> <p>We were unable to find any studies addressing test-retest reliability.</p> <p>Support has been provided for construct validity<sup>49</sup>. Discriminant validity has been shown for a group of college students, with evidence of (a) convergent validity in comparing the results of the SPS with other measures of social support, with correlations varying from <math>r=.035</math> to <math>r=0.46</math>, and (b) evidence of divergent validity in comparing the SPS with measures of conceptually distinct constructs (e.g. social desirability, personality, depression, number of stressful events), with correlations varying from <math>-0.28</math> to <math>0.03</math><sup>49</sup>. Hierarchical multiple regression analysis then confirmed that, in considering all of the non-social provision variables together, they accounted for only 14.3% of the variance in social provision scores, and that the SPS is related to the other measures of social support over and above the non-social support other variables<sup>49</sup>. Convergent and divergent validity was also shown for a group of older adults<sup>50</sup>.</p> <p>Concurrent validity has been found in comparing the SPS with the Sense of Support Scale with a group of corporate and university employees, <math>r=0.72</math><sup>51</sup>.</p>
<p>Adult Subjective Assessment of Participation (ASAP)<sup>52</sup></p>	<p><u>Time to complete:</u> 30 minutes.</p> <p><u>Description:</u> This self-report questionnaire examines level of participation in different life occupations or situations outside of work and basic self-care. This is a recently developed measure and to date has been used for research purposes. The ASAP consists of 43 activities, grouped into seven activity categories: taking care of family and home, entertainment/recreation, activities with children, educational and enrichment activities, physical activities and sport, self care and care of others, and quiet activities. The ASAP has seven activity categories, but only those categories that represent social participation were used: learning and applying knowledge, and the three recreation and leisure categories, entertainment/recreation, physical activities and sport, and quiet activities. For this study, an additional activity category was added, religion and spirituality. The five activity categories that were used contain 37 social participation activities.</p> <p>There is a score for each of seven scales. The outcome is a participation profile for each individual, revealing various patterns of social participation. The subject first selects all activities that they have performed within the previous four months, thus providing for a measure of diversity. They then rate their participation for each activity</p>

	<p>selected, using six additional scales. The scales and scoring for each are as follows:</p> <p><b>Diversity:</b> maximum 100%, representing percentage of activities in which an individual participates.</p> <p><b>Frequency/intensity:</b> scale varies from ‘once or twice in the last four months’ (score 1) to ‘several times per day’ (score 7). The total score (maximum 7) is the calculated mean rating for all activities in which an individual participates.</p> <p><b>Enjoyment:</b> scale varies from ‘not enjoying it at all’ (score 1) to ‘enjoying it very much’ (score 6); total score, maximum 6, is again the mean rating.</p> <p><b>Satisfaction with performance:</b> scale varies from ‘very much unsatisfied’ (score 1) to ‘very much satisfied’ (score 6). The total score, maximum 6, is again the mean rating.</p> <p><b>Level of assistance:</b> score for each option is 1 for ‘full assistance’, 2 for ‘partial assistance’, 3 for ‘no assistance’. The total score, maximum 3, is the mean rating.</p> <p><b>With whom the individual participates:</b> A total score is calculated by determining the percentage of activities performed with others, in proportion to the total activities in which the individual participates.</p> <p><b>Where the individual participates:</b> A total score is calculated by determining the percentage of activities performed outside of the home, in proportion to the total activities in which the individual participates.</p> <p><u>Psychometrics and use with individuals with TBI:</u> The ASAP has been found to have good reliability and validity, using four groups of individuals: individuals with mental illness, individuals with orthopaedic upper limb injuries, older adults, and a healthy control group<sup>52</sup>. Factor analysis, using principle components analysis with varimax rotation, confirmed the seven factors (activity categories). Shopping was found to be a factor on its own, and was therefore merged with the category ‘taking care of family and home’. There was good test-retest reliability for the frequency/intensity scores on all but two of the items, with correlations varying from 0.55 to 1.0. There was evidence of construct (discriminant) validity. The ASAP was found to be sensitive to differences in participation levels between healthy control group and each of the other three groups.</p> <p>The ASAP was used in a recent study involving individuals with TBI and was found to discriminate between adults with TBI and adults without disability<sup>53</sup>.</p>
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<b>Subjective Quality of Life (SQOL)</b>	
<p>Quality of Life and Health Questionnaire (QOLHQ)<sup>54, 55</sup></p>	<p><u>Time to complete:</u> 10 minutes.</p> <p><u>Description:</u> This self-report scale covers subjective well-being as it relates to physical symptoms, outlook on life, daily activities, and a global rating of quality of life. The first score is the total for the first three items; each is scored using a 4-point scale from ‘none’ (e.g., ‘Emotions and outlook on life are rarely or never a problem’) to ‘severe’ (e.g., ‘Extremely disturbing problem...’). The second score is produced from the fourth item, the global rating of quality of life. This is a single item, 11-point scale, from 0, ‘Worse possible quality of life’, to 10, ‘Best possible quality of life’.</p> <p><u>Psychometrics and use with individuals with TBI:</u> The validity of the QOLHQ has been tested with individuals with advanced cancer<sup>54</sup>. It was found that the sum of the first three items correlated with the global quality of life score (<math>r=0.66</math> to <math>0.71</math>). Convergent validity was demonstrated by comparing results of the QOLHQ with the results of an in-depth, standardized telephone interview (<math>r=0.43</math> to <math>0.71</math>).</p> <p>Specific to individuals with TBI, one study found the global appraisal item to have concurrent validity with moderate correlation with the Sickness Impact Profile (SIP), <math>r=0.46</math><sup>56</sup>. The 136-item SIP, developed to measure health status for use in assessing effects of health care services (Gilson 1975) is frequently used to measure health-related quality of life of individuals with TBI<sup>57</sup>. The benefit of a single item measure over the SIP is the reduced burden (time required and mental fatigue) to the evaluatee<sup>56</sup>.</p> <p>We are not aware of any reliability studies specific to the QOLHQ as a whole, or the single global appraisal item on its own.</p>
<p>Abdel-Khalek Happiness Scale (AKHS)<sup>58</sup></p>	<p><u>Time to complete:</u> less than 5 minutes.</p> <p><u>Description:</u> The most common assessment technique for subjective well-being or SQOL has been identified as a single-occasion, self-report happiness scale<sup>59</sup>. The AKHS is a single-item, numerical appraisal of happiness<sup>58</sup>. The evaluatee is asked, ‘Do you feel happy in general?’ and asked to circle a number along a horizontal line, from 0 (minimum happiness) to 10 (maximum happiness).</p> <p><u>Psychometrics and use with individuals with TBI:</u> For a sample of university undergraduates, the AKHS was found to have good test-retest reliability over an interval of one week, <math>r=0.86</math><sup>58</sup>. In the same study, the AKHS was found to have good concurrent validity (with the Oxford Happiness Inventory and the Satisfaction With Life Scale); good convergent validity (high and positive correlations with optimism, hope,</p>

