

**The Promotion of Physical Activity for Individuals with Severe  
Neurological Disability Living in a Residential Service**

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## **Abstract**

### **Introduction**

Physical activity (PA) participation is promoted and encouraged for all of the population. Despite this, persons with disability, and especially those with severe disability, are less physically active than the able-bodied population, with consequent impact on their overall health and well-being. Reasons for this may be due to the severity of impairment and the presence of multiple impairments. However, it may also be a consequence of expectations about participating in PA, from self and others, combined with environmental barriers in accessing PA opportunities which may be especially pertinent when the individual lives in residential care. This study aimed to investigate and evaluate the processes required to implement PA for individuals with severe neurological disability who live in a residential service.

### **Method**

This study used a qualitative case study design made up of a series of five individual cases (three men, two women) who lived in one residential care facility. Each case involved planning and where possible, implementation of an individualised mode of PA for the participant over a six week timeframe. Data was collected via notes of observations, notes from reflections and discussions with the supervisory team and with an advisory team, as well as semi-structured interviews with participants at six and 12 weeks. The case series was analysed and synthesised inductively for common themes to reveal processes that hindered or promoted participation in PA, and to discover what the experience meant for the study's participants.

### **Results**

All five participants completed the intervention. Four participants were successful in achieving participation in PA. Participants identified physical, social, or emotional benefits to being physically active. Analysis revealed three broad themes: 1) There's more than one road to Rome, 2) Benefits and barriers, and 3) The ripple effect. The themes identified that the approach to PA participation needs to be individually adapted but that a simplicity of approach proved to be the most sustainable, that individuals with disabling conditions are interested in being physically active for its worth towards their health and well-being, and

that ideas and interest in PA participation can spread throughout a residential service where individuals live together and interact on a daily basis with staff of the service.

### **Conclusion**

This study found that it is possible to achieve individualised PA for people with severe neurological disability, when they are provided with support to facilitate the process. The three main themes identified suggest that being physically active is important to people with severe disability and therefore health care providers have a responsibility to seek ways of engaging their clients in more PA. Health care professionals will need to be creative and learn to problem-solve in order to do this, however, once this process is started the ‘ripple effect’ might result in widening awareness and action regarding the PA of persons with severe disability. This study informs individuals with disabilities and their support persons, health care professionals who work with individuals as well as people who provide PA opportunities or funders of health care for individuals with disabling conditions that necessitate residential care, about ways for their clients to achieve health and well-being via PA for their clients and the benefits they may receive from it.

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## **List of Abbreviations**

ACSM	American College of Sports Medicine
CP	Cerebral palsy
FAM	Functional Assessment Measure
FIM	Functional Independence Measure
FIM+FAM	Functional Independence Measure and Functional Assessment Measure
ICF	International Classification of Functioning, Disability and Health
MET	Metabolic Equivalent of Task
NZ	New Zealand
PA	Physical activity
PADS-R	Physical Activity and Disability Survey Revised version
SPARC	Sport and Recreation New Zealand
TBI	Traumatic brain injury
USA	United States of America
WHO	World Health Organization

## **1. Background to the Thesis**

Following experience working in acute neurological and rehabilitation units in hospitals overseas, in 2009 I commenced work as the physiotherapist in a long-term care and slow stream rehabilitation service for younger adults with neurological conditions. This residential service holds at its core five values – excellence, hospitality, justice, respect, and compassion. The focus of the service is to enhance quality of life for its residents. Residents who live in this service present with a wide range of chronic neurological diagnoses including stroke, traumatic brain injury, multiple sclerosis, cerebral palsy and Huntington’s disease. For many residents, their primary neurological condition is often associated with complex secondary conditions and co-morbidities.

I observed how extremely physically inactive residents are during their daily lives. Most residents are reliant on a power or manual wheelchair for all mobility, a hoist for transfers and engage in PA mostly only whilst eating at mealtimes (if they are able to feed themselves) or in scheduled, supported therapeutic interventions, for example, practising walking in the physiotherapy sessions. I was keen to see if PA could be incorporated further into residents’ lives. However, in researching the promotion of PA for people with disability, it became clear that people with severe impairment are poorly represented in the literature. Low levels of PA in these residents may be to some extent due to the severity of their physical and cognitive impairments, although physical and attitudinal barriers from within the environment, both from the facility itself and the general community environment outside of the hospital environs, may also have an impact. I wished therefore to determine whether it was possible to increase participation in PA for residents in such a service, and how this could be achieved.

Although it would be unlikely that the residents would achieve PA levels to that which is recommended (1,2), nevertheless even a small change could be worthwhile. I wished to use the environment and opportunity in which I work to investigate ways to facilitate PA and examine barriers to this particular group of the population. Such information would aid promotion of PA for other people with severe disability, as it would identify problems and

strategies to overcome these, both for the individual themselves and for their support network.

Physical activity is widely promoted for all populations (1–3) however people with disability and especially individuals with severe disability (4–7) show very low levels of PA (8). This is likely to have a negative effect on their already complex and severe impairments, their overall health and wellbeing. Barriers to PA participation, both actual and perceived may prevent or interfere with participation in PA for this population. Living in an institutional setting may also add further unique complexities to accessing PA. This thesis therefore aims to assess and evaluate the processes and experiences of individuals with severe neurological disability who live in a residential service in accessing PA.

## 2. Introduction

Regular participation in physical activity (PA) has many long term health benefits, including reducing the risk factors, incidence and impact of non-communicable diseases (9). Physical activity levels are however decreasing globally, leading to an increase in the incidence of non-communicable diseases (10). Consequently, international, national and local health policies are now focused on increasing participation in PA for all populations (1,10–14). Despite this focus, the facilitation and implementation of PA for individuals with disability is unclear, especially for individuals who are non-ambulatory and have multiple impairments, for example those who have lived for a long time with disabling neurological conditions. The following sections will discuss the definitions, literature, policy, and background in relation to the promotion of PA for individuals with severe neurological disability.

### 2.1 Physical Activity and Exercise

Physical activity is a broad, varied, and complex construct. The widely accepted definition of PA is that it “is any bodily movement produced by skeletal muscle that results in energy expenditure” (15 pg 126). Physical activity can be considered in four dimensions: intensity (amount of effort expended), type, amount (which can be counted in units of time) and frequency (how often) (16–19). Physical activity includes many tasks considered part of everyday routine as well as recreational activities, for example, household chores, mowing the lawns, dancing or throwing a ball for the dog are all included in the definition of PA (20). Exercise is considered a subgroup of PA, in that exercise is a form of PA specifically planned and carried out in order to improve health (10,21).

### 2.2 Disability and Health

The terms disability and health have a number of definitions and create debate in the literature. The World Health Organization (WHO) describes disability as “an umbrella term, covering impairments, activity limitations, and participation restrictions” (22). The WHO has developed its International Classification of Functioning, Disability and Health framework (ICF) to identify factors that relate to disability (23). Development of the ICF acknowledges the role of personal and environmental factors as well as the contribution of a health

condition in disability. This framework has extended the definition of disability from a purely medical model to one which includes psychosocial factors. In contrast the New Zealand (NZ) Disability Strategy (24) however describes disability as arising from the barriers created by a world designed for only one way of living, that is, an able-bodied way of living, thereby defining disability within a social model.

In 2006, 17 percent of New Zealanders were reported to be living with a long term disability, with two thirds described as having physical impairments (25). It is important to consider that the presence of disability does not necessarily suggest the presence of poor health. Health was defined by the WHO in 1948 as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (26) and this definition still stands. The definition requires an absoluteness of wellness as implied by the use of the word ‘complete’, meaning that an individual is either well or unwell. Consequently, health focus and healthcare spending to date has commonly reflected this definition, resulting in a focus on treatment of disease itself, rather than on optimising available wellness for individuals with disabilities (27). In contrast, Rimmer (1999) (27) proposed that health was more of a continuum rather than a stable position. Therefore individuals would naturally go through periods of changing status of health throughout their lifetime. If this concept were applied to individuals with severe neurological disability, then their health would be in a dynamic state, altered by onset, episodes and progressions of complications, regardless of their disability (27). Modern medical and technological advances can minimise many complications of chronic health conditions with the result that individuals with disabilities now have a greater life expectancy than previously although still not yet reaching that of the general population (28,29).

Much complexity and debate exists over appropriate definitions of disability and health. For the purpose of this thesis the WHO definition of disability, “an umbrella term, covering impairments, activity limitations, and participation restrictions” (22) will be used along with Rimmer’s concept of a changing status of health throughout a lifetime (27).

### **2.2.1 Severe Neurological Disability**

Severity of disability lacks definition in the medical literature. Individuals with a severe disability are defined in the legal profession as “someone who has a severe physical or mental impairment which seriously limits one or more functional capacities...” (30). For the purpose of this thesis, I have defined persons with severe physical disability as those individuals with physical impairments that result in them requiring a power or attendant propelled wheelchair for the majority of their mobility.

Individuals with severe neurological disabilities are, as a group, particularly susceptible to potentially debilitating concomitant complications. Secondary complications are often the result of living for years with altered movement patterns, overuse of normally non-weight bearing joints (for example when arms become the weight-bearing limbs for transferring between the wheelchair and bed), reduced sensation and long-term medication use (31). Consequently, severe neurological disability can initiate a descending cascade of complications including altered postures, musculoskeletal malformations and muscle and joint contractures, osteoporosis, overuse syndromes, pain, pressure areas and skin breakdown, respiratory compromise and infections, arthritis, urinary tract infections, obesity, reliance on others for daily cares and reduced self-efficacy (31–33). The NZ Disability Survey in 2006 found that 60% of people with disabilities reported multiple disabilities (25). Severe neurological disability as defined above with its secondary complications can have the potential to impact on an individual’s ability to be physically active.

### **2.2.2 History of Care in New Zealand for Individuals with Disability**

Little is known about the barriers to PA participation for individuals with severe neurological disability, especially those who live in residential care. In order to examine the barriers to PA participation for this group, it is necessary to describe the historical and current context concerning the nature of care for these individuals. Attitudes and services for individuals with disabilities have changed drastically in the last 150 years. In early 19<sup>th</sup> century NZ, individuals with disabilities were primarily supported by their families. Charities provided only small amounts of support and no taxpayer support was available (34) In the late 1800s ‘institutions’ were opened for

orphans, unmarried mothers and the elderly (35). These places also often included individuals with disabilities (34) as NZ society in the early 20<sup>th</sup> century fostered eugenic social beliefs (35) and institutional care, was encouraged and even legally required following the Mental Defectives Act of 1911 (36). At that time even children as young as five years old were placed in institutions, where residents had little personal identity and life expectancy was short (36). In 1924 a pension was established for people with sight impairments (34). This was well ahead of the social security reforms that led to the establishment in the late 1930s of the Invalids Benefit, a benefit available for people who were permanently unable to work (37).

As soldiers with mental illness and impairments returned from World War I this led to the general public becoming more aware of and gaining a greater understanding of disability. This positive turn led to a focus on rehabilitation, including therapies such as physiotherapy and speech and language therapy, with the aim that individuals with disability could integrate back into their society (34). No details regarding PA in these programmes are available from the public records, however it could be expected that participation in such therapies would involve participation in PA. Large institutions for individuals with disabilities often provided activities and a community way of life for their residents such as growing and harvesting vegetables (38), vocational training and sheltered employment (39). In about 1954, the focus on large institutions for individuals with disabilities started to be challenged by the community (34). Government funding started to be directed away from large institutions and instead towards building smaller residential services (34). Deinstitutionalisation continued during the 1980s, enabling people with disability to live either in their own dwelling or in care situations in houses within the community, thereby moving people back into the community.

Some individuals with disabilities are unable to live in their own dwelling or in a residential house as they require care and support unavailable at home or in a smaller residential house. Provision for such individuals in NZ is therefore via residential services where they receive full time care. Currently five percent of individuals with disabilities in NZ live in residential services, with five per cent of this group being

under 65 years old (25). Eighty two percent of adults living in residential care services require a high level of care, with one third of these living in hospital level care services (25).

## **2.3 Recommendations for Physical Activity**

Lifestyle, environmental and technological changes over the last century have resulted in greatly reduced amounts of PA as part of daily life, especially in higher income countries. As an example, the number of people working in agriculture, a very physical occupation, has dropped from 50% of the working population in NZ 100 years ago, to just 2% today (40). With the mechanisation of many manual tasks, and increase in computer use, more and more of the workforce are sitting for longer periods on a daily basis (40). The WHO estimates that physical inactivity is responsible for 3.2 million deaths worldwide annually (41). Furthermore, high-income countries demonstrate the lowest levels of PA. In NZ, Sport and Recreation New Zealand (SPARC) estimate physical inactivity to be responsible for over 2600 deaths annually (20). Owing to this increasing trend towards physical inactivity and the consequent burden of non-communicable diseases such as cardio-vascular disease, diabetes and cancer, national and international bodies now are heavily focused on the promotion of PA (1,10–14). As a result, evidence-based guidelines have been created aiming to guide both global policy makers and the general population towards increasing participation in PA.

### **2.3.1 International and National Recommendations for Physical Activity**

The World Health Organization (WHO) has created global recommendations for levels of PA for health (1) (appendix A). These guidelines provide advice on the four dimensions of PA, that is: amount, frequency, intensity, and type, for all age groups (1). In short these guidelines are for individuals to be physically active for 150 minutes of moderate intensity PA each week, with muscles strengthening exercises at least two days per week. Accrual of the recommended weekly quantities of PA can be from short periods of activity, that is, of ten minutes duration at a time (1). The American College of Sports Medicine (ACSM) has recently produced updated PA guidelines recommending that adults participate in cardiorespiratory exercise of moderate intensity for a total of at least 150 minutes per week, along with at least 75 minutes per week of

vigorous intensity exercise, or a combination of the two (2). In addition the ACSM recommends resistance exercises on two to three days per week, as well as flexibility exercises for each of the major muscle groups and neuromotor exercises such as coordination and balance exercises (2). The NZ Health Strategy (11) identifies increasing levels of PA and reducing obesity as two of their 13 population health objectives. The NZ health strategy has adopted and incorporated the WHO recommendations for PA into the strategy. According to the 2007/2008 SPARC survey, however, less than 50% of NZ adults met the internationally recommended levels of PA (42).

At a national level, The Hillary Commission created NZ guidelines for PA in 2001 (20) (appendix B). The intention of the NZ guidelines was to change public attitudes to PA, by promoting it as fun, low cost and by encouraging individuals to become creative and resourceful in incorporating PA into their day (20).

### **2.3.2 Physical Activity Recommendations for Individuals with Disabilities**

Individuals with disabilities have been shown to be substantially less likely to participate in the recommended amounts of PA compared to the general population (4–7). This may partially be due to incidental PA being difficult to achieve especially, for example, by those individuals with severe neurological disability who are reliant on aids for mobility. If the individual is reliant on a power wheelchair for mobility, taking the stairs is not going to be possible. Furthermore, personal, environmental and societal barriers may account for lower levels of PA participation. Therefore finding ways to be physically active may require a little more thought and planning.

The WHO state that their PA guidelines apply to people with disabilities, yet acknowledge that these guidelines may need to be adapted to meet the abilities of the individual (1). Whilst there are no international recommendations for PA in persons with disability, the 2008 Physical Activity Guidelines for Americans detail further recommendations for individuals with disabilities (13) (appendix C). Specifically, the guidelines encourage people with disabilities to become physically active by seeking

advice from health professionals to select and modify PA for the individual. The ACSM guidelines reinforce that PA needs to be tailored to the individual's physical function and health status as well as highlighting that adults will still gain benefits from participating in PA even if they are unable to meet the ACSM recommended levels (2).

