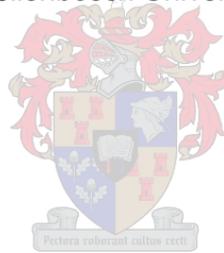


**Levels of community integration achieved by adults with disabilities post discharge from a specialised in-patient rehabilitation unit in the Western Cape**

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Research assignment presented in partial fulfilment of the requirements for the degree  
Masters in Human Rehabilitation Studies at the Faculty of Medicine and Health Sciences at  
Stellenbosch University



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## Declaration

By submitting this research assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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March 2016

## Abstract

**Background:** Community integration is one of the most important outcomes of rehabilitation. Rehabilitation services should strive to optimise community integration of persons with disabilities through the processes of functional restoration, prevention of secondary complications, provision of assistive devices and/or environmental modification. Studies conducted in South Africa show that rehabilitation services in the country often do not achieve community integration of persons with disabilities. The need to quantify the levels of community integration of persons with disabilities who received in-patient rehabilitation was identified.

**Aim:** To determine the levels of community integration of adults with disabilities post discharge from a specialised in-patient rehabilitation unit in the Western Cape Province.

**Methods:** A quantitative, cross-sectional, descriptive study design was used. Individuals discharged from the rehabilitation centre between 1 September 2012 and 30 November 2012, who met the inclusion criteria, made up the study sample. Fifty-nine individuals participated in the study. A demographic and medical data sheet was used to gather information from the participants' medical folders. Levels of community integration were determined with the Reintegration to Normal