	<p>self-esteem, and positive affect); and adequate discriminant validity (significant and negative correlations with anxiety, pessimism, and negative affect).</p> <p>We are not aware of any studies having used this happiness scale with individuals with TBI. However, it appears to be simple to understand and take little time to complete, and with its good psychometric properties, a good measure of happiness for this population and our study.</p>
<p>University of California at Los Angeles Loneliness Scale (UCLA-LS)<sup>60</sup></p>	<p><u>Time to complete:</u> 10 minutes</p> <p><u>Description:</u> We used a 10-item version of the UCLA-LS<sup>61</sup> instead of the full 20-item version. This self-report questionnaire is considered to focus on intimate and interpersonal loneliness<sup>62</sup>. Each item is rated on a 4-point scale, from ‘I never feel this way’ (1 point) to ‘I often feel this way’ (4 points). A total score is calculated by summing the ratings. The total score ranges from 10 to 40. Scores between 15 and 20 are considered a normal experience of loneliness and a score above 30 indicates that the individual is experiencing severe loneliness<sup>61</sup>.</p> <p><u>Psychometrics and use with individuals with TBI:</u> The UCLA-LS has been found to have high internal consistency, with coefficient alpha of 0.96<sup>60</sup>. All items were found to have correlations with the total score of at least 0.50<sup>60</sup>.</p> <p>For a sample of university students, test-retest reliability was found to be high over a two-month interval, with a correlation of 0.73<sup>60</sup>.</p> <p>The UCLA-LS was found to have face validity, and concurrent validity in correlating scores of the UCLA-LS with self-descriptions of loneliness (<math>r=0.79</math>)<sup>60</sup>. Evidence of convergent validity was found in that (a) individuals with higher scores on the UCLA-LS were more likely to volunteer for a clinical discussion program for people who self-identified themselves as lonely, than individuals who did not volunteer to participate in this program, and (b) individuals with higher scores of loneliness on the UCLA-LS had higher scores on measures of emotional correlates of loneliness, including feeling empty, awkward, restless, bored and shy<sup>60</sup>.</p> <p>To the best of our knowledge, the UCLA-LS has not been used in studies involving individuals with brain injury. However, a revised version was used with community-dwelling adults with intellectual disabilities in an investigation of the relationship between leisure activities, friendships and quality of life <sup>63</sup>. The study found feelings of loneliness (as measured using the UCLA-revised) to correlate with friendships: the more friends, the less the feeling of loneliness.</p>

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## Appendix D: Study-specific questionnaires