### **2.3.3 Levels of Physical Activity by Individuals with Severe Neurological Disability**

Current evidence is that individuals with disabilities (16,43) including those with severe neurological disability (7,44), are less likely to participate in PA than the general population. The Healthy People 2010 (12) report states that 56% of adults with disabilities in the United States of America do not partake in any PA. A year prior to the commencement of this thesis, a behavioural mapping study was completed with individuals with severe disability living in the residential service used in this study. This study aimed to record the physical activity levels of residents through the most active part of the day, on two week days and one weekend day. Twenty participants (who were included if they were able to perform some PA), were observed every 10 minutes between the hours of 0700 and 1730 to see what activities they achieved in each 10 minute timeframe. This study was limited by a lack of recording when the participants were away from the residence and may have been completing PA in the community environment. Behavioural mapping is recommended as an objective measure for a small population that is bound in one physical location (17) and has shown validity in measuring PA levels of children (45,46) although this measure can be limited by participants being aware they are under observation thereby upping their levels of PA for the purpose of the study. The behavioural mapping study found that the individuals spent 79.9% of their day completing activities that required less than 1.5 Metabolic Equivalent of Task (METs) (8), indicating very low energy expenditure. This lack of PA is even more significant when considering that individuals with disabilities often exhibit significantly lowered baseline levels of cardiovascular health and fitness compared to the general population, thereby further increasing their morbidity and mortality risk (47). Although evidence demonstrates benefits of PA for individuals with disability, the nature of living with physical disability can limit participation in PA in many ways, for example due to reduced mobility, reduced coordination, and spasticity.

Demonstrated benefits of PA participation in people with disabilities include physiological improvements (for example increased cardiovascular fitness) (47–50), functional improvements such as improved mobility (50–52) and psychological improvements such as exercise self-efficacy (53). However, in studies where these benefits have been demonstrated, participants were ambulatory, and most often classified as having mild to moderate impairments (51). Individuals with multiple pathologies or those living in residential services are frequently excluded from research studies (32,53). Therefore the generalisability of health benefits from PA may not pertain to individuals with severe disabilities.

## **2.4 Barriers to Accessing Physical Activity for Individuals with Severe Neurological Disabilities**

Many factors hinder people from accessing PA. These include social, personal, financial, and environmental factors. These factors can be termed barriers to PA. The Ministry of Health in NZ suggests that a lack of time, other commitments and responsibilities, a lack of knowledge about available PA opportunities, and injury were among the commonly voiced barriers by the general population to participating in PA (54). Encouragingly however, a survey by SPARC (42) in 2007/2008 found that 57% of the surveyed adults wished to be more physically active.

From an international perspective, barriers to PA participation have been identified in a number of studies as arising from the personal, societal and environmental context of individuals with wide ranging disability (43,55–62). A study of barriers to exercise in stroke survivors living in the United States of America (USA) (57) found that the physical impairments from the stroke, a lack of motivation and environmental factors were the major reported barriers, although this was limited by a small sample size of 13 participants. Rimmer et al (2004) (56) explored this topic from a wider perspective, by interviewing individuals with disabilities, architects, recreation professionals and city planners. These informants added further barrier areas of cost, regulatory, emotional, information, attitudes and resource availability. In NZ, an individualised approach to overcoming barriers was recommended by Kayes et al (2010) (63) following qualitative assessment of individuals living with Multiple

Sclerosis. This study involved semi-structured interviews with 10 participants (seven females, 3 males) with low to high levels of self reported disability. Common barriers to PA synthesised from the literature are categorised in figure 2.1 below.

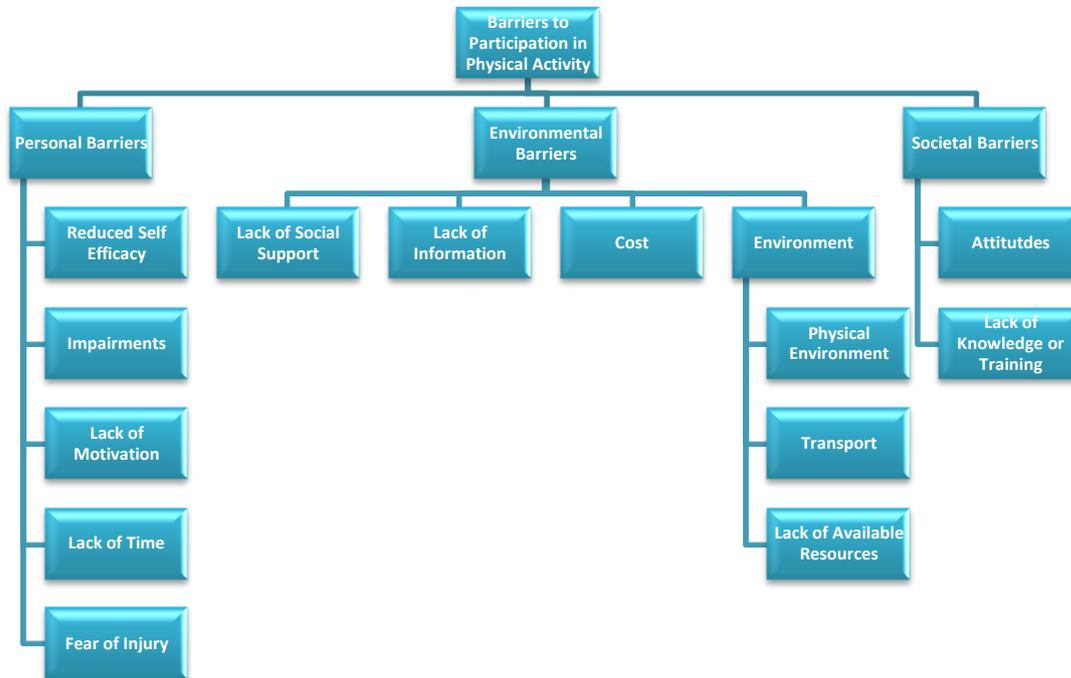


Figure 1: Barriers to participation in physical activity for individuals with disability

## 2.5 Facilitation of Physical Activity Participation for Individuals with Severe Neurological Disabilities

Many facilitators to participation in PA have been identified in both the general population and in people with disability. For the general NZ population, SPARC identified provision of social support, encouragement, advice on fitting PA into a daily routine and advice on appropriate forms of PA for the individual as facilitators to participation in PA (64).

In NZ, the NZ Disability Strategy underpins facilitation of participation in PA for individuals with disabilities (24). This document promotes the development of an inclusive society through elimination of barriers, including barriers to recreation (24). Specifically, facilitators have been identified as i) better education of recreation and sports organisations in issues related to disabilities and ii) supporting development of sports projects for individuals with disabilities (24). In interviews with individuals with disabilities, Rimmer (2004) (56) identified several facilitators to participation in PA which included a more accessible built

environment, more adaptive equipment, support for greater training and education for community centre employees, initial trial free passes to exercise facilities to allow trial before requiring membership and assistance from health professionals to transition from exercising during prescribed therapy to exercising in a community setting. Persons with impairments following a stroke identified social support, a planned activity to fill in the day and external motivators such as the need to walk the dog as facilitators to participating in PA (57). Both these studies were however completed in the USA and therefore may have limited transference to the NZ setting. Figure 2 illustrates facilitators to participation in PA which have been synthesised from the literature.

Health professionals also have a role in promoting individuals with disabilities into PA, although facilitating this can be limited by funding, prioritisation and resource availability (65,66). In summary, the identification of and use of facilitators can help overcome the barriers that present to a specific population in order to achieve participation in PA.

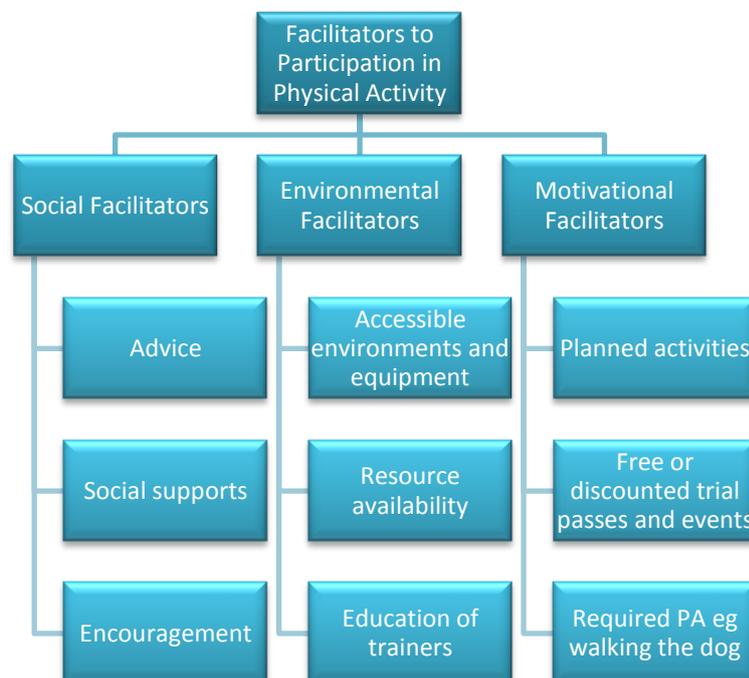


Figure 2: Facilitators to participation in physical activity

## 2.6 Aim

The aim of this thesis is to investigate and evaluate the processes required to implement community based PA for individuals with severe neurological disability who live in a residential service. Specific objectives are to i) identify barriers to PA participation for individuals with severe neurological disability in NZ, ii) identify strategies that enable PA participation by individuals with severe neurological disability who live in residential services, iii) gain insight into the processes required to minimise barriers and use facilitators to enable PA participation for individuals with severe neurological disability and iv) explore the experiences of individuals with severe neurological disability in participating in PA. This study aims to inform individuals with severe neurological disability, their families and support persons as well as health care professionals who work with individuals with severe neurological disability in facilitating participation in PA.

### 3. Methods

#### 3.1 Design

This study used a qualitative, bounded, case study methodology as described by Baxter and Jack (2008) (67) that included a series of five individual participants who lived in one residential service. Baxter and Jack (2008) (67) define a case study as being bounded by a specific context, that it is exploratory in reporting on a “situation in which the intervention has no clear single set of outcomes” (67 page 550) and that it is an attempt to investigate a holistic context with “imbedded units” (67 page 550). This study further meets the case study design defined by Baxter and Jack (67) as the contextual conditions (the residential care setting, the support workers, transport and community) of this case study are relevant to the study and as the physiotherapist and researcher, I was part of the study rather than purely an objective outside observer. The case study was bounded by being one residential service, at one point in time, one physiotherapist, and of one philosophy of care by the service. In this case study the imbedded units are the five individuals who live in one residential service. The physical activity and disability survey revised (PADS-R) (44) was used as a descriptive qualitative measure of the amount of PA participation completed by the participants to further describe the sample.

Participants presented with severe neurological disability (with complex and severe levels of impairment), which necessitated living in a residential care service. Because each participant has such individual needs for their care and daily life, I considered that a series of cases within the boundaries of a ‘case study’ (this being one particular residential service), would provide in depth and insightful information from which to inform a new area of research regarding promoting PA for individuals with severe levels of impairment. This approach would also identify and provide strategies that can be used to inform health care practices to promote and implement PA for this particular population.

The data consisted of individual semi-structured interviews with participants, field notes made up of observations of the participants by the lead researcher (who was also involved in

the study's intervention phase), reflections, discussions and suggestions by the research team and an advisory team, and a self reported survey on PA.

### **3.2 Participants and Recruitment Method**

One of the Northern Regional Ethics Committees (the Northern Y Regional Ethics Committee) granted ethical approval for this study. I recruited participants from a residential service for people with physical disabilities situated in a metropolitan area of New Zealand. The service provides hospital level care for individuals with physical disabilities who are under the age of 65 years old on admission. Depending on the needs of the individual, services include long-term care, palliative care or slow stream rehabilitation. At the time of recruitment, the service had 65 residents. Fifty four residents were living on one site and 11 in two community homes located elsewhere in the metropolitan area. Both sites were included in the recruitment. In consultation with members of staff at the residential service, individuals who met the inclusion and exclusion criteria (see table 1 below) were identified. Nine of the sixty five residents met the inclusion and exclusion criteria. This required that they were resident at the service, were reliant on a wheelchair, had the potential ability to participate in some form of PA, were able to communicate with the researchers by voice or via other communication device, and that they could take part in the interviews. I, as the lead researcher and the physiotherapist within the residential service, met each of the nine potential participants to explain the study, and of these nine, five consented to participate. They provided full and informed written consent in accordance with the ethical requirements for the study. Participation was voluntary and did not involve withdrawal from any activities or therapy intervention the participants were already receiving, that is, the study and its intervention were supplementary to existing activities and therapies.

Table 1: Inclusion and exclusion criteria for selection in the study

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>• Be a full time resident at the residential service</li> <li>• Be reliant on a power wheelchair or attendant to propel their wheelchair for the majority of their mobility</li> <li>• Be able to communicate either verbally or via technology such as a communication device in order to participate in interviews</li> </ul>	<ul style="list-style-type: none"> <li>• Inability to perform any voluntary movement of the limbs or trunk</li> <li>• Being medically unwell or unstable</li> </ul>

### 3.3 Data Collection and Intervention

Figure 3 illustrates the intervention and data collection process. I completed the interventions with individual participants over an eight-month period, with staggered start dates, so that up to three participant scenarios were running concurrently.

Over a period of eight months, I met with each participant individually in order to devise and facilitate a tailored PA programme. To begin this, the participant and I together explored and discussed what general and PA interests the participant held. In consultation with an advisory group (see description of this below), these ideas were shaped into what the participant and I perceived to be achievable in the participant’s local environment. The local environment could include i) the immediate living environment of the participant, that is within his/her residence or ii) the broader community around the residential service, including the wider metropolitan area. Each participant was encouraged to complete as many of the required decisions and organisational tasks as they were able in arranging to attend his/her chosen activity. For example, they were encouraged to review websites related to the activity, contact people necessary to be involved in the activity and enquire about cost of attendance. In addition, baseline levels of PA over the past week for each participant was collected by the lead researcher in consultation with the participant using the Physical Activity and Disability Survey – Revised (PADS-R) (44) .

Each participant and I then implemented the chosen activity for a period of six weeks. I aimed to attend to help set up the activity for the first one or two weeks only, with the intent that the participant would then be able to continue the PA with other support if required. After a period of six weeks, the participant and I repeated the PADS-R survey and undertook a semi-structured interview together. After this point, the participant chose whether to continue the activity, to stop the activity, or to take on a different activity, but was required to continue the activity by him/herself from this point on. It was aimed that by this stage the participants would have been empowered to continue with the PA themselves and have overcome the barriers through the intervention period. If further barriers were to arise, they would be able to refer back to me as the physiotherapist to assist in overcoming these. To add to the data, the PADS-R and semi-structured interviews were repeated again six weeks later to establish if the participant had continued PA.

To advise and support this study, an advisory group of health and recreational professionals was set up to communicate (via email) with the research team (myself and two research supervisors) at irregular intervals (normally at the start of an intervention for a new participant) to provide advice and suggestions on strategies and ideas for PA for individual participants. The group consisted of a personal trainer, a community physiotherapist working with individuals with multiple sclerosis and Parkinson's disease, and a local council community facilitator.

### **3.4 Data Sources**

I used several data sources. Because little is known about the facilitation of and the possible benefits of PA participation in the population of individuals with severe neurological disability, especially those who live in residential care, I therefore chose to use interviews, observations and a measure of PA, the Physical Activity and Disability Survey – Revised (PADS-R) (44) (appendix D), as sources of data for this study. In order to engage individuals with severe neurological disability in PA, the facilitators and perceived benefits of physical activity for them need to be understood. I therefore chose semi-structured interviews to record the participants' experiences and what this engagement meant to them. As I was also part of the case study, it was appropriate to collect my experiences of the case study as data.

These experiences were collected as field notes of my observations of the interventions as well as observations of comments and behaviours of staff or other residents in the facility that related to the interventions, in order to record overall observations and experiences. The Functional Independence Measure and Functional Assessment Measure (FIM+FAM) was used as a demographic descriptor of the participants' functional ability and was measured at baseline.

### **3.4.1 Physical Activity and Disability Survey –Revised (PADS-R)**

The PADS-R is a survey that measures levels of PA over the past week and has been modified to be more relevant to individuals with severe neurological disability hence the most appropriate for this population. The PADS-R survey captures data relating to reported PA completed in the past week. Reported participation in PA is recorded in six domains: exercise, leisure time PA, general activity, therapy, employment and wheelchair use. The overall score is then calculated through scoring coefficients and correlation matrices in a Microsoft Excel spreadsheet (68). A score of 0.0 is the mean score, a negative score signifies a low amount of PA participation over the past week and a positive score a higher than average level of PA participation compared to other people with chronic neurological conditions (69). Appendix E shows examples of the score make up over a range of PADS-R scores. The lowest score that can be achieved is -2.49.