Date: \_\_\_\_\_

Participant number: \_\_\_\_\_

**SUBJECT CHARACTERISTICS**  
**\*check the answer(s) that apply**

<p>1. Gender:</p> <p style="margin-left: 20px;"><input type="radio"/> Male</p> <p style="margin-left: 20px;"><input type="radio"/> Female</p>
<p>2. Date of injury (if &gt; 2 years ago, year of injury is sufficient): _____</p>
<p>3. Cause of injury:</p> <p style="margin-left: 20px;"><input type="radio"/> motor vehicle accident</p> <p style="margin-left: 20px;"><input type="radio"/> fall</p> <p style="margin-left: 20px;"><input type="radio"/> assault</p> <p style="margin-left: 20px;"><input type="radio"/> other: _____</p>
<p>4. Any other injuries at same time?</p> <p style="margin-left: 20px;"><input type="radio"/> Fractures</p> <p style="margin-left: 20px;"><input type="radio"/> Musculoskeletal injury (soft tissue injury)</p> <p style="margin-left: 20px;"><input type="radio"/> Other: _____</p>
<p>5. Types of rehabilitation services/supports to date: check all that apply, &amp; <u>date(s)</u> if available</p> <p style="margin-left: 20px;"><input type="radio"/> Inpatient rehabilitation _____</p> <p style="margin-left: 20px;"><input type="radio"/> Outpatient rehabilitation _____</p> <p style="margin-left: 20px;"><input type="radio"/> Homecare OT/PT _____</p> <p style="margin-left: 20px;"><input type="radio"/> Community rehab _____</p> <p style="margin-left: 20px;"><input type="radio"/> Case manager _____</p> <p style="margin-left: 20px;"><input type="radio"/> Psychological/clinical counselling _____</p> <p style="margin-left: 20px;"><input type="radio"/> Alcohol and drug services _____</p> <p style="margin-left: 20px;"><input type="radio"/> Vocational rehabilitation _____</p> <p style="margin-left: 20px;"><input type="radio"/> Other: _____</p>
<p>6. Other services/supports to date: (check all that apply, &amp; <u>date(s)</u> if available)</p> <p style="margin-left: 20px;"><input type="radio"/> Driver assessment/rehab _____</p> <p style="margin-left: 20px;"><input type="radio"/> Group home, family care home, or transitional living supports _____</p> <p style="margin-left: 20px;"><input type="radio"/> Network of support/Circle of support _____</p> <p style="margin-left: 20px;"><input type="radio"/> Community centre supports (e.g., subsidy; program for individuals with disabilities) _____</p> <p style="margin-left: 20px;"><input type="radio"/> One-to-one volunteer _____</p> <p style="margin-left: 20px;"><input type="radio"/> BI drop-in centre _____</p> <p style="margin-left: 20px;"><input type="radio"/> Stroke Recovery Group _____</p> <p style="margin-left: 20px;"><input type="radio"/> Formal peer support program/service _____</p> <p style="margin-left: 20px;"><input type="radio"/> Other: _____</p>
<p>7. Educational status at time of injury:</p> <p style="margin-left: 20px;"><input type="radio"/> Less than 8 years of education</p> <p style="margin-left: 20px;"><input type="radio"/> More than 8 but less than 12 years of education (not graduated from grade 12)</p> <p style="margin-left: 20px;"><input type="radio"/> Graduated from grade 12, no additional education</p> <p style="margin-left: 20px;"><input type="radio"/> Graduated from grade 12, some additional education but not completed</p> <p style="margin-left: 20px;"><input type="radio"/> Certificate or diploma from trades school or college</p> <p style="margin-left: 20px;"><input type="radio"/> University degree: Specify (degree/area of study): _____</p>

Date: \_\_\_\_\_

Participant number: \_\_\_\_\_

<p>8. Pre-injury work status:</p> <ul style="list-style-type: none"><li><input type="radio"/> Not employed (paid or unpaid)</li><li><input type="radio"/> Volunteer work</li><li><input type="radio"/> Part-time paid employment</li><li><input type="radio"/> Full-time paid employment</li></ul>
<p>9. Living situation <u>at time of injury</u></p> <ul style="list-style-type: none"><li><input type="radio"/> on own</li><li><input type="radio"/> with parent(s)</li><li><input type="radio"/> with spouse (may also include children)</li><li><input type="radio"/> with children (single parent)</li><li><input type="radio"/> with roommate(s)</li><li><input type="radio"/> supported living setting (group home, family care home, etc.)</li><li><input type="radio"/> other: _____</li></ul>
<p>10. <u>Current</u> living situation</p> <ul style="list-style-type: none"><li><input type="radio"/> on own</li><li><input type="radio"/> with parent(s)</li><li><input type="radio"/> with spouse (may also include children)</li><li><input type="radio"/> single parent living with children</li><li><input type="radio"/> with roommate(s)</li><li><input type="radio"/> in supported living (group home, family care home, etc.)</li><li><input type="radio"/> other: _____</li></ul>
<p>11. Independent living skills (check the one that best applies – current status)</p> <ul style="list-style-type: none"><li><input type="radio"/> independent</li><li><input type="radio"/> paid caregiver (personal care)</li><li><input type="radio"/> other paid support (life skills worker, other)</li><li><input type="radio"/> unpaid caregiver/supports (including friends, family)</li></ul>
<p>12. Income source (primary source)</p> <ul style="list-style-type: none"><li><input type="radio"/> disability pension (LTD, CPP-D, WCB, PWD)</li><li><input type="radio"/> depend on family or spouse</li><li><input type="radio"/> ICBC benefits, or settlement from litigation</li><li><input type="radio"/> savings</li><li><input type="radio"/> other: _____</li></ul>
<p>13. Income amount – yearly</p> <ul style="list-style-type: none"><li><input type="radio"/> &lt;\$10,000</li><li><input type="radio"/> \$10,000 to \$19,999</li><li><input type="radio"/> \$20,000 to \$29,999</li><li><input type="radio"/> \$30,000 to \$39,999</li><li><input type="radio"/> \$40,000 to \$49,999</li><li><input type="radio"/> ≥ \$50,000</li></ul>

Date: \_\_\_\_\_

Participant number: \_\_\_\_\_

**BRAIN INJURY DROP-IN CENTRE ATTENDANCE PATTERNS:  
Group 1: individuals attending at a Brain Injury Drop-In Centre**

How did you hear about the brain injury drop-in centre?

- From a friend
- From a family member
- From my case manager
- From another therapist/clinician
- Other: \_\_\_\_\_

Why did you decide to attend?

- I was bored and needed something to do
- It sounded like fun
- To meet friends
- To get more help with my recovery/rehabilitation
- To get help with some personal affairs
- To meet others who have a brain injury, for some ideas and support
- Other: \_\_\_\_\_

For how long have you attended? Specific number of months or years if known: \_\_\_\_\_

- More than a year
- Between 6 and 12 months
- Between 3 and 6 months
- 3 months

How often do you attend?

- Once a week on average
- Twice a week
- Three or more times per week
- Other: \_\_\_\_\_

Would you attend more often if you could?

- Yes. Explain why you don't: \_\_\_\_\_
- No. Explain why you would not: \_\_\_\_\_

What is the best part about attending?

- Fun activities
- Socializing with the staff
- Socializing with the other participants
- Outings
- I am learning new skills
- I am able to contribute to the program
- Other: \_\_\_\_\_

Date: \_\_\_\_\_

Participant number: \_\_\_\_\_

Are there any negatives, if so, what?

- I don't care for the activities
- I have not made any friends
- There is not enough to do
- Other: \_\_\_\_\_

Are there any barriers to attending (anything that makes it difficult, or stops you from attending as often as you would like?)

- Transportation difficulties (explain: \_\_\_\_\_)
- It is difficult to get myself organized or motivated to get there
- I need someone to go with me, and they are not always available
- Cost (explain: \_\_\_\_\_)
- The centre is not open often enough (explain: \_\_\_\_\_)
- Other: \_\_\_\_\_

What types of activities do you participate in at the drop-in centre?

- Watch movies
- Use the computer
- Socialize/visit/talk with staff
- Socialize/visit/talk with other participants
- Cooking
- Games
- Help out (clean-up, planning activities, etc.)
- Eat a snack or a meal
- Other: \_\_\_\_\_

Date: \_\_\_\_\_

Participant number: \_\_\_\_\_

**BRAIN INJURY DROP-IN CENTRE ATTENDANCE PATTERNS:**  
**Group 2: individuals not attending at a Brain Injury Drop-In Centre**

Have you heard about brain injury drop-in centres? (if not, describe to the person)

- No
- Yes, from a friend
- Yes, from a family member
- Yes, from my case manager
- Yes, from another therapist/clinician
- Yes, from someone else: \_\_\_\_\_

Would you like to attend? Why?

- No, explain: \_\_\_\_\_
- Yes, I'm bored and need something to do
- Yes, it sounds like fun
- Yes, to meet friends
- Yes, to get more help with my recovery/rehabilitation
- Yes, to get help with some personal affairs
- Yes, to meet others who have a brain injury, for some ideas and support
- Yes, other: \_\_\_\_\_

If yes to the above, how often would you like to attend?

- Once a week on average
- Twice a week
- Three or more times per week
- Other: \_\_\_\_\_

What do you think would be the best part about attending?

- Fun activities
- Socializing with the staff
- Socializing with the other participants
- Outings
- To learn new skills
- To contribute to the program
- Other: \_\_\_\_\_

What do you think would be a negative aspect of attending?

- I might not care for the activities
- I might not make any friends
- There might not be enough to do
- Other: \_\_\_\_\_

Date: \_\_\_\_\_

Participant number: \_\_\_\_\_

If you would like to attend, then what are the barriers to attending (what stops you from attending)?

- Transportation difficulties (explain: \_\_\_\_\_)
- It is difficult to get myself organized or motivated to get there
- I need someone to go with me, and they are not always available
- Cost (explain: \_\_\_\_\_)
- The centre is not open often enough (explain: \_\_\_\_\_)
- Other: \_\_\_\_\_

What types of activities would you like to participate in at a drop-in centre?

- Watch movies
- Use the computer
- Socialize/visit/talk with staff
- Socialize/visit/talk with other participants
- Cooking
- Games
- Help out (clean-up, planning activities, etc.)
- Eat a snack or a meal
- Other: \_\_\_\_\_

Date: \_\_\_\_\_

Participant number: \_\_\_\_\_

**BRAIN INJURY DROP-IN CENTRE ATTENDANCE PATTERNS:**

**Extra Questions for Group I**

How important is attending at a brain injury drop-in centre to you?

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>not at all important</b>	<b>a little important</b>	<b>somewhat important</b>	<b>quite important</b>	<b>very important</b>

How would life look if you were not attending at a brain injury drop-in center?