I completed the PADS-R with the participant. If the participant was not able to provide all the information, this was supplemented with information from the individual's clinical records and the diary kept by the residential service to record outings of the residents into the community. Further information if required was gained from the residence's staff member/s who had responsibility for a particular participant's care. If this was required, the support staff member was not informed of the purpose of the requested information in order to reduce potential bias in the answers. I used the standard provided PADS-R Microsoft Excel template (68) to calculate scores for levels of PA.

### **3.4.2 Interviews**

I collected qualitative data via semi-structured interviews with the participants after six weeks of intervention using an interview guide with open-ended questions designed to elicit the participants' experiences and opinions of PA (appendix F). Interviews took place according to each participant's choice of time and venue and took approximately 15 minutes. Participants were encouraged to have a support person present if they wished to.

Interviews commenced with the question of "can you tell me the story of your starting the physical activity?" Questions and prompts were added in order to gain further clarification from participants for example "can you tell me more about that?" The interviews were audio-taped in their entirety and were then transcribed verbatim by the lead researcher.

### **3.4.3 Field notes**

I also kept a detailed log of field notes detailing the processes, challenges, and facilitators involved in interventions and the processes for completing the study. This incorporated personal reflections, personal observations and personal experiences at each opportunity of interaction with participants, and also reflections about the development and implementation of each participant's chosen PA. The field notes included documentation of discussions and decisions made in consultation with the participants, with the advisory group and the research group, as well as comments and observations from other people who became involved in implementation of the PA choices (for example volunteers or service managers). Field notes pertained not only to each participant, but were also written reflections of the developing series of participant interventions.

### **3.4.4 Functional Independence Measure and Functional Assessment Measure (FIM+FAM)**

The FIM+FAM is made up of an 18-item Functional Independence Measure (FIM) and 12 Functional Assessment Measure (FAM) items to give a total 30 item scale (70)

(appendix G). Each item is measured on a seven point ordinal scale with a score of one indicating the person requiring total assistance in the task through to a score of seven which indicates the person being completely independent in the task in a timely and safe manner. In this measure, the highest score achievable is 210, which indicates complete and safe independence in self-care activity, sphincter control, mobility, locomotion, communication, full psychosocial adjustment and cognitive functioning. The lowest possible score is 30 indicating full dependence in all of these domains.

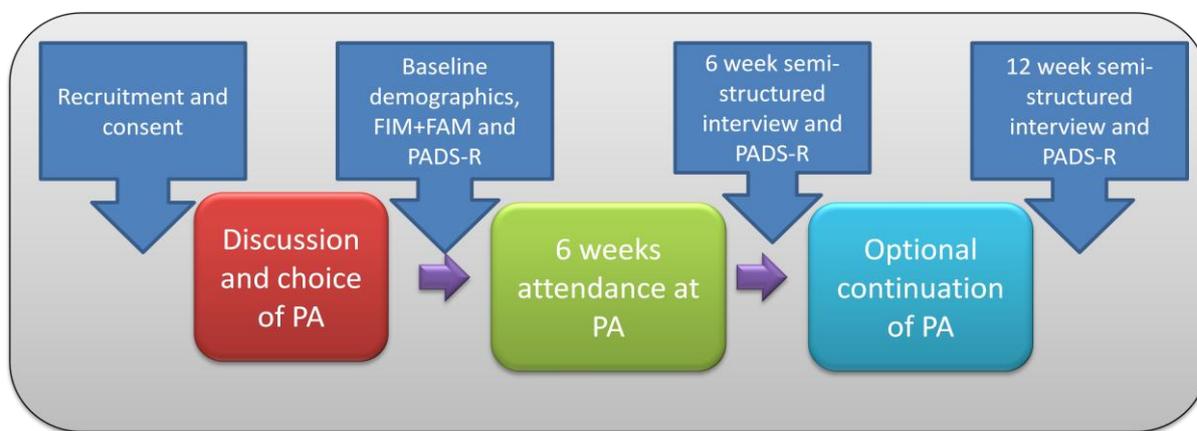


Figure 3: Flow chart of the phases of the study

### 3.5 Analysis

I used the thematic analysis method described by Braun and Clarke (2006) (71) as a method which offered the best fit to interpret and describe the data in this study. The general inductive approach of Thomas (2006) (72) was also considered as a potentially useful method of analysis. However Thomas' method focuses more on organising evaluative data into a model or framework, compared to Braun and Clarke offering a flexible approach to establishing phenomena from experiential data. Therefore Braun and Clarke's thematic analysis was felt to be the best fit for the type of data this study was collecting. Thematic analysis identifies patterns and themes evident within the data, keeping the richness of the raw data. Braun and Clarke (2006) (71) offer several distinctions in their description of thematic analysis. 1) Whether the purpose is for "a rich description of the data set or a detailed account of one particular aspect" (71 pg 11). 2) Whether the aim is "inductive or theoretical analysis" (71 pg 12). 3) Whether "semantic or latent themes" are to be identified (71 pg 13),

and 4) and define whether “essentialist/realist vs constructionist thematic analysis” is to be completed (71 pg 14). For this study the distinctions were defined as being 1) to achieve a rich description of the overall data set rather than targeting one particular aspect. This is because investigation of ways that individuals with severe neurological conditions can be physically active is an under-researched topic in a population whose experiences and views are unknown. 2) This was an inductive analysis (a bottom up approach where the data leads the formation of themes rather than trying to fit the data to pre-existing themes in a top-down style). 3) The analysis was looking for semantic themes where data is interpreted at the surface level rather than trying to establish underlying meaning behind the data, and 4) used an essentialist/realist approach whereby experiences of the participants are interpreted in a straight forward way rather than making an attempt to investigate or theorise sub-cultures within the data. The data set was analysed for each individual participant, and then across the series of participants, using data from the 10 interviews and five sets of field notes. The thematic analysis consisted of familiarisation with the data set through multiple readings to gain a greater understanding of the data. Similar concepts were then grouped together, for example, experienced benefits of PA. These broad groups formed initial codes. Initial codes sharing a common theme were then grouped to form potential themes. Themes, with sub-themes were reviewed, defined, and finally named to provide an accurate reflection of the overall story portrayed in the study.

## 4. Results

In order to best reflect the integral role of myself as lead researcher as well as being the physiotherapy provider for the residential service, these results are narrated in the first person. A description of each individual participant is presented below with the participant's health conditions, impairments, activities, and participation illustrated in the style of the World Health Organization's classification for Functioning, Disability, and Health (ICF). The descriptions of the individual participants are followed by presentation of themes that emerged from analysis of the case study. The themes reflect both individual (participants) and shared experiences (series of participants).

### 4.1 Participants

Table 2 details the demographics of the five participants. Two participants had a diagnosis of quadriplegic cerebral palsy, two of a stroke (one right sided, one left sided) and one person had a diagnosis of multiple sclerosis. All participants had one or more secondary conditions and co-morbidities. These included asthma, diabetes, heart disease, obstructive airways disease, obesity, renal dysfunction, skeletal malformation and contractures. The functional ability of the group indicated by the scores on the FIM+FAM showed a mean of 113.6 (range 96/210 to 141/210).

All five interventions were completed without any of the participants withdrawing from the study. Four of the five participants were successful in achieving their goal for their chosen PA. The fifth participant was able to identify and find a suitable PA but was unable to find the appropriate support required for him to enable regular attendance at the activity in the timeframe allowed by the study.

**Physical Activity for Individuals with Severe Neurological Disability Living in a Residential Service**

Table 2: Summary of demographics of the five participants

<b>Participant</b>	<b>Health Condition and Impairments</b>	<b>Secondary impairments, co-morbidities and secondary conditions</b>	<b>Age</b>	<b>Main mode of Mobility</b>	<b>Years since onset</b>	<b>FIM+FAM score</b>
One SK (Female)	Stroke resulting in right hemiplegia, dysphagia, poor saliva control, reduced speech intelligibility, and reduced insight, safety awareness and impulsivity.	Multiple previous strokes, asthma, obesity, type II diabetes, osteoarthritis of both knees and chronic obstructive pulmonary disease.	54	Attendant propelled manual wheelchair	2	114/210
Two CD (Male)	Quadriplegic cerebral palsy resulting in global spasticity and mild cognitive impairment.	Soft tissue contractures, skeletal malformation, bowel cancer resulting in colostomy, obesity	69	Power wheelchair	69	107/210
Three HR (Male)	Stroke resulting in right hemiplegia, spasticity of right arm and leg and nominal aphasia.	Soft tissue contractures, renal dysfunction, and overweight.	64	Power wheelchair	9	110/210
Four ZD (Male)	Quadriplegic cerebral palsy resulting in global spasticity.	Soft tissue contractures, skeletal malformation, mild intellectual impairment, restrictive airways disease and renal dysfunction	72	Power wheelchair	72	141/210
Five PD (Female)	Multiple sclerosis resulting in lower limb paralysis, upper limb muscle weakness, limited trunk control, bladder and bowel dysfunction	Soft tissue contractures, stuttering speech disorder	56	Power wheelchair	18	196/210

#### 4.1.1 Participant One – SK

SK is a 54-year-old woman who has been living in residential care for the past two years following a left sided stroke. Her dream is to one day return to living independently in her own home. The impairments that have the greatest impact on SK’s daily life are that of right hemiplegia, dysphagia, poor saliva control, reduced insight and safety awareness, and impulsivity. She also has complex co-morbidities of obesity, type II diabetes, osteoarthritis of both knees and chronic obstructive pulmonary disease. SK’s impairments, activities and participation are detailed in figure 4. SK is reliant on standby or light physical assistance and verbal prompts for standing transfers, bathing, grooming and dressing. She is able to walk short distances (up to 30 metres) with a two wheel/two caster walking frame and the assistance of one person. However, she fatigues easily, and therefore requires an attendant to push her in a manual wheelchair for the majority of her mobility. SK is able to transfer in and out of the passenger’s side of a car with assistance but is unable to drive or use public transport independently.

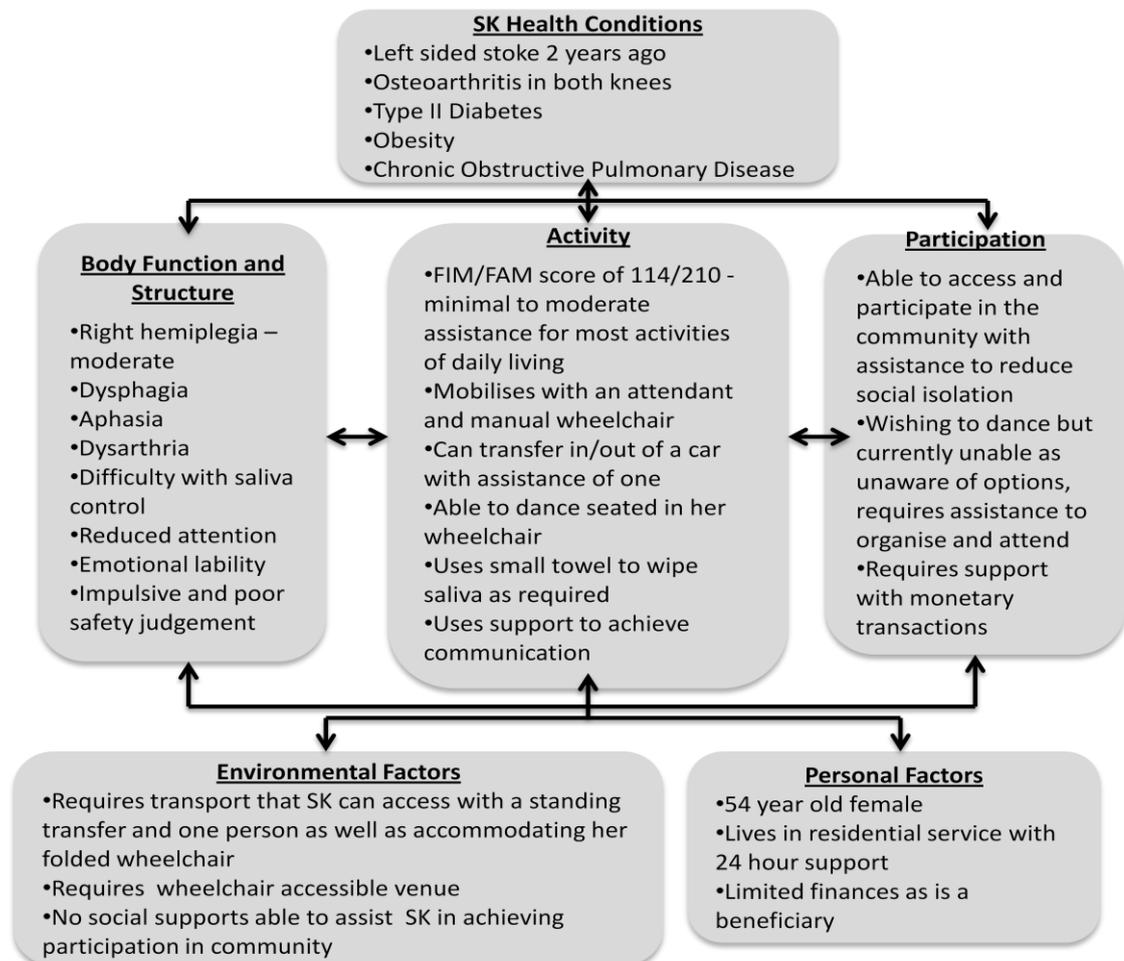


Figure 4: SK's presentation in relation to the ICF model of Functioning, Disability and Health

At our first interaction for the intervention phase of the study, SK expressed a wish to try dancing as her chosen PA. I consulted with the advisory group members by email to ask for suggestions to access dance activities for SK. Being reliant on an Invalids Benefit for income, she has limited finances. She also requires help from a support person when out in order to access transport and ensure her personal safety because of her impulsivity. One member suggested a mixed abilities contemporary dance group that is active in the city that SK resides in. I accompanied SK to a public performance of the dance group, which she thoroughly enjoyed and expressed interest in dancing with this group. SK and I together wrote an email to the dance group teacher to ask about the possibility of SK attending the classes. The teacher was very willing to include SK in classes, so I arranged transport and accompanied SK to the first class. SK found the class to be enjoyable and appropriate for her and she very much wanted to continue to attend. However, I needed to find a suitable support person to help her attendance because of the challenges with transport and SK's personal safety. This person would need to be available once a week during school term times (which is when the classes run), have a full driver's licence and access to a vehicle, be physically able in order to push a wheelchair and assist SK with transfers in and out of the car as well as being able to fold and lift the wheelchair in and out of the car. It would also be preferable that the support person enjoyed contemporary dance and could participate in the class as needed. SK did not have any family or friends who would be able to complete this role. Together, SK and I decided to advertise for a volunteer via liaison with the volunteer coordinator of the residential care service. SK and I wrote an advertisement which was placed by the volunteer coordinator on the internal communication notice board and around internal emails. Although the advertisement was intended to be advertised externally as well, through a miscommunication with the volunteer coordinator, this did not happen. SK and I received no response to the internal advertising and I therefore accompanied SK to a full term's classes on a voluntary basis. A volunteer was finally recruited when a staff member at the service overheard my conversation about the lack of response to our advertisement for a volunteer to assist SK to attend dance classes. The staff member mentioned that her daughter could be interested because she had completed her tertiary studies, therefore had some spare time, and loved contemporary dance. This volunteer proved to be very competent and appropriate for the position.

SK's participation in dance classes has continued into a third term and she has recently participated in the dance group's annual public performance.