### Appendix E: Missing data

Measure	Missing data	Steps taken to deal with the missing data
Participant characteristics questionnaire	-7 subjects did not respond to the question relating to their monthly income, either because they did not know the information, or chose not to respond	-no action taken
Zung Self-Rating Depression Scale (SRDS)	<p>-11 subjects (3 in the BIDC group, 8 in the Comparison group) did not respond to item 6: “I still enjoy sex.”</p> <p>-one of these 11 subjects (from the Comparison group) also did not answer the items: “I have crying spells or feel like it” and “I feel that others would be better off if I were dead”</p>	-as per Shrive et al. <sup>1</sup> , each subject’s mean score was imputed in place of the missing response(s)
Frontal Systems Behavior Rating Scale (FrSBe)	-6 participants (2 in the BIDC and 4 in the Comparison group) did not respond to item 38: “Am interested in sex.”	-as per instruction manual <sup>2</sup> , a raw score of 1 was assigned to each of the missing responses.
	-for the entire FrSBe, the responses for 1 participant (Comparison group) were considered to not be an accurate representation of his/ her behaviour, in comparing his/her responses to his/her observed behaviours. He/she chose to not ask a family member, caregiver or friend to assist. For all other situations where the assessor had any concern about the accuracy of the participant’s responses on the FrSBe, there was a family member or caregiver present who was able to contribute to the response.	-one participant was removed from the descriptive analysis of FrSBe scores (correlational study and comparison study)

### **References (Appendix E)**

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## Appendix F: Linearity (applicable to correlational study)

Social participation

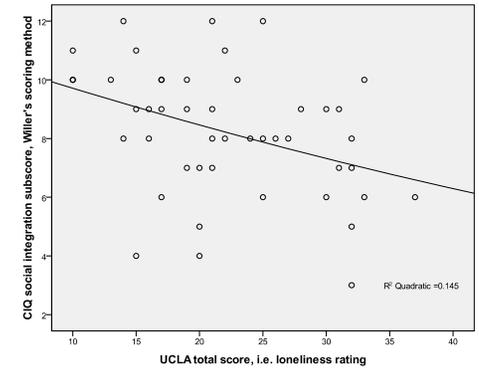
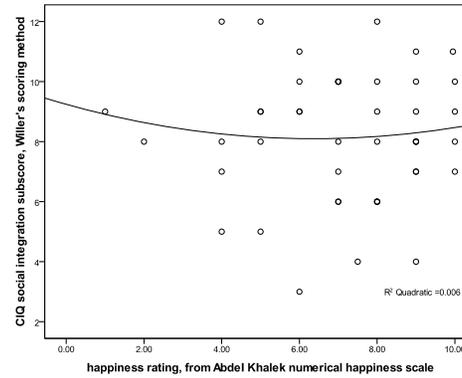
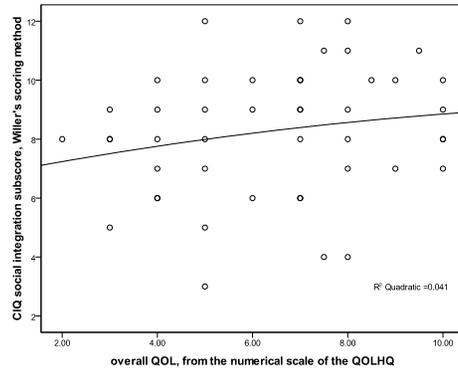
Subjective quality of life

Global rating of QOL (QOLHQ)

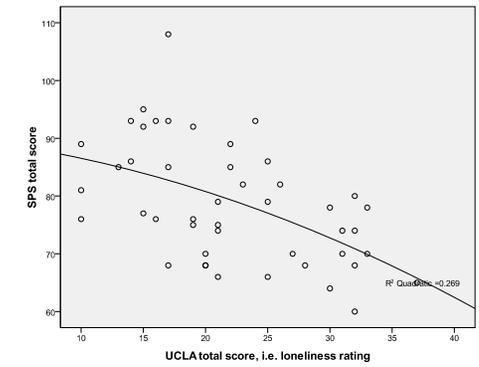
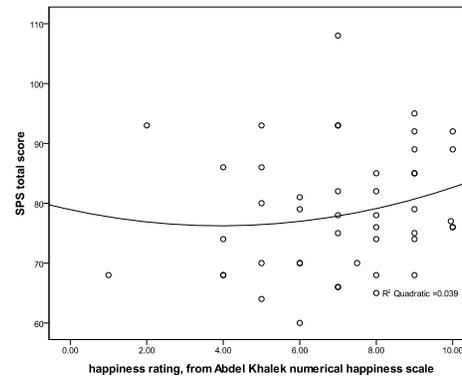
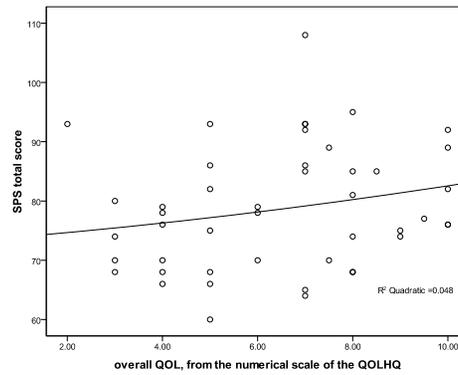
Happiness (AKHS)

Loneliness (UCLA-LS)

General social integration (CIQ-SI)



Perceived social supports (SPS)



$R^2$  Quadratic = 0.145  
 $R^2$  Linear = 0.145

$R^2$  Quadratic = 0.269  
 $R^2$  Linear = 0.266

■ Statistically significant correlations ( $p < 0.01$ ) are shaded in grey

Social participation

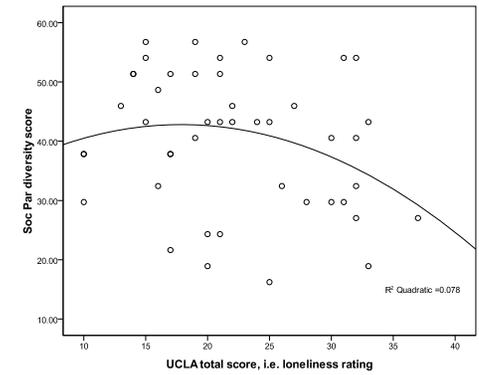
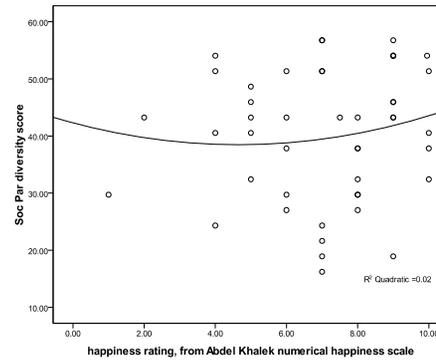
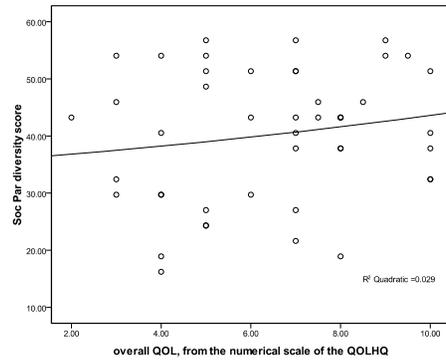
Subjective quality of life

Global rating of QOL (QOLHQ)

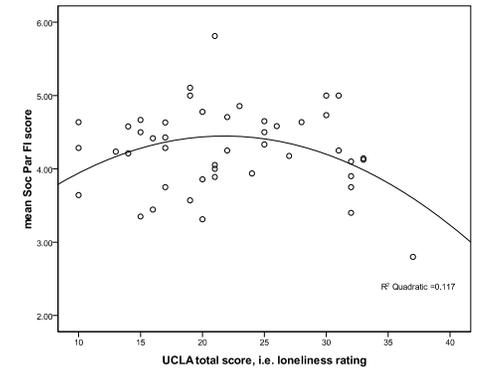
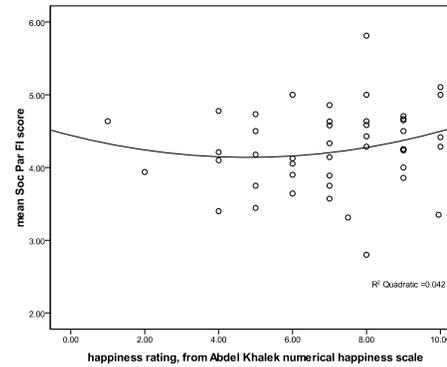
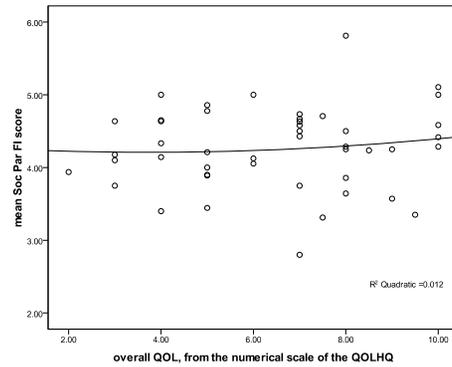
Happiness (AKHS)

Loneliness (UCLA-LS)

Diversity of activities (ASAP)



Frequency/intensity (ASAP)



■ Statistically significant correlations ( $p < 0.01$ ) are shaded in grey

Social participation

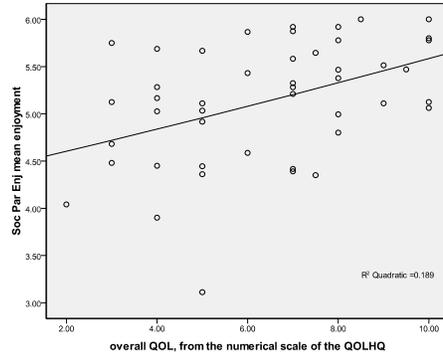
Subjective quality of life

Global rating of QOL (QOLHQ)

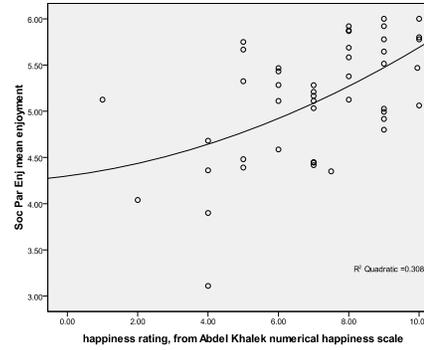
Happiness (AKHS)

Loneliness (UCLA-LS)

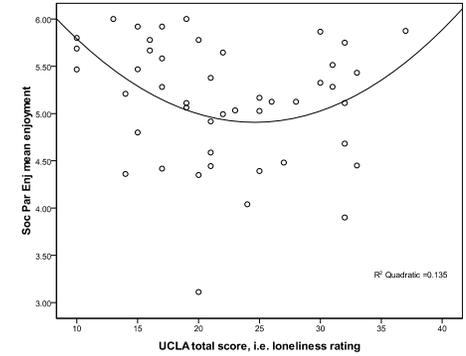
Enjoyment (ASAP)