#### **4.1.2 Participant Two –CD**

CD is a 69-year-old man with quadriplegic cerebral palsy (CP) which has resulted in global spasticity and a mild cognitive impairment. CD also has secondary impairments and co-morbidities of soft tissue contractures, skeletal malformations of his spine and limbs, bowel cancer resulting in a colostomy and is obese. He has been reliant on a wheelchair for mobility since he was a child and now uses a power wheelchair. CD uses a hoist for transfers and requires full assistance for his daily care activities. Once in his chair, CD chooses how he spends his day. He particularly enjoys running errands for staff in the residential service. He delivers mail and assists with shifting items with a small trailer attached to the back of his power wheelchair. CD requires some support when out in the community especially for any tasks that requires reading or writing, because, being of a generation where children with disabilities were not taught literacy, he was not taught to read or write. CD is reticent to engage in new situations that require interaction with unknown people or tasks and accordingly needs time to become familiarised when engaging in an unfamiliar setting. CD's health presentation is detailed in figure 5 below.

On first meeting with CD after he had consented to participate in the study he quickly identified that he wished to have an activity based around animals, specifically dogs. On further exploring of how this could be made possible, CD suggested that he may be able to assist one of his long-time friends to exercise her dogs. This friend already visited the service with her dogs once a week to provide pet therapy for the residents. CD and I discussed this with the friend who agreed to set up a time for CD to throw a ball for the dog on a weekly basis, on CD's request that this take place in the grounds of the residence. Given that the dog's owner has impaired mobility, a further support person was required to assist CD in exercising the dog. One of the service's permanent volunteers who usually accompanies residents on outings or assists them to use the computer, was available and keen to assist with the dog exercising activity each week. Throwing a ball was challenging for CD because of his muscle weakness, soft tissue

contractures and skeletal changes of his fingers, wrists, elbow and shoulders and dystonic movement patterns in his upper limbs. CD's style of ball throwing therefore required some problem solving. Over a period of two weeks, the most efficient throwing techniques for CD was identified by trialling various factors including the tilt of his wheelchair, a "ball thrower" (a plastic device that holds a ball in its claw and has a long handle that can be flicked to release the ball at speed) and different sizes and properties of balls.

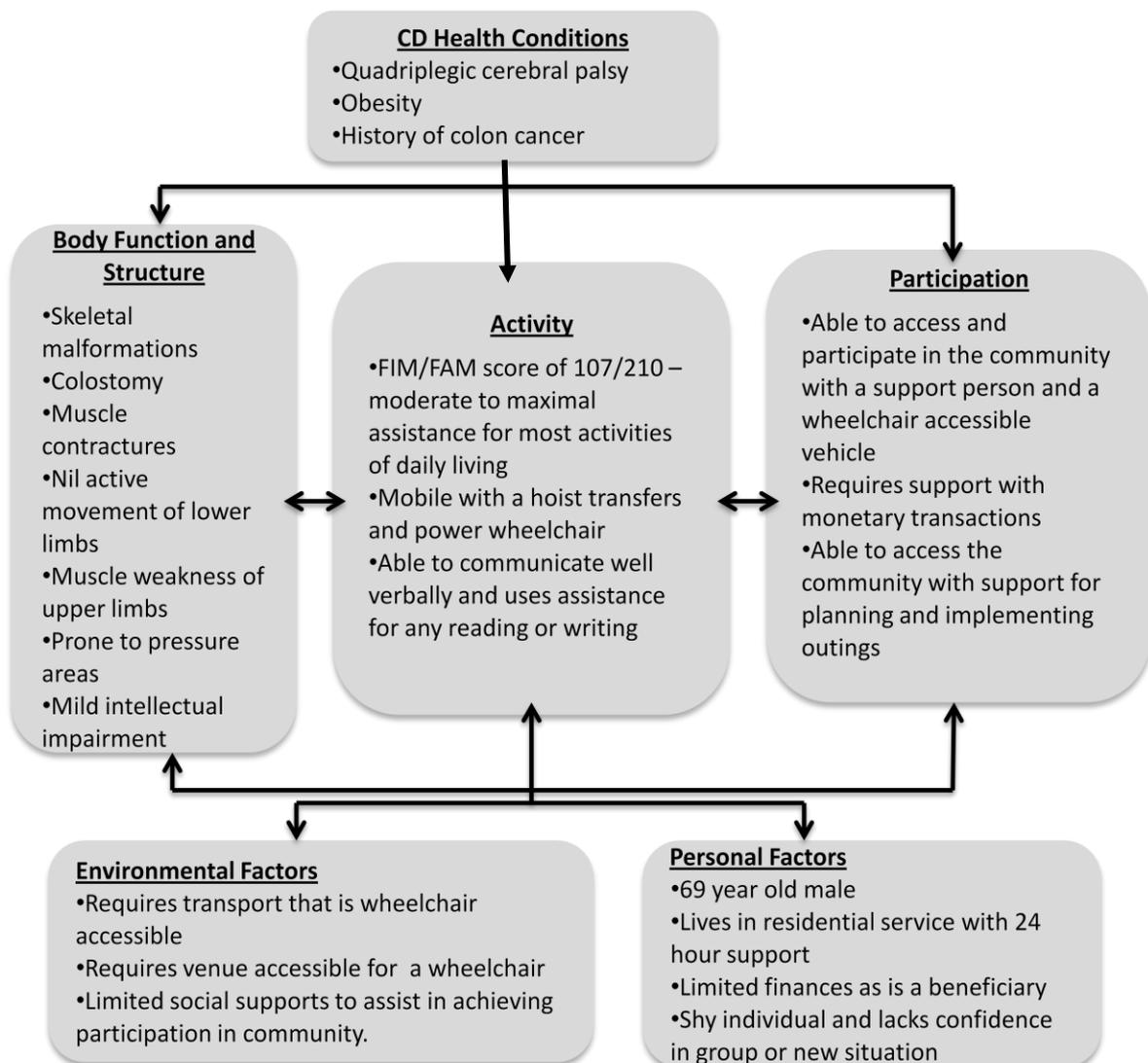


Figure 5: CD's presentation in relation to the ICF model of Functioning, disability and Health

CD continued his dog exercising for the six-week intervention period. Over this time, CD greatly improved his throwing ability (from initially achieving about 10 throws of one-metre distance during a 30 minute session to 40 throws of five to eight metre

distances in a session). There were, however, limitations to this activity: inclement weather prevented the activity on two of the sessions, and the dog's lack of interest in fetching the ball meant that the volunteer was kept occupied fetching the ball or trying to motivate the dog to fetch the ball. Over the weeks, a number of other residents observed the activity and joined in with CD's dog exercising sessions. After the six weeks, CD chose to discontinue the dog exercising activity, stating that he enjoyed it but was keen to try another PA. By 12 weeks CD had not restarted this activity or sought another activity independently, as was intended when setting up this study. Although he remained keen to try another PA he appeared unable to independently initiate any ideas of possible activities or how he might access them.

#### **4.1.3 Participant Three – HR**

HR is a 64-year-old man who resides at one of the service's community homes. HR had a left sided stroke nine years ago, which resulted in his move into residential care. He has residual right sided hemiplegia with spasticity in his right arm and leg, and nominal expressive aphasia. HR has soft tissue contractures of his right calf and elbow, wrist and fingers, renal dysfunction and is overweight. He is able to participate in his daily care routine, although he requires one person to assist him with showering and two people for dressing. HR completes all his own shaving, hair and teeth brushing. HR transfers between his wheelchair and bed using one person to assist with a standing transfer and he uses a power wheelchair for all of his mobility. In physiotherapy sessions, HR is able to walk with assistance of two people and a gutter frame for up to 100 metres. Although HR has a strong connection with his family, they are all living overseas at present, so HR currently has little local social support. He enjoys watching sports especially rugby and takes pleasure in socialising with people often proudly talking about his family. He enjoys contributing to everyday life at his community home, for example taking out the recycling to the bin each day and setting the table for meals. Figure 6 below summarises HR's health condition.

After HR had consented to be a participant in the study, I met with him to discuss his interests for PA. Coincidentally, in the previous week, I had organised a volunteer to meet with HR on a weekly basis at the community home as a social contact. When I

asked HR about his interests for PA, he responded that he had already started playing pétanque with this volunteer. HR had been given the pétanque set for Christmas by his sister but had not played it with anyone until the volunteer started visiting. It was therefore interesting to discover that once the opportunity was available, HR had spontaneously initiated playing pétanque. Throughout the six-week intervention period, HR required minimal input from me, simply to acknowledge that he was continuing to play and that it was working well with his volunteer. In addition, he chose to continue with the activity beyond the 12-week monitoring period. HR also extended the opportunity to be physically active to other residents at the community home by inviting them to participate in pétanque and by including them in other activities (for example card games and board games) in the time spent with the volunteer. He spoke repeatedly in the interviews about the social aspect that pétanque and other games afforded him, and of how important having the social interaction of the volunteer was to him.

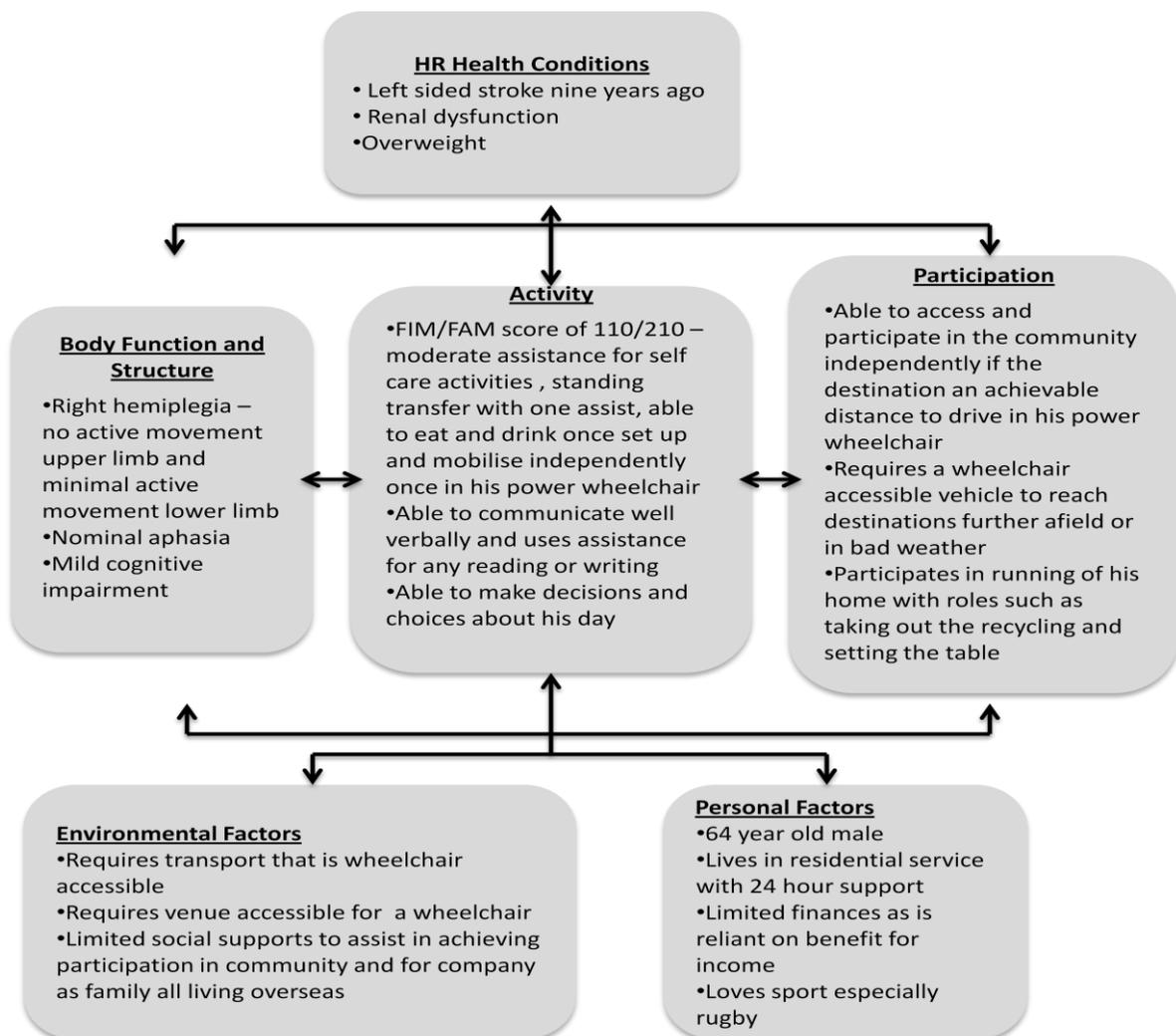


Figure 6: HR's presentation in relation to the ICF model of Functioning, Disability and Health

#### 4.1.4 Participant Four – ZD

ZD is a 72-year-old man with quadriplegic CP. ZD requires full assistance with the majority of his self-care activities, but is able to complete his grooming independently once set up with the equipment he requires such as his electric razor or comb. ZD uses a hoist for all transfers and a power wheelchair for all mobility. Once ZD has had assistance to transfer him into his power wheelchair he is independent and often leaves the grounds of the residential service to watch the traffic go by on the main road into the city. ZD enjoys outings into the community. For this, he requires a wheelchair accessible vehicle and a support person. ZD enjoys cars and aircraft, woodwork and bowls. He also enjoys helping others out with any tasks he can manage to do in his wheelchair, for example carrying flattened cardboard boxes to the recycling area. ZD's closest family support (his siblings and their families) live an hour's drive away. Figure 7 details ZD's health condition further.

When I first met ZD to discuss options for PA, he suggested power wheelchair racing. Once we had discussed that this did not in fact involve PA, he suggested bowls. ZD had previously played bowls when it was a scheduled activity at the residence. However, in order to play bowls, he required an adapted gutter shoot, to hold the bowl and align it with the target. Consequently, he had found that he had limited involvement in actually bowling the bowl and was disappointed by this. A member of the email advisory group suggested boccia as an appropriate activity that ZD may be interested in. Boccia is an adapted form of indoor bowls played by people with physical disabilities. The players throw the different density leather balls over arm, bowl them underarm, or push them down a gutter depending on the player's ability. I described the game of boccia to ZD and together we looked at pictures and descriptions of the game on the internet. ZD was keen to try the game. I therefore contacted a local sports and recreation organisation for people with physical disabilities. They were able to provide us with information on the local options and invited us to attend a session to ascertain if the game suited ZD. The sessions were on a Saturday morning, 35km across town from ZD's residence. Because the residential service's wheelchair accessible van is available on a Saturday for residents to use for personal reasons, I was able to take ZD to the session using this van.

We found the Boccia members were very welcoming, explained the game, and gave ZD the opportunity to trial the game. ZD was pleasantly surprised to find he was more able in boccia than he had been in standard bowls and was therefore also more physically active in boccia than in standard bowls.