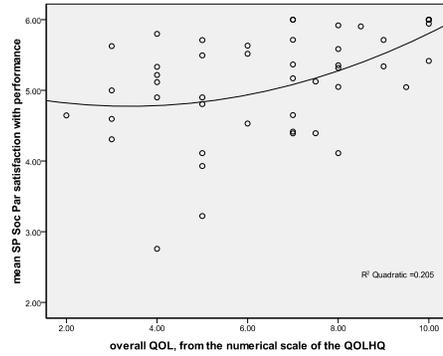
R<sup>2</sup> Quadratic = 0.189  
R<sup>2</sup> Linear = 0.189



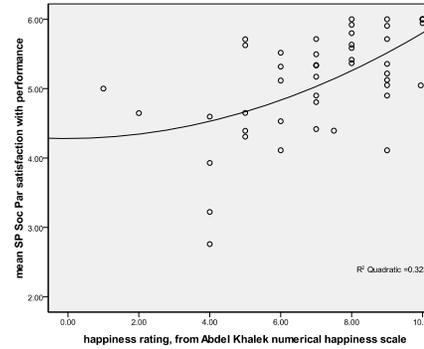
R<sup>2</sup> Quadratic = 0.308  
R<sup>2</sup> Linear = 0.302



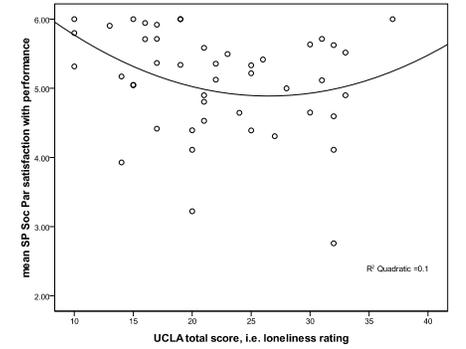
Satisfaction with performance (ASAP)



R<sup>2</sup> Quadratic = 0.205  
R<sup>2</sup> Linear = 0.18



R<sup>2</sup> Quadratic = 0.323  
R<sup>2</sup> Linear = 0.309



■ Statistically significant correlations (p<0.01) are shaded in grey

Social participation

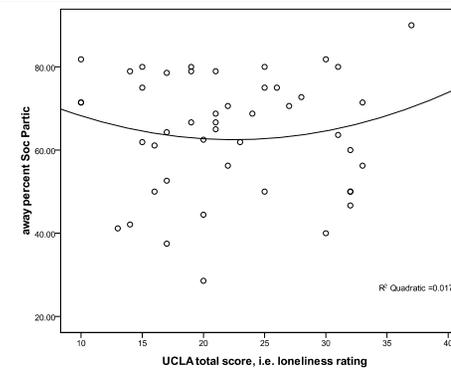
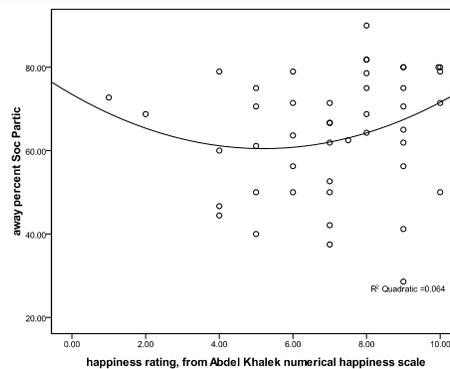
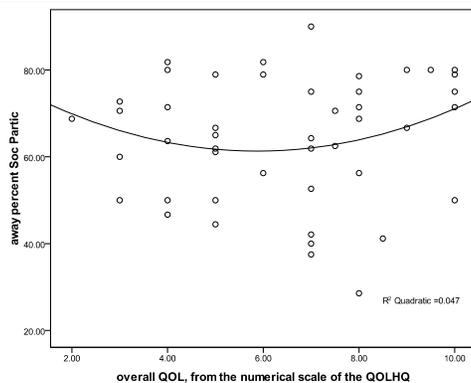
Subjective quality of life

Global rating of QOL (QOLHQ)

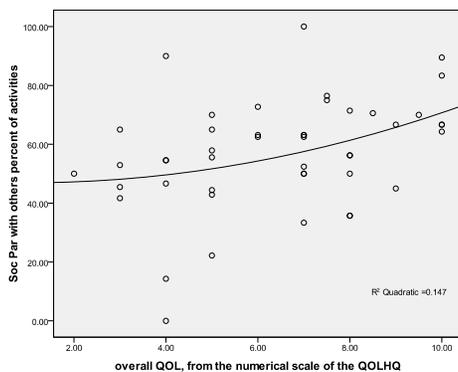
Happiness (AKHS)

Loneliness (UCLA-LS)

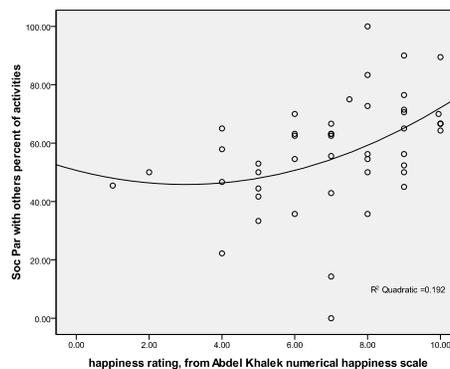
Where:  
proportion of activities away from home (ASAP)