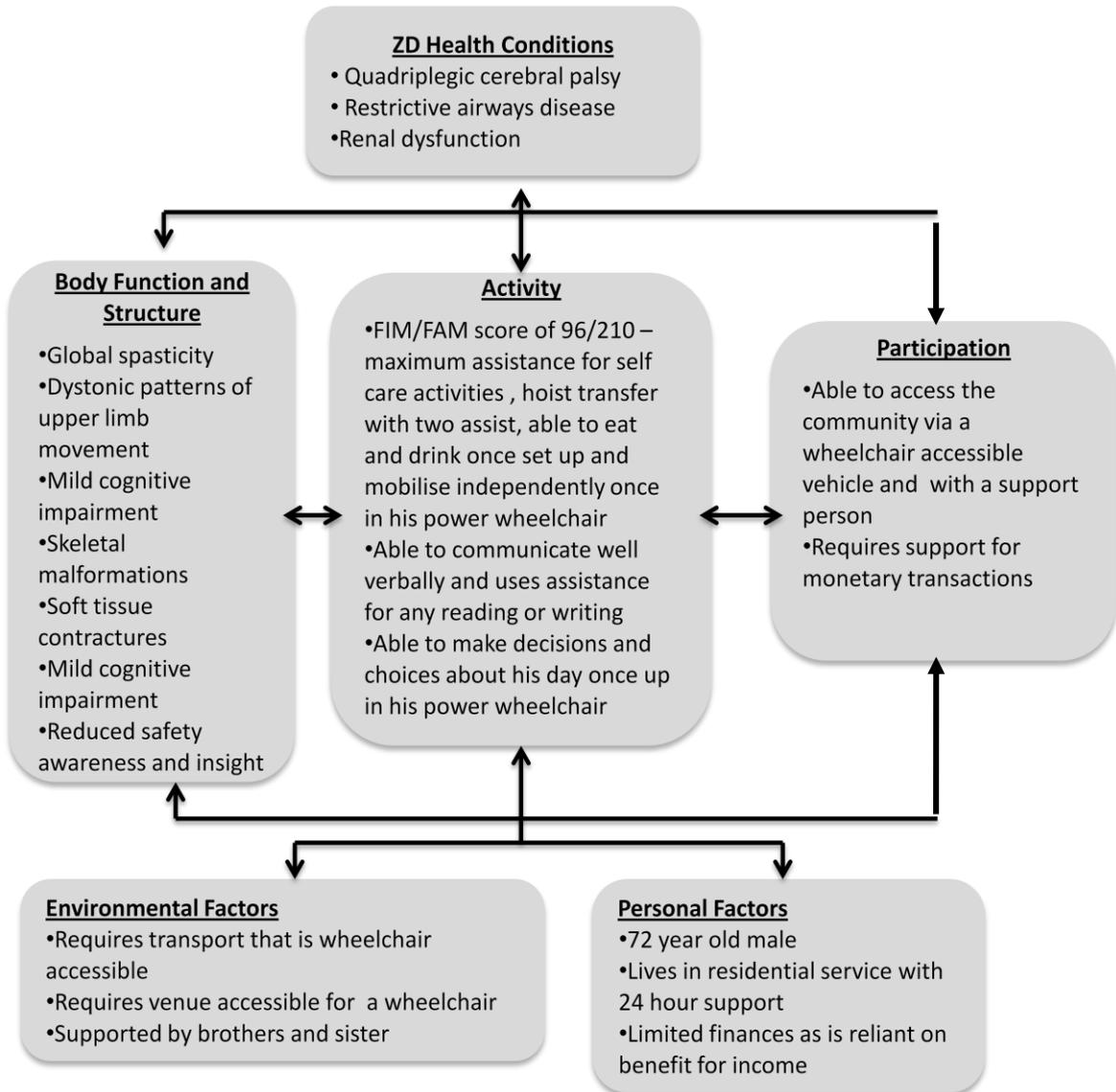


Figure 7: ZD's presentation in relation to the ICF model of Functioning, Disability and Health

The cost of club playing membership was \$40 for the year. ZD was keen to start playing boccia on a weekly basis. As he felt unable to explain Boccia himself, he asked me to speak with his brother who manages his finances about spending this amount of money for this type of activity. His brother was happy for ZD to spend the \$40 per year membership. Although his brother was keen to transport and accompany ZD to the

game each Saturday, he found that it clashed with the church service he and his family attended weekly. We decided that as the residential service's van was available on Saturdays we could use this as transport for ZD instead of a taxi, as taxi costs would be prohibitively expensive. We did however then require a volunteer who was able and willing to drive the van so that ZD could be transported to boccia each week. I consulted with the residential volunteer co-ordinator who advertised for a volunteer both internally (through staff emails and on notice boards within the residential service) and externally (through local church groups and volunteer recruitment agencies). As the six and then 12 week intervention periods passed, we were unable to recruit a suitable volunteer. Disappointingly, although we explored other options around using staff to drive the van, or suggesting the use of car-pooling with other boccia players who lived in the vicinity, we were not able to find a solution by the 12 week point. Therefore ZD did not participate in boccia except for the first trial session.

#### **4.1.5 Participant Five – PD**

PD is a 56-year-old woman who was diagnosed with multiple sclerosis 18 years ago. She now resides in one of the service's community homes. The multiple sclerosis has resulted in bilateral lower limb paralysis, upper limb muscle weakness, and limited trunk control. Her health condition is detailed in figure 8. PD transfers using a sliding board technique with the assistance of two people and uses a power wheelchair for all her mobility. PD often independently drives in her power wheelchair to the local shops but to go further afield requires a wheelchair accessible vehicle. PD lacks confidence in social situations owing to a childhood stutter that has recently returned. PD plays a significant role in the running of her community home. This includes ordering the fruit and vegetables, planning menus and setting the table for mealtimes. She enjoys following sport, especially netball. PD has two daughters who live in the same city and visit her often.

After PD had given consent to participate in the study, I met her to discuss her PA interests. She quickly identified netball as the PA of choice. I suggested joining a school team to assist with their drills and practises. PD however suggested that it may be less challenging for transport and its associated costs if other netball players were to come to

her residence, given there was a netball hoop at the community home. PD also put forward the suggestion that there was another resident in the home who could join in and possibly benefit from PA in the form of netball.

We therefore needed to find a volunteer or volunteers who would be willing to come to the home weekly to play with PD and the other resident who was keen to play. Since we did not require the volunteer/s to provide transport (and therefore did not require someone over 25 years of age for insurance purposes) and were looking for people who would be willing to play netball as a community service, the volunteer coordinator of the service suggested approaching a school that participates in community service activities. I contacted a local school with this suggestion. The result of this was that two 17 year old girls volunteered to come each week to play netball with PD and the other resident that PD had invited to join in. As all volunteers recruited to work in the service have to undergo an interview to deem their suitability for the position and complete a police security check, PD assisted with this by alternating with me in asking and answering questions and completing the paperwork necessary for this volunteer recruitment. PD also explained her disability to them and explained the type of support she would require to play netball.

The two volunteers attended for three weeks during the school term and then had a break during the school holidays. However, following school holidays they did not recommence the sessions. When I telephoned them to check the reason, they explained that they were overcommitted with sports and activities and were unable to continue as volunteers for the netball with PD. By this time, PD felt that the weather was getting too cold for outside activities and had instead initiated playing badminton indoors with staff members. PD had herself purchased a badminton set and balloons. She used a balloon instead of a shuttlecock as a balloon gave more time for the lining up of shots. PD declared that badminton was her preferred activity until the weather warmed up. She stated that she would be keen to recommence the netball in the summer.

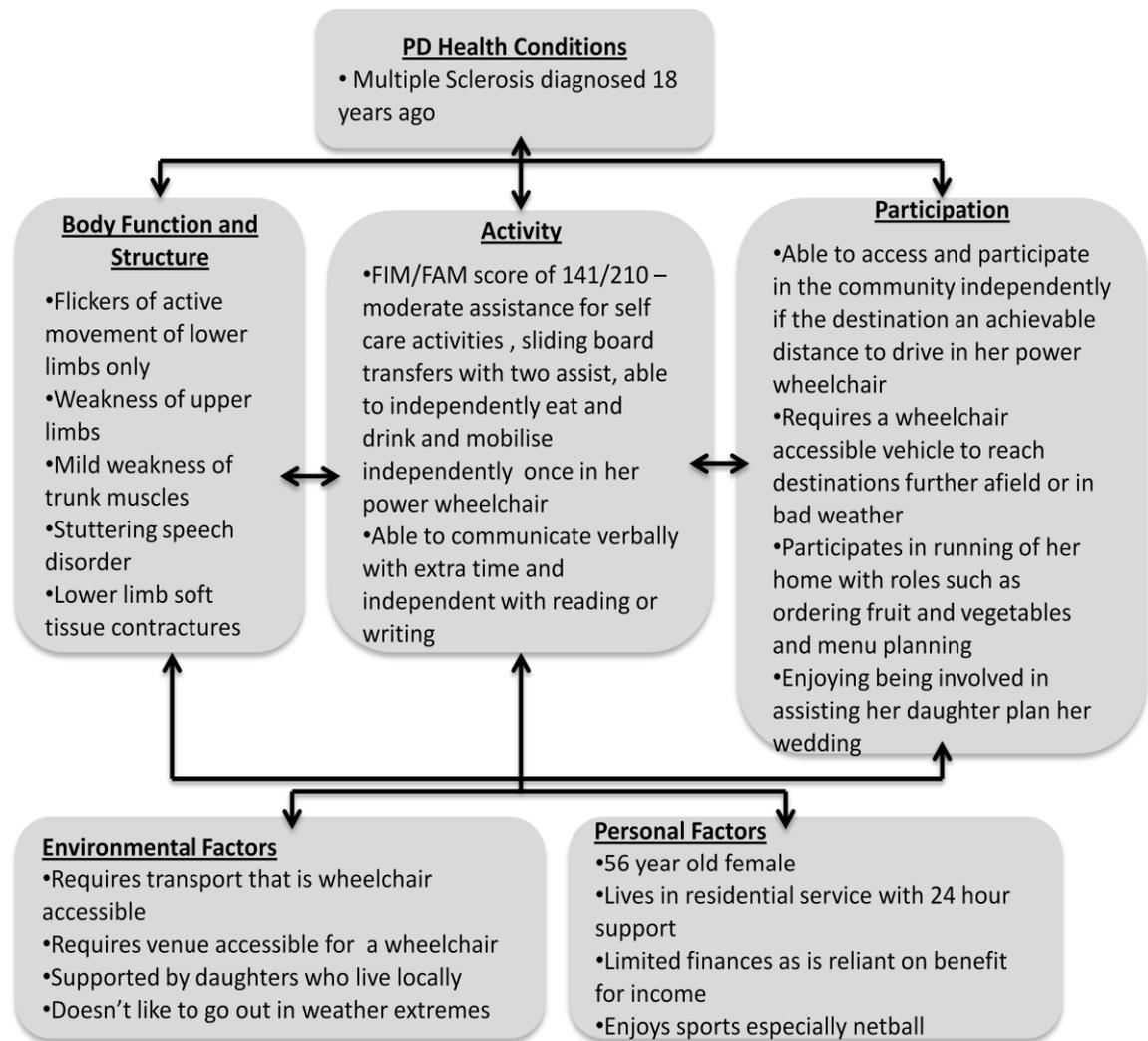


Figure 8: PD's presentation in relation to the ICF model of Functioning, Disability and Health

#### 4.2 Physical Activity and Disability Survey – Revised (PADS-R)

The PADS-R scores of participants are presented in table 3. The PADS-R measures level of PA over the past week. We had aimed to use the PADS-R scores as a measure of the participant's PA and as a supplementary evaluative measure of each participant's level of PA from the intervention. The PADS-R uses a Microsoft Excel template (68) to calculate the score. For the interpretation of the PADS-R, a higher score is said to indicate a relatively greater level of PA participation over the past week. However, the scores for the PADS-R of the participants in this study need to be interpreted with caution. This is because on analysis, I uncovered an inaccuracy in the scoring formulae. This inaccuracy results in individuals who use a power chair receiving a higher PA score than individuals who propel a manual chair. The anomaly remains even when there are equal levels of PA in the other categories. This

means that it may not be a useful measure to quantify PA activity for individuals such as our participants. In addition, on calculating intra-participant scores, I discovered a further error where if the participant participated in active therapy (thereby increasing their levels of PA), they achieved a lower score than when not receiving therapy. As a result I am unable to compare PA scores across participants. Consequently, although PADS-R scores of my participants were collected and calculated (table 3), they have limited value for analysis except as an intra-participant measure. In addition, this must discount ZD who received further therapy within the time of the study intervention. I have notified the author of the PADS-R measure of the scoring anomalies.

Table 3: PADS-R scores of participants at baseline, six and 12 weeks

<b>Participant</b>	<b>PADS-R baseline</b>	<b>PADS-R six weeks</b>	<b>PADS-R 12 weeks</b>	<b>Wheelchair used</b>	<b>Therapy input over intervention period</b>
SK	-2.99	-2.20	-2.20	Manual wheelchair	Stayed the same
CD	-2.43	-2.05	-2.43	Power wheelchair	Stayed the same
HR	-2.00	-1.39	-1.47	Power wheelchair	Stayed the same
ZD	-2.14	-2.65	-2.65	Power wheelchair	Added therapy between 0 and 6 week point and continued this to 12 week point
PD	-2.14	-0.90	-0.90	Power wheelchair	Stayed the same

Taking these above limitations in the PADS-R scoring into account, some comparisons can still be made. All participants achieved very low levels of PA at baseline. SK, DC, HR and PD all were successful in achieving participation in a PA and this increase in PA participation can be seen in an improvement in their PADS-R score at six weeks compared to their baseline score. CD elected to discontinue his chosen PA at six weeks and this is reflected in his 12

week PADS-R score returning to that of his baseline score. SK's baseline score, which is the lowest score of all the participants, reveals the scoring anomaly, as SK used a manual wheelchair which she self propelled at times, versus the other four participants who all used power wheelchairs. Logically, SK should have achieved a better score as she was participating in PA by propelling her wheelchair. Similarly, ZD's score is illogical as his score worsened when he added therapy to his activity levels, even though all other factors were consistent.

### **4.3 Analysis for Themes**

Three broad themes, with several sub-themes, were evident from the data. These are summarised in table 4. The three themes were: 1) There is more than one road to Rome, 2) Benefits and barriers, and 3) The ripple effect. I have described these themes and sub-themes more fully in the sections below. Narration is again in the first person. Initials after quotations identify the participant followed by the source of the data. 'All' denotes a field note or note from researcher meetings from across all case studies. I have used the term 'participant' when referring to the individual and the term 'case' when referring to the experience and events of that participant's progress through the intervention. Data from across the series of all five participants is labelled as 'the case'.

Table 4: Summary of themes

Theme	Sub-theme	Description
1) There is more than one road to Rome	1a) Address the barriers	The most frequent barriers that were found during this study were finding suitable transport and the availability of volunteers. It was necessary to address these in order to achieve the desired activity.
	1b) It takes time and planning	Extra time and planning was required in setting up the activities compared to what had been expected when proposing the study.
	1c) Use your networks and resources	Using already available networks and resources accelerated the process in achieve the PA.
	1d) Keep it simple	Keep to the desired activity and keep it simple. The simplest ideas and activities were the ones that were the easiest to accomplish and maintain.
	1e) Flexibility allows things to happen	Flexibility was required in order to modify activities to the needs of the individual. This also involved challenging preconception about the ability of individuals to choose and problem solve around barriers and managing unpredicted events as they arose.
2) Benefits and barriers	This theme demonstrated the physical and emotional benefits that the participants achieved were the same as any other member of the population as well as the verification that the motivations and challenges in achieving PA were the same as for the general population.	
3) The ripple effect	Over the timeframe of this study, it was observed that the participation and benefits of the PA could flow on to further activities, benefits, awareness and participation beyond the original five participants' activities.	

#### 4.3.1 Theme one: There is more than one road to Rome

This first theme, “there is more than one road to Rome”, encompasses the realisation that there is more than one route to reach a goal, with some routes taking longer than others. The theme demonstrates a combination of perseverance, creativity, and challenging of preconceptions to achieve the desired goal of PA. The theme has five sub-themes: i) address the barriers, ii) it takes time and planning, iii) use your networks and resources, iv) keep it simple, and v) flexibility allows things to happen.

##### *a) Address the barriers*

I first had to identify then address barriers to participation in order to progress towards the goal of PA. Of all participants’ barriers to participation, the most common were availability of suitable transport (wheelchair taxi’s are not available around the start and end of the school day because they are required to transport school children with disabilities to and from school) and cost appropriate transport, and the availability of suitable volunteer or support staff. ZD identified a transport barrier to accessing his PA of choice:

*So in other words I am stuck on that side of it [in regards to transport] because I couldn’t go by taxi because it costs. (ZD six week interview)*

For one participant, when barriers such as transport were not present, the participant, HR, had spontaneously started the PA himself. Using a pétanque set he had been given as a gift, he had taken the opportunity that presented of having a volunteer visit on a social basis, to initiate physical activity. I reflected on this in my notes:

*If the barriers aren’t there, people may initiate the activity themselves. This seems to back up the idea that people with disabilities want to take part in PA but the barriers mean it doesn’t happen. Once the barriers were removed, the PA happened spontaneously. (Researcher’s field notes about HR)*

At times, however, it appeared that sensitivity or an expectation regarding barriers is inflated; that there are preconceptions and assumptions about potential barriers that do not or may not come to fruition. For example when SK went to a first trial of her dance class, the director discussed the cost with SK and me. The cost for one term (about two months) was \$60. I assumed this would be a barrier to SK's participation, but my preconception was challenged by the director and SK:

*The director of the company explained the cost and stated 'however I wouldn't want this to be a barrier so if she was unable to pay, this could be negotiated'. My thoughts were that this is the director's income and I was therefore surprised to have her volunteer this. I guess we expect some barriers that may not actually be that concrete. (Researcher's field notes about SK)*

*I can pay. I get my benefit every week. It's worth it. (SK 6 week interview)*

*b) It takes time and planning*

Time and planning, over and above what we as a research team had anticipated for the setting up of an intervention, often resulted in delays in commencing the proposed PA. Issues of time and planning frequently were points of discussion within the research team. The recruitment of appropriate support personnel, often on a voluntary basis, proved the most time consuming and limiting.