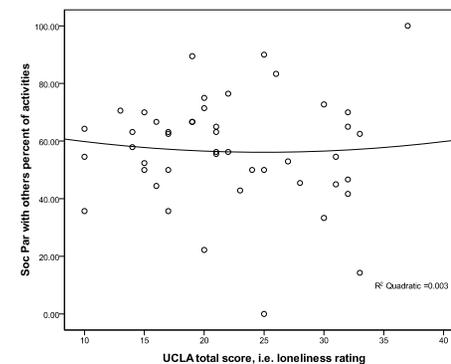
With whom:  
proportion of activities with others (ASAP)



R<sup>2</sup> Quadratic = 0.147  
R<sup>2</sup> Linear = 0.141



R<sup>2</sup> Quadratic = 0.192  
R<sup>2</sup> Linear = 0.165



■ Statistically significant correlations (p<0.01) are shaded in grey

## Appendix G: Comparison study – sample size testing

Sample size testing was conducted using information from the Community Integration Questionnaire (CIQ) because this was the only measure (out of all of the social participation and subjective quality of life instruments) that had sufficient information available in the literature e.g., mean scores and standard deviations.

As a result of sample size testing<sup>1</sup>, it was decided to recruit 25 individuals for each group (BIDC group and Comparison group). We were successful in recruiting 23 participants for each group.

1. Cicerone (2004)<sup>2</sup>, intensive cognitive rehabilitation program for community-dwelling adults with TBI, intervention group (pre and post test, CIQ social integration scale):

### Sample Size

Input:	
Expected Average1	7.0
Expected Average2	8.6
Std Dev 1; Tolerance	2.3
Std Dev 2	1.8
Alloc Ratio	1.00
Continuity Correction	<input checked="" type="checkbox"/>

This procedure by SISA, 1989,1997.

RESULTS for double sided

alpha	power			
	0.6	0.7	0.8	0.9
-----				
0.1	13	17	22	29
0.05	18	22	27	36
0.01	28	34	41	51
0.001	44	51	59	72

RESULTS for single sided

alpha	power			
	0.6	0.7	0.8	0.9
-----				
0.1	9	12	16	22
0.05	13	17	22	29
0.01	24	28	35	45
0.001	40	46	54	66

optimum allocation ratio equals: 0.78

Help Sample Size

2. Douglas (2006)<sup>3</sup>: community leisure activities group (pre and post for ‘sustained activities’ group, using CIQ social integration scale):

## Sample Size

**Input:**

Expected Average1	7.2
Expected Average2	9.3
Std Dev 1; Tolerance	2.6
Std Dev 2	1.9
Alloc Ratio	1.00
Continuity Correction	<input checked="" type="checkbox"/>

This procedure by SISA, 1989,1997.

cleared

RESULTS for double sided

alpha	power			
	0.6	0.7	0.8	0.9
0.1	9	12	15	21
0.05	13	16	20	26
0.01	21	24	29	36
0.001	32	37	43	51

RESULTS for single sided

alpha	power			
	0.6	0.7	0.8	0.9
0.1	6	8	11	16
0.05	9	12	15	21
0.01	17	20	25	32
0.001	29	33	38	47

optimum allocation ratio equals: 0.73

Help Sample Size

3. Geurtsen (2008)<sup>4</sup>, residential brain injury program, pre and post test, using full CIQ:

# Sample Size

**Input:**

Expected Average1	14.0
Expected Average2	17.2
Std Dev 1; Tolerance	3.9
Std Dev 2	5.2
Alloc Ratio	1.00
Continuity Correction	<input checked="" type="checkbox"/>

cleared

RESULTS for double sided

alpha	power			
	0.6	0.7	0.8	0.9
<hr style="border-top: 1px dashed black;"/>				
0.1	16	20	26	36
0.05	21	26	33	44
0.01	34	41	50	62
0.001	54	62	72	88

RESULTS for single sided

alpha	power			
	0.6	0.7	0.8	0.9
<hr style="border-top: 1px dashed black;"/>				
0.1	10	14	19	27
0.05	16	20	26	36
0.01	29	35	43	54
0.001	48	56	66	80

optimum allocation ratio equals: 1.33

[Help Sample Size](#)

This procedure by SISA, 1989,1997.

### References (Appendix G)

- [1] Sample size testing was conducted using the calculator available at: <http://www.quantitativeskills.com/sisa/calculations/samsize.htm> (accessed November 19, 2008)
- [2] Cicerone KD, Mott T, Azulay J, Friel JC. Community integration and satisfaction with functioning after intensive cognitive rehabilitation for traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* 2004;85:943-50
- [3] Douglas JM, Dyson M, Foreman P. Increasing leisure activity following severe traumatic brain injury: Does it make a difference? *Brain Impairment* 2006;7:107-18
- [4] Geurtsen GJ, Martina, JD, Van Heugten, CM, Geurts, ACH. A prospective study to evaluate a new residential community reintegration programme for severe chronic brain injury: The Brain Integration Programme. *Brain Injury* 2008;22: 545-554.