*No further replies were received from the advertisement for a volunteer... It took longer than a full school term to find an appropriate volunteer. (Researcher's field notes about SK)*

In addition, planning for attendance and participation in the activities required us to be creative and work through all of the possible scenarios to find solutions. As one example of this, SK required particular planning for the potential that she have a hypoglycaemic episode while dancing. Because the dance class was held at what

would be her usual mealtime, I therefore had to undertake time and planning with the residential service's kitchen and staff to arrange for her to have a snack before leaving the premises and to take a snack with her to consume should she show signs of hypoglycaemia. This was complicated by her dietary needs because of her swallowing difficulty for certain types of food. Therefore in order to meet her modified diet, I liaised with the speech language therapist and we decided on a banana as a snack before leaving the premises and for SK to carry a container of seedless jam in case of hypoglycaemia.

Innovative thinking and problem solving was also necessary to create alternative methods to achieve the desired PA task for CD:

*CD tried throwing a tennis ball which he was able to throw only approximately 20cm with it then rolling about a metre. [The volunteer] had a ball thrower and brought this along to trial. CD however didn't have enough wrist movement to be able to launch the ball and preferred to throw the ball freehand. He tried different sized balls and the tennis ball proved the most successful. We tried putting his power chair into some tilt to improve the trajectory of the ball and this improved the distance thrown to a couple of metres. (Researcher's field notes about CD)*

*c) Use your networks and resources*

We found that using already available resources, personal contacts and networks accelerated the process of setting up the activity and the recruitment of required support personnel. In addition, use of already present opportunities made things easier:

*AB: So whose idea was the netball?*

*PD: Well there's always been a netball pole down around further, I thought well if I buy a ball then we can use it. (PD 6 week interview)*

Contacting and liaising with communities that have a focus on community service such as schools or church groups, made it simpler to recruit appropriate support persons as volunteers.

*Valuable resources are groups who are committed to community service eg Duke of Edinburgh award groups, volunteer agencies and also use resources such as a local council accessible community's facilitator or schools with a community service focus.*  
(Researcher's field notes about PD)

*d) Keep it simple*

Consistently over the interventions, simplicity appeared to be the key to success in setting up and being able to maintain PA. As the researcher I had intended on creating simple activities, hoping that this would mean fewer barriers to overcome and a greater chance of success in setting up and maintaining the activity. On reflection however, I realised my ideas were still far too complex. As an example, I had envisaged an activity in the local community and away from the resident's home to be assisting in netball drills with a local school team. However, when I suggested this to PD, she suggested it would be better for people to come to her at her community home to save her the cost and inconvenience of travel.

*It struck me that even though I set out to aim for simple activities, even with this aim though – I was aiming for too complex. The motto seems to be keep it REALLY simple.* (Researcher's field notes about HR)

This idea was also identified by one of the participants:

*AB: What would you suggest to people with disabilities who wanted to start some physical activity?*

*HR: Do something easy at home.* (HR 6 week interview)

*e) Flexibility allows things to happen*

In order to achieve the desired PA task, I found that everyone involved needed to be flexible in their preconceived approaches. This included challenging the researchers' own preconceptions. One preconception was that participants would wish to complete their PA out of their home environment, and to be included in the local community. This however was contrary to the wishes of three of the participants (HR, PD and CD). All of these participants preferred to be PA in their own living environment. HR described his thoughts about the location of his PA here:

*AB: Do you mind that it's [the PA] not in the community?*

*HR: I'm not interested in going out. I don't even bother going to the shop. Not interested in going to the shop. (HR 6 week interview)*

I reflected across the series of participants on this in a field note:

*Instead of the people with disabilities going into the community, why not bring the community to the people with disability? We talk of integration but why do people with disabilities have to integrate into the general community? Why not meet half way – breaking down of the boundaries between the residential facility and the community. It's not that people with disabilities don't want to participate in PA – if the barriers are taken away, PA may evolve. If given the resources, they may self-initiate. (Researcher's field note)*

Over the series of participants there were obstacles that, even with extensive planning, limited the participation in PA for the participants. Some of these were inclement weather, the inconsistency of volunteers, or the lack of interest of a dog to fetch a ball thrown to it. CD commented on this:

*I didn't do every week because some weeks it was too hot and then it was raining or something like that so you couldn't be outside so there was one or two weeks missing. (CD 6 week interview)*

*AB: What about the reliability of people coming in?*

*PD: Oh makes it awkward. That time of day too for school kids. It would be nice a bit earlier but with school, young ones, you've got to fit, you've got to fit in with them too...They were [reliable] for a starter but then with school they each have long holidays and also their exams too. (PD 6 week interview)*

*AB: Can you tell me what the best bit of doing the activity was?*

*CD: I think the best bit was throwing the balls at the dogs. But then the dogs didn't go and chase the ball, they kept running away from the ball (laughs). (CD 6 week interview)*

Therefore, flexibility about expectations for PA also needs to be a factor when planning PA participation.

#### **4.3.2 Theme two: Benefits and barriers**

This theme encompassed the outcomes of the intervention and the overall experience for the participants. All of the participants were able to identify benefits of their PA, personal goals and revealed that their motivations or lack of motivation for PA is the same as their non-disabled peer group. Benefits included improvements in physical ability, identification of enjoyment of the social contact and emotional benefits. SK expressed emotional benefits and HR social benefits:

*AB: How does dancing make you feel?*

*SK: Good inside [taps chest]. (SK 12 week interview)*

*AB: What has the best bit been?*

*HR: The company. (HR 12 week interview)*

ZD described the universality of his Boccia experience:

*AB: So it's easy?*

*ZD: Yeah it is. For anybody.*(ZD 6 week interview)

CD chose throwing a ball for dogs as his PA. He showed improvements in his physical ability of throwing. Where he had initially been throwing only 10 throws in a session with a maximum distance of one metre:

*The volunteer came to tell me on week four to come and have a look at how far CD was throwing the ball – with the tennis ball and without tilt of the chair he was now having the ball go five to eight metres and completing around 40 throws in one session. (CD researcher's field notes)*

PD also identified physical benefits as well as social:

*"...[benefits] of throwing the ball up in the hoop bit of exercise for my arms... And it was good to meet young people too [the volunteers]." (PD 6 week interview)*

For SK her participation in dancing prompted her to form life goals:

*If I keep going I might become a teacher. That's my goal. (SK 6 week interview)*

Her dancing also prompted SK to identify physical and activity based goals that now seemed more achievable:

*Yes I don't want to sit in the wheelchair anymore. [If you exercise] you get skinny. I want to learn how to go to the toilet and get off the toilet. (SK 6 week interview)*

The participants identified many of the same motivations and challenges towards PA as the general population face. SK focused on losing weight as one motivator for her continued participation in dancing:

*I want to lose this [indicates stomach]. (SK 6 week interview)*

CD identified the variability in motivation in choosing to participate in his PA:

*Sometimes I feel like doing it and sometimes I don't. (CD 6 week interview)*

### **4.3.3 Theme three: The ripple effect**

The third theme I have labeled the ripple effect. This describes the flow on effect beyond that of the five participants in this study. Because of participation in PA by the participants, and the discussions that this entailed with staff and other residents at the residential facility and its two community houses, I noticed more attention and enthusiasm towards PA spreading through staff (including management staff) and other residents:

*After the first two participants I noticed an increase in awareness of PA of residents with staff – managers talking about ways to facilitate greater participation using my study participants as examples. (Researcher's field notes)*

Participants also extended the ripple effect themselves by inviting other residents and staff to join in their PA:

*AB: Does anyone else join in?*

*HR: Yeah my neighbour [another resident]. I might see if some of the staff will play it. HR (6 week interview)*

*And also the other day [names support worker], [HR] and I went out, that was good too. [HR] did really well with one hand, geez it was amazing. Did well. Got them in. Did he what. So, so, something else different to do. And even one girl [names a support worker] went out with me one day [and] played with the ball. (PD 6 week interview)*

The ripple effect was further demonstrated with participants initiating further PA including sourcing resources:

*PD: I enjoyed it but then again we are starting to different things which I am enjoying too now.*

*AB: Yeah? Like what?*

*PD: Like the badminton bats and also the ball, the blow up ball, very good fun ..... it [the badminton set] was left there last night and [names two support workers] and I played it. Good fun. So I think I will buy some bats to keep at the home now so then other people can when they are bored. (PD 6 week interview).*

These themes and results along with the limitations of the study will be discussed in the next chapter.

## 5. Discussion

The aim of this study was to investigate and evaluate the processes required to implement individualised modes of community based PA for individuals with severe neurological disability who live in a residential service. This study entailed a bounded case study consisting of five individual participants living in one residential service. The data was analysed for themes across the series of participants. I identified three broad themes with sub-themes ie 1) There is more than one road to Rome, 2) Benefits and barriers, 3).The ripple effect. The discussion will identify both novel findings from this study and how some of our results support studies with similar aims. In summary this study clearly demonstrated through themes that it is possible for individuals with severe neurological disability who live in residential care to participate in PA. Success is facilitated by a number of factors including: choosing PA that is of personal interest to the individual, addressing the barriers, allowing more time and planning than expected, using existing networks and resources, keeping the chosen PA task simple and being flexible. This research also revealed that participants in this study had similar goals, motivations for, and perceived the same benefits of being physically active as anyone in the general population. Furthermore, the facilitation of PA for the five participants led to participation in PA for other individuals in the residential service who were not participants in this study.

Of note is the low number of participants who met the inclusion and exclusion criteria in order to be considered for the study. Of 64 residents living in the service, only nine met the criteria for the study, though the criteria were not overly stringent. This illustrates the complexity of impairments experienced by residents at this service, who were excluded because they were unable to perform any voluntary movement (which would be required in order to participate in PA) or were unable to communicate in order to be able to participate in interviews. This might explain why people with complex conditions are commonly excluded from studies investigating participation in PA or barriers and facilitators to PA. It is reassuring however to discover that, with perseverance and a unique and individualised approach, it is possible for individuals with severe and complex conditions to participate in PA.

Barriers to PA for individuals with neurological disability are commonly cited in the literature (55–57,63,75–79). Kirchner *et al* (78), in identifying environmental factors that act as barriers for individuals with physical disabilities, advised that strategies to overcome barriers need to be individualised and would be expected to take greater time, cost and effort than for the able bodied population. For example, their participants reported altering planned routes to overcome problems with narrow footpaths or a lack of curb cuts. The existence of barriers was also evident in the current study, with the most frequent being the availability of appropriate transport options and support staff. Four of the five participants required a wheelchair accessible vehicle with a wheelchair hoist and driver to access venues away from their residence. The fifth participant was able to transfer into the front seat of the car but only if her support person was trained in how to assist her to do this and furthermore, knew how to pack the wheelchair into the car. Although wheelchair accessible taxis are available in the city where this study took place, they commonly provide limited availability especially around the starting and finishing time of the school day, as the taxis are pre booked to transport school children in wheelchairs to and from school. Therefore for those participants whose preferred PA required transport between the hours of 8:00 - 9:30 am and 2:30 - 4:00 pm, this form of transport was unavailable, thus presenting a barrier to attendance and requiring further problem solving.

Literature commonly cites the cost of attendance at recreational programmes as a barrier (56,77,80). A review study in 2012 (75) identified that the cost of accessing suitable venues and recreational programmes was an important barrier from the perspective of people with disabilities. Our study however found that it was not the cost of attendance at the PA that was perceived as being the main barrier, but the cost of transport. Cost was an important consideration for the participants in our study as all were reliant on an Invalid's Benefit for income and this may have been a point of difference to participants in studies conducted in countries other than NZ. An Invalid's Benefit is a Government funded weekly payment for people who are severely limited in how much they can work owing to long term disability, sickness or injury (37) It is possible that health professionals advising persons with disability about PA engagement might perceive potential barriers as real barriers and that this preconception might in itself become a barrier, thereby resulting in reduced promotion of PA by health professionals. For example, one study that interviewed physiotherapists who were

working with individuals with chronic neurological conditions about their perceptions, found that physiotherapists acknowledged promotion of PA for their clients as part of their role, but perceived that the environment and the health care system limited them in doing this (65). This fits with my misperception of cost as a barrier in SK's case study.

Successfully setting up and completing the chosen PA with participants required greater time and resources (especially support persons) than was initially anticipated. Like Kirchner *et al* (78) in their study with people with visual or motor impairments identified, I also found that the participants and I needed extra time and planning in order to overcome barriers. For example, recruitment of an appropriate volunteer for one participant took more than 12 weeks. In this study I experienced greater speed and success in setting up the chosen PA with the participant if already known networks and resources were utilised. This included using existing volunteer staff members who were already familiar with the participants as they had already proven a reliable commitment to the residents and had existing skills in supporting individuals with severe disability. Using existing volunteers also reduced the time involved in completing security checks, checking references and training time required for the role. However, in recruiting new volunteers, contacting groups that demonstrate a dedication to community service, such as schools or church groups, proved to accelerate the recruitment of volunteers, as did having a personal connection to the groups (for example contacting a school where you know someone on the staff). Other successful recruitment occurred through incidental contact, for example, through a conversation about the difficulties in recruiting a support person being overheard by someone who was able to fill that role. As the participants and I experienced, making use of own personal and professional informal networks and available resources to draw upon creates more efficient and effective possibilities for participants. Since conducting this study, the residential service is now in the process of creating a "friends of" supporters and community stakeholder's electronic network which would create a further network to draw upon. This is a similar approach to that promoted by Gingras (81) to enhance community relationships and collaborative programming between services in order to maximise resources.

The initial intention of our study was to find PA ideas that fitted the participants' interests and abilities. Some of the early ideas were however found to be too complex and required further

refinement in order to be achievable. Also due to a series of predicted and unpredicted events, a high level of individualised flexibility was required for participants to continue with their PA. In order to optimise success, frequent problem solving and consideration of alternative solutions was required. It was interesting to discover that it was frequently the participants who challenged the complexity of the task and offered simpler and consequently more successful options. Three of the five participants chose to have support persons come to their home and assist them with completing their chosen PA there. This challenged our ideas that residents would want to participate in PA activities that were integrated into and available in the wider community. Literature and policy (24,79,81,82) encourage full integration of individuals with disabilities into society. Van de Ven *et al* (83) defined integration as consisting of a number of elements, one element being an individual taking part in and contributing to their society. Each of the participants had the choice of location for their PA and three chose their own environment, for its familiarity, simplicity and the reduction in barriers, especially transport and cost. This preference fits with a study by Milner and Kelly in 2009 (84) where individuals with disabilities in NZ identified that they enjoyed the security, comfort and predictability of an environment known to them and where support persons understood their needs.

Before this study, our perception of community participation related more to encouraging people with severe disabilities to leave their place of residence. I propose that participation might be better considered as a person's place of residence being recognised as part of the community as suggested by Hammel (85), and individuals should have the choice to pursue PA on their own terms rather than being required to fit into standards defined by social and health care policy. It could be argued that this preference for activity in the home setting and reluctance to go out into the community is brought on by long term residence in an institutional setting where residents' daily events are structured. Long term residence can create an institutionalisation where residents dislike variance from their daily routine and lack confidence in situations outside their own environment. However, two of these participants (HR and PD), who chose to have the PA in their own home, had health conditions acquired later in life. This would indicate that institutionalisation may be less of a factor, and that it was individual choice that had more of an influence on PA in this population. It may be a point of consideration for other service providers including physiotherapists and possibly

warrants further research to investigate why inclusion into the wider community is conceived to be a desirable action for people with disabling conditions. Milner and Kelly (2009) (84) reinforce this with their proposal that the path to community inclusion is not unidirectional where individuals with disability access the general community, but should involve the able bodied community also coming in to the environment of individuals with disabilities.

Participants in this study recognised the same motivators as for the non-disabled population in PA participation. They perceived benefits and motivators of losing weight, working towards achieving physical goals, and the emotional benefits of social interaction and enjoyment of completing PA. One of the participants also acknowledged his variability in motivation towards PA, which has been identified as a barrier in stroke survivors (57) as well as in the general population (64). This demonstrates that PA is important for everyone, and even though these participants were unlikely to achieve the levels of PA participation as the general population or PA guidelines, they still achieved positive benefits. This is reinforced by the ACSM guidelines (2) which states that if people are unable to achieve the recommended levels of PA participation they can still receive benefits through a dose-response relationship.

The ripple effect represented the observed flow on effect towards participation and enthusiasm for PA beyond the five individual cases to other residents and staff of the service. It appears that the modelling of examples of participants becoming PA and how this highlighted successful participation in PA, led to other residents and staff partaking in PA beyond that of the research study. Previous research has shown that individuals with CP living in residential care were less physically active than their peers living in the community (55). On closer examination this study identified that the difference was heavily influenced by the attitudes of the caregivers towards PA, so that where caregivers had a negative attitude towards PA, then their residents did not participate in PA. This study therefore supports the concept that the attitude of support staff is an important consideration in participation in PA, in that with enthusiasm and participation of staff, the participation of residents increased. It also suggests that if staff members are able to observe the benefits of PA for individuals with severe neurological disability, and can learn through modelling experiences as to how PA can be modified and integrated into the daily routine of the service, then participation levels of the

residents may rise. Physiotherapists therefore have the potential to facilitate change through modelling of PA participation.

It would be expected that health care professionals (for example physiotherapists) who work with individuals with severe neurological disability would have greater awareness of barriers and also strategies for their clients to access PA (although a preconception of barriers has also been shown in our attitudes towards integrated PA participation for our participants). However, access to health care professionals for individuals with severe neurological disability is often limited by restrictions. Therefore individuals with disability themselves, and their care givers and family need to be equipped with the strategies to overcome these barriers, in order to be more successful in achieving chosen PA.

## **5.1 Data Sources**

This study utilised two data types. Qualitative data was collected from participant semi-structured interviews and field notes. Supportive descriptive data was collected through the use of the PADS-R questionnaire and the FIM+FAM measure of functional ability. During the semi structured interviews it became evident that participants had great difficulty in responding to broad, open-ended questions even with the use of further direct questioning and prompts. This difficulty may have been partially due to the cognitive impairments present with the majority (four of five) of participants, however this does not fully account for these limitations. It is possible that individuals who live in residential care learn to depend on those who care for them to make decisions and, although support persons aim to involve residents in all decisions, it may be rare that they have the opportunity to express their opinions or are expected or provided the opportunity to speak at length about their thoughts and feelings. This may be why the residents found it difficult to provide full answers and required more direct questioning. Adults following a traumatic brain injury (TBI) have been previously shown to have dysfluency in conversation, with reduced narration, greater listener burden and with frequent omissions (86). Although none of the participants in this study had a TBI, their impairments were similar to that of a TBI especially as regards to receptive and expressive communication, concentration, and memory. Therefore the findings in this study may also be applicable to this study. Mobile methodology, a method where participant interviews take

place while immersed in journeys to places of significance to them (87), might be an appropriate methodology to use in future in this population.

Although the interviews provided valuable and insightful information, such as participants revealing their life goals and benefits of PA, more detailed descriptions of the participatory experiences would have been useful in order to dissect further the knowledge they realised. The field notes provided a record of the experiences, observations and reflections over the series of participants. This data proved to be very useful in that it added depth and description to support the limited, but valuable, voiced experiences of the participants in the interviews

The PADS-R was collected in order to help further describe the observed effects of PA for our participants. The PADS-R is a questionnaire that measures PA participation over the past week and has been modified for people with chronic neurological conditions (44). The PADS-R measures PA in six domains (exercise, leisure time PA, general activity, therapy, employment and wheelchair use) and calculates a score using scoring coefficients and correlation matrices in a Microsoft Excel template. However, during the analysis phase of this study I discovered inaccuracies in the scoring formulae (refer to section 4.2). These inaccuracies may not have previously been detected as the participants in this study were much more limited in levels of PA than populations involved in the development and testing of the survey (44). I have contacted the author of this measure to advise of these anomalies (appendix H) (69). I suggest that in its current form, the PADS-R is not suitable for use in a population that is reliant on wheelchairs for mobility. It may be that the most suitable and accurate measure of PA levels for this participant group would be time in motion analysis where participants are observed at regular intervals throughout the day to record all their activities, although this approach involves extensive time and resources to complete (17,88). Pedometers and waist mounted accelerometers, commonly used methods of measuring levels of PA in research (89,90) would be precluded for studies that included participants with the level of mobility as in our study, as pedometers and accelerometers require an ambulatory population. Wrist accelerometers are a possibility because they can be used in individuals who propel their manual wheelchairs with their upper limbs as they measure the acceleration of the body part where the unit is attached rather than the absolute acceleration of the body (91). However there is as yet no literature establishing if they are accurate with individuals

who use power wheelchairs. The use of heart rate monitors as a PA measure could be confounded by other factors such as medication or co-morbidities such as autonomic dysreflexia (88), factors especially prevalent in a population such as I have used in our study.

## **5.2 Limitations and Recommendations**

Several limitations exist within this study and these will be discussed in relation to 1) the study design and methodology and 2) the results.

### **5.2.1 Limitations in Study Design and Methodology**

This study used a bounded case study design as described by Baxter and Jack (2008) (67). Other designs considered were participatory action research (92,93), and mixed methods (94) however the case study design was felt to be the best fit for the aims of the study, the participants and the environment. A key factor which resulted in selection of a bounded case study design was the positioning of my own participant role as physiotherapist within the context under observation. A limitation of using this study design however was criteria stated by Baxter and Jack that “you cannot manipulate the behaviour of those involved in the study” (67 pg 545) and as the both physiotherapist and an external observer/researcher, it could be argued that I did manipulate the behaviour of the participants.

As the physiotherapist participant, I worked alongside the participants promoting as much independence from the residence in setting up their chosen PA as possible. However as residents in this service did not usually engage in any sort of PA of their choice prior to implementation of this study, this combined with their complex levels of impairments, did often require considerable input and guidance from me. Whilst I made detailed field notes and attempted through these to separate my roles of participant and researcher it is highly probably that this dual role influenced the data analysis in a different way than if I had not been involved in both roles. As the researcher I also completed recruitment, the baseline measures, PADS-R measure and semi-structured interviews as well as the analysis rather than these being completed by a blinded and impartial external assessor. Whilst this data was intended to assist in more fully describing the qualitative data, the scoring again may have been influenced by my roles as both physiotherapy participant and researcher.

### 5.2.2 Limitations in Results

I had not anticipated the briefness of participant descriptions in response to open-ended questions and found that it was necessary to ask more specific questions during the interviews in order to elicit participant experiences and opinions more fully. In future studies, in order to gain meaningful qualitative data with greater ease, it would be worth exploring other options. One such example could be the use of photography to elicit conversation and discussion (95,96) or mobile methods (interviews of participants while they are immersed in a journey) (87) may also be appropriate. In addition, until the identified anomalies in the use of the PADS-R have been attended to by the authors of the instrument, this approach to measuring levels of PA is of limited use.

Future research should be directed to establishing and developing further PA opportunities for individuals with severe neurological disabilities and should include larger sample sizes and outcome measures appropriate for measuring the levels of PA, for example using ‘time in motion’. The PADS-R measure was not accurate in measuring PA in our population. An appropriate and accurate survey or tool is required so that further research into either developing the PADS-R or another tool for this purpose is required.

## 6. Conclusion

This research is novel in that it explores the process of facilitating PA in a participant group (severe neurological disability in a residential setting) that is commonly under-represented in the literature. The results offer a positive message to individuals with severe neurological disability both living in residential care and in their own homes regarding strategies to achieve higher levels of meaningful PA.

This study found that it is possible, with support, for people with severe neurological disability to achieve participation in individualised PA. However, success requires time, problem solving, identifying and utilising available resources as well as addressing known barriers. Participation in PA appeared valuable to the participants, with them identifying benefits and life goals. As well as benefits to our participants, we discovered a ripple effect of promoting PA that went beyond the intervention group. This study informs individuals with disabilities and their support persons, health care professionals who work with individuals as well as people who provide PA opportunities or funders of health care for individuals with disabling conditions that necessitate residential care, about ways for their clients to achieve health and well-being via PA for their clients and the benefits they may receive from it.

## 7. References

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## **8. Appendices**

### **8.1 Appendix A-World Health Organization global recommendations on physical activity for health**

#### **16-65 year olds**

- Adults aged 18–64 should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous-intensity activity.
- Aerobic activity should be performed in bouts of at least 10 minutes duration.
- For additional health benefits, adults should increase their moderate-intensity aerobic physical activity to 300 minutes per week, or engage in 150 minutes of vigorous-intensity aerobic physical activity per week, or an equivalent combination of moderate- and vigorous-intensity activity.
- Muscle-strengthening activities should be done involving major muscle groups on two or more days a week.

#### **65 years and older**

- Adults aged 65 years and above should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate- and vigorous intensity activity.
- Aerobic activity should be performed in bouts of at least 10 minutes duration.
- For additional health benefits, adults aged 65 years and above should increase their moderate intensity aerobic physical activity to 300 minutes per week, or engage in 150 minutes of vigorous intensity aerobic physical activity per week, or an equivalent combination of moderate-and vigorous-intensity activity.
- Adults of this age group, with poor mobility, should perform physical activity to enhance balance and prevent falls on three or more days per week.
- Muscle-strengthening activities should be done involving major muscle groups, on two or more days a week.

- When adults of this age group cannot do the recommended amounts of physical activity due to health conditions, they should be as physically active as their abilities and conditions allow.

Reference: World Health Organization. Global recommendations on physical activity for health. [Online]. 2010 [cited 2011 Jan 1]; Available from:  
URL:[http://whqlibdoc.who.int/publications/2010/9789241599979\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241599979_eng.pdf)

## 8.2 Appendix B - New Zealand Guidelines for Physical Activity

1. View movement as an opportunity, not an inconvenience.
2. Be active every day in as many ways as possible
3. Put together at least 30 minutes of moderate-intensity physical activity on most if not all days of the week.
4. If possible, add some vigorous exercise for extra health and fitness.

Reference: Sport and Recreation New Zealand. Movement = health: a resource for health professionals [Online]. 2005 [cited 2011 Apr 16]; Available from:  
URL:[http://www.moh.govt.nz/moh.nsf/Files/grx/\\$file/movement-equals-health.pdf](http://www.moh.govt.nz/moh.nsf/Files/grx/$file/movement-equals-health.pdf)

### **8.3 Appendix C - 2008 Physical Activity Guidelines for Americans Recommendations for Adults with Disabilities**

- Adults with disabilities, who are able to, should get at least 150 minutes a week of moderate-intensity, or 75 minutes a week of vigorous-intensity aerobic activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.
- Adults with disabilities, who are able to, should also do muscle-strengthening activities of moderate or high intensity that involve all major muscle groups on 2 or more days a week, as these activities provide additional health benefits.
- When adults with disabilities are not able to meet the Guidelines, they should engage in regular physical activity according to their abilities and should avoid inactivity.
- Adults with disabilities should consult their health-care provider about the amounts and types of physical activity that are appropriate for their abilities.

Reference: US Department of Health and Human Services. 2008 physical activity guidelines for Americans. [Online]. 2009 [cited 2010 Jul 25]; Available from:  
URL:<http://www.health.gov/paguidelines/pdf/paguide.pdf>

## 8.4 Appendix D - The Physical Activity Disability Survey (PADS) Revised Version (August 2007)

This questionnaire asks you questions about the types of **exercise** and **physical activities** you participated in over the **last week** and the time you spent doing these activities.

If you compared the activities you took part in over the **last week** to the activities you would take part in on a **typical week**, would you say you did (please circle):

Much less than usual	Less than usual	About the same as usual	More than usual	Much more than usual
1	2	3	4	5

### 1. EXERCISE

Did you exercise in the **last week**? Exercise is any activity you do on a regular basis for the primary purpose of increasing or maintaining fitness. Please note: this does not include activities you do for leisure or recreation.

YES		NO	
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If **NO**, please go to question 2

If **YES**, what kind of exercise did you do?

Please list the exercise activities below that you did in the **last week** for the primary purpose of maintaining or improving your health and fitness. For each activity indicate the activity type and intensity (using the keys below), how many days per week you did the activity and how many minutes per day.

#### Activity types

- A = Aerobic Exercise (aerobic activities are those exercises done for a sustained period of time which result in an increase in your heart rate and breathing rate e.g. walking, jogging, attending an aerobics class, bicycling, etc)
- S = Strength Exercise (strength activities e.g. lifting weights or using elastic bands or weight training machines, pilates, core body strengthening & stability, tai chi, etc)
- F = Flexibility Exercise (flexibility refers to activities that involve muscle stretching e.g. yoga, etc)

#### Intensity

- L = Light activities - don't sweat or breathe heavily
- M = Moderate activities - breathe a little harder and may sweat
- V = Vigorous activities - breathe hard and sweat

Activity Type (A, S or F)	Activity	Days/Week	Minutes/Day	Intensity (L, M or V)

**Exercise Matrix**

	Light	Moderate	Vigorous
Flexibility	1	2	4
Strength	2	4	8
Aerobic	3	6	12

Activity Score (for each activity listed) = Days/week x Minutes/day x Exercise Matrix Score  
 Total Exercise Score = sum of all Activity Scores

**SCORE 1 =  $\ln(\text{Total Exercise Score}/60)+0.1$**

**2. LEISURE TIME PHYSICAL ACTIVITY**

Did you participate in any sports, recreational, or leisure time activities in the **last week**? These activities may not necessarily result in sustained increases in heart rate and breathing rate. Examples include hiking, boating, skiing, dancing, bowling and sports activities.

YES		NO	
-----	--	----	--

If NO, please go to question 3

If YES, what type of activities did you do?

Please list **the leisure time physical activities** below that you did in the **last week** for leisure or recreation. For each activity indicate the activity type and intensity (using the keys below), how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

**Activity types**

E = Endurance (endurance activities are leisure time physical activities that you maintain for a sustained period of time that make you sweat and breathe a little harder than usual e.g. tramping/hiking, tennis, dancing, skiing, sports fishing, sexual activity, etc)

NE = Non-Endurance (non-endurance activities are leisure time physical activities that you might do in shorter bouts of activity and/or do not cause you to sweat and breathe a little harder e.g. boating, fishing by the jetty, bowling, etc)

**Intensity**

L = Light activities - don't sweat or breathe heavily

M = Moderate activities - breathe a little harder and may sweat

V = Vigorous activities - breathe hard and sweat

Activity Type (E or NE)	Activity	Days/Week	Minutes/Day	Intensity (L, M or V)

*Leisure Time Physical Activity (LTPA) Matrix*

	<i>Light</i>	<i>Moderate</i>	<i>Vigorous</i>
<i>Non-endurance</i>	1	2	4
<i>Endurance</i>	2	4	8

*Activity Score (for each activity listed) = Days/week x Minutes/day x LTPA Matrix Score*

*Total LTPA Score = sum of all Activity Scores*

**SCORE 2 =  $\ln(\text{Total LTPA Score}/60)+0.1$**

**3. GENERAL ACTIVITY**

3.1 From **Monday through Friday last week**, how many **waking hours a day** did you spend inside your home (please tick one)?

Less than 6 hours a day	4
6 to 8 hours a day	3
9 to 10 hours a day	2
11 to 12 hours a day	1
13 hours or more	0

**3.1:**      *Less than 6 hours a day = 4*  
               *6 to 8 hours a day = 3*  
               *9 to 10 hours a day = 2*  
               *11 to 12 hours a day = 1*  
               *13 hours or more = 0*

3.2 On **Saturday and Sunday last week**, how many **waking hours a day** did you spend inside your home (please tick one)?

Less than 6 hours a day	4
6 to 8 hours a day	3
9 to 10 hours a day	2
11 to 12 hours a day	1
13 hours or more	0

**3.2:**      *Less than 6 hours a day = 4*  
               *6 to 8 hours a day = 3*  
               *9 to 10 hours a day = 2*  
               *11 to 12 hours a day = 1*  
               *13 hours or more = 0*

**SCORE 3 =  $(3.1 + 3.2)/2$**

3.3 During the **last week**, how many **hours a day** did you sleep including naps?

	HOURS
--	-------

3.4 During the **last week**, how many **hours a day** were you sitting or lying down (including work), but excluding sleeping?

	HOURS
--	-------

**SCORE 4** =  $24 - (3.3 + 3.4)$

3.5 During the **last week** did you do any **indoor** household activities, such as cleaning, food preparation, childcare activities, etc?

YES		NO	
-----	--	----	--

If **NO**, please go to question 3.6

If **YES**, please list all the **indoor** activities that required some **physical activity** (e.g. cleaning, hanging washing, food preparation, etc) that you did in the **last week**. Please also include here any physical activities you did as a part of your role as caregiver (e.g. parenting activities). For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	Days/Week	Minutes/Day

*Activity Score (for each activity listed) = Days/week x Minutes/day*  
*Indoor Activity Score = sum of all Activity Scores*  
**SCORE 5** =  $\ln(\text{Indoor Activity Score}/60)+0.1$

3.6 During the **last week** did you do any **outdoor** household activities, such as gardening, walking to and from shops, etc?

YES		NO	
-----	--	----	--

If **NO**, please go to question 3.7

If **YES**, please list all the **outdoor** activities that required some **physical activity** (e.g. gardening, mowing lawns, walking to shops) that you did in the **last week**. For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

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Activity	Days/Week	Minutes/Day

*Activity Score (for each activity listed) = Days/week x Minutes/day*

*Outdoor Activity Score = sum of all Activity Scores*

**SCORE 6 =  $\ln(\text{Outdoor Activity Score}/60)+0.1$**

3.7 During the **last week** did you climb any stairs at home?

YES		NO	
-----	--	----	--

If **NO**, please go to question 3.8

3.7a If **YES**, how many flights of stairs do you have at home (one flight of stairs is 5-10 steps)?

	FLIGHTS
--	---------

3.7b If **YES**, how many times a day did you climb these stairs in the **last week**?

	TIMES A DAY
--	-------------

*Total Flights = 3.7a x 3.7b*

**SCORE 7:** No flights = 0  
 1-6 flights/day = 1  
 7-10 flights/day = 2  
 11+ flights/day = 3

How much assistance do you need to perform activities of daily living, such as dressing and bathing (please tick one)?

Without assistance	2
Some assistance	1
Full assistance	0

**SCORE 8:** Without assistance = 2  
 Some assistance = 1  
 Full assistance = 0

#### 4. THERAPY

During the **last week** did you receive physiotherapy or occupational therapy or another type of therapy that involves physical activity? **If you have already listed therapy related activities previously in this questionnaire, DO NOT complete this section.**

YES		NO	
-----	--	----	--

**If NO, please go to question 5**

How many days a week did you receive a therapy that involved physical activity in the **last week**?

	DAYS/WEEK
--	-----------

How long did each activity-based therapy session last?

	MINUTES
--	---------

**SCORE 9:**    *No therapy = 0*  
                   *1 session/week = 1*  
                   *2+ sessions/week = 2*

#### 5. EMPLOYMENT/SCHOOL

Are you currently employed, participate in any volunteer work or do you attend School?

Employed/Attend School/Volunteer Work	
Not employed/Do not attend school/ Do not do any volunteer work	
Retired	

**If you are NOT EMPLOYED, DO NOT ATTEND SCHOOL, DO NOT DO ANY VOLUNTEER WORK or ARE RETIRED, please go to question 6**

5.1 For most of your work/school day, do you:

Move around	2
Stand	1
Sit	0

**SCORE 10:**    *Move around = 2*  
                   *Stand = 1*  
                   *Sit = 0*  
                   *Not employed = 0*

5.2 During the **last week** did you climb any stairs whilst at work/school?

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YES		NO	
-----	--	----	--

If NO, please go to question 5.3

5.2a If YES, how many flights of stairs do you have at work/school (one flight of stairs is 5-10 steps)?

	FLIGHTS
--	---------

5.2b If YES, how many times a day did you climb these stairs in the last week?

	TIMES A DAY
--	----------------

*Total Flights = 5.2a x 5.2b*

**SCORE 11:**    *Not employed = 0*  
                  *No flights = 0*  
                  *1-6 flights/day = 1*  
                  *7-10 flights/day = 2*  
                  *11+ flights/day = 3*

5.3 During the last week did you get any physical activity in your transportation to and from work/school (e.g. walking to work)?

YES		NO	
-----	--	----	--

If NO, please go to question 6

**Physical Activity for Individuals with Severe Neurological Disability Living in a Residential Service**

If **YES**, please list all the transportation physical activity you did in the **last week** (e.g. walking or wheeling a wheelchair to and from work). For each activity indicate how many days per week you did the activity and how many minutes per day. **Do not list activities here that you have already listed previously in this questionnaire.**

Activity	Days/Week	Minutes/Day

*Activity Score (for each activity listed) = Days/week x Minutes/day*  
*Transport Activity score = sum of all Activity Scores*

**SCORE 12 =** Not employed = 0  
 No transport activity = 0  
 1 to 60 minutes/week = 1  
 61+ minutes/week = 2

**6. WHEELCHAIR USERS**

During the last week did you use a wheelchair?

YES		NO	
-----	--	----	--

**If NO, stop this questionnaire**

If **YES**, during the time that you were awake, how much time a day did you spend in your wheelchair in the **last week** (please tick one)?

All day	
Most of the day	
A few hours	

What type of wheelchair did you primarily use in the **last week** (please tick one)?

Manual	
Power	

**If POWER WHEELCHAIR, stop this questionnaire**

If **MANUAL**, did you push your own wheelchair at any time during the **last week**?

YES		NO	
-----	--	----	--

**If NO, stop this questionnaire**

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If **YES**, on average, how many minutes a day did you push yourself in your wheelchair in the **last week**?

Less than 60 minutes	
60 minutes or more	

<b>SCORE 13</b> =	<i>No wheelchair use</i> =	0
	<i>Pushed for less than 60</i> =	1
	<i>Pushed for 60 minutes or more</i> =	2

<b>SCORING SUBSCALES</b>	
EXER/LTPA ( <b>SCORE A</b> ) =	$(0.7071((\text{SCORE } 1 - 0.535)/2.344)) + (0.7071((\text{SCORE } 2 + 1.571)/1.643))$
GENERAL ( <b>SCORE B</b> ) =	$(0.3748((\text{SCORE } 3 - 2.031)/1.338)) + (0.4481((\text{SCORE } 4 - 8.350)/4.977)) + (0.4399((\text{SCORE } 5 - 1.314)/1.962)) + (0.3811((\text{SCORE } 6 + 0.490)/1.742)) + (0.3045((\text{SCORE } 7 - 0.914)/1.108)) + (0.4766((\text{SCORE } 8 - 1.704)/0.585))$
THERAPY ( <b>SCORE C</b> ) =	SCORE 9
EMPLOYMENT ( <b>SCORE D</b> ) =	$(0.6021((\text{SCORE } 10 - 0.301)/0.704)) + (0.6290((\text{SCORE } 11 - 0.351)/0.783)) + (0.4918((\text{SCORE } 12 - 0.099)/0.374))$
WHEELCHAIR ( <b>SCORE E</b> ) =	SCORE 13

<b>TOTAL SCORE</b>	
<b>TOTAL PADS</b> =	$(0.5349(\text{SCORE } A/1.074)) + (0.6369(\text{SCORE } B/1.540)) + (-0.0967((\text{SCORE } C - 0.104)/0.378)) + (0.5005(\text{SCORE } D/1.184)) + (-0.2198(\text{SCORE } E - 0.165)/0.497))$

Reference: Kayes NM, Schuller PJ, McPherson KM, Taylor D, Kolt GS. The physical activity and disability survey - revised (PADS-R): an evaluation of a measure of physical activity in people with chronic neurological conditions: supplementary material. [Online]. 2009 [cited 2010 Oct 24]; Available from:

URL:<http://cre.sagepub.com/content/early/2009/05/15/0269215508101750/suppl/DC1>

### 8.5 Appendix E - PADS-R Examples of Raw Data over a Range of Scores

	PADS -R Score	Exercise	LTPA	General Activity	Therapy	Employment	Wheelchair Use
1	-0.4 (low score)	No exercise	No LTPA	>13 waking hours inside (M-F) 6-8 waking hours inside (weekend) 14 hours/day sleeping 10 hours/day sitting/lying down No indoor household activity No outdoor household activity No stairs Full assistance with ADLs	3 days/week @ 30 minutes/day	Not employed	Power wheelchair
2	0.0 (equal to the mean score)	Strengthening exercises 4 days/week @ 8 minutes/session Varying intensity levels	No LTPA	9-10 waking hours inside (M-F) <6 waking hours inside (weekend) 8 hours/day sleeping 3 hours/day sitting/lying down Indoor household activity includes cleaning, washing, preparing meals and ironing No outdoor household activity No stairs No assistance required for ADLs	No therapy	Not employed	No wheelchair use
3	3.5 (high score)	Karate - 2 days/week @ 2 hours/day (vigorous intensity) Horse riding - 7 days/week @ 90 minutes/day (moderate intensity)	No LTPA	<6 waking hours inside (M-F) 9-10 waking hours inside (weekend) 7 hours/day sleeping 2 hours/day sitting/lying down Indoor household activity includes food preparation and general cleaning Outdoor household activity includes walking the dog Climbs one flight of stairs, 10 times a day at home No assistance required for ADLs	No therapy	Employed Moves around most of the day at work Climbs two flights of stairs, 6 times a day at work No transportation activity	No wheelchair use

Abbreviations: LTPA – leisure-time physical activity; M-F – Monday to Friday; ADLs – activities of daily living

Reference: Kayes NM. PADS-R scoring [online].E-mail to Amelia Buick. 26 Mar 2012.

## 8.6 Appendix F - Semi-structured Interview Question Guide

### Questions for semi structured interview at six weeks

Suggested interview questions will be:

1. Can you tell me the story about you starting (physical activity)?
2. Can you tell me about (the activity)?
3. What do you find the highlight of (the activity)?
4. What did you find most difficult/challenging about (the activity)?
5. Is there anything else you would like to tell me?

Prompting guide questions that can be used will be:

You mentioned a moment ago about.....can you tell me more about that?

What did you mean when you said....?

Can you give me an example of that?

### Questions for semi structured interview at 12 weeks

Suggested interview questions will be:

1. Have you continued with (chosen physical activity)?
2. Why or why not?
3. Have you started any other physical activity?
4. Would you recommend PA to others?
5. Is there anything else you would like to tell me?

Prompting guide questions that can be used will be:

You mentioned a moment ago about.....can you tell me more about that?

What did you mean when you said....?

Can you give me an example of that?

## 8.7 Appendix G - Functional Independence Measure and Functional Assessment Measure

### FUNCTIONAL INDEPENDENCE MEASURE™ AND FUNCTIONAL ASSESSMENT MEASURE Brain Injury

Scale:

- 7 Complete Independence (timely, safely) (Patient Stamp)
- 6 Modified Independence (extra time, devices)
- 5 Supervision (cuing, coaxing, prompting)
- 4 Minimal Assist (performs 75% or more of task)
- 3 Moderate Assist (performs 50%-74% of task)
- 2 Maximal Assist (performs 25% to 49% of task)
- 1 Total Assist (performs less than 25% of task)

SELF CARE ITEMS		Adm	Goal	D/C	F/U
1. Feeding					
2. Grooming					
3. Bathing					
4. Dressing Upper Body					
5. Dressing Lower Body					
6. Toileting					
7. Swallowing*					
<b>SPHINCTER CONTROL</b>					
8. Bladder Management					
9. Bowel Management					
<b>MOBILITY ITEMS (Type of Transfer)</b>					
10. Bed, Chair, Wheelchair _____					
11. Toilet _____					
12. Tub or Shower _____					
13. Car Transfer* _____					
<b>LOCOMOTION</b>					
14. Walking/Wheelchair (circle)					
15. Stairs					
16. Community Access*					
<b>COMMUNICATION ITEMS</b>					
17. Comprehension-Audio/Visual (circle)					
18. Expression-Verbal, Non-Verbal (circle)					
19. Reading*					
20. Writing*					
21. Speech Intelligibility*					
<b>PSYCHOSOCIAL ADJUSTMENT</b>					
22. Social Interaction					
23. Emotional Status*					
24. Adjustment to Limitations*					
25. Employability*					
<b>COGNITIVE FUNCTION</b>					
26. Problem Solving					
27. Memory					
28. Orientation*					
29. Attention*					
30. Safety Judgement*					

\*FAM items

Admt	Date	D/C	Date	Admt	Date	D/C	Date
RN	_____	_____	_____	ST	_____	_____	_____
PT	_____	_____	_____	PSY	_____	_____	_____
OT	_____	_____	_____	REC	_____	_____	_____

Reference: SCVMC. Functional Independence Measure and Functional Assessment Measure. [Online]. 1999 [cited 2010 Aug 22]; Available from: URL:<http://tbims.org/combi/FAM/famform.pdf>

## 8.8 Appendix H - Personal Correspondence with Author of PADS-R regarding Anomalies

Dear Nicola

I am using the PADS-R as an outcome measure). I am now aware however that in the calculating of the score that people who use a power wheelchair end up with a higher score than those who use a manual chair. I was wondering if you can advise me how to correct for this?

I have otherwise found the PADS-R very easy to use and the only one that comes close to showing any change in my group of patients.

Thanks for you help  
kind regards  
Amelia Buick

26<sup>th</sup> March 2012

Hi Amelia,

It is an anomaly that was hidden in the data we used in the scoring development process due to the size and diversity of our sample. It is the kind of anomaly that I was trying to overcome as I had similar issues with the original PADS. My gut feeling is that the issue is the scoring coefficient that is given to that subscale when calculating the total PADS-R score. The scoring coefficient for the wheelchair subscale is a -ve and I think that is what causes the problem. I also identified that exact same problem occurs with the therapy subscale (which also has a -ve scoring coefficient).

So, I think the solution would be to use the following formula to calculate the total PADS-R score. This should fix the problem for both the therapy and wheelchair subscales.

$$=SUM((0.5349*(B2/1.074))+(0.6369*(C2/1.54))+(0.0967*((D2-0.104)/0.378))+(0.5005*(E2/1.184))+(0.2198*(F2-0.165)/0.497))$$

I attach a test excel sheet which shows the effect this has on the overall PADS-R score where all other subscales remain stable, but where the therapy and wheelchair score changes.

Now, the only issue with this is that this is a fairly pragmatic solution which feels intuitively right and makes clinical sense when one looks at the data. My hesitation is that I don't know how robust this is as a solution in a mathematical sense and I have not yet been able to seek some advice on this. Tweaking the data in this way without some further advice makes me a tad nervous. So, I think if you use this solution you need to do so with that caution in mind.

I hope that helps as a solution in the meantime! It is a bit of a brain teaser - that is for sure!

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In terms of what the score itself indicates - that is a tough one because the best way to communicate that is by looking at other published studies which have used the PADS-R and comment on how your scores differ from other populations, etc. However, it is a new scale and not yet widely published so difficult to make this comparison. Added to this, any published work to date will have used the flawed scoring system so if you use the revised approach to scoring I have suggested then of course you would be comparing apples with oranges when comparing against other published data. The way I did it in my PhD (where of course I had a similar issue) was to include a table which summarised the participant responses for a range of PADS-R scores to give some clinical sense of what the total score meant in terms of level of activity. I attach the table I used now in case it is useful and to show you what I mean.

Looking forward to hearing more about your work when you are ready to disseminate.

Kind regards,

Nicola

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School of Rehabilitation and Occupation Studies  
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Reference: Kayes NM. PADS-R scoring [online].E-mail to Amelia Buick. 26 Mar 2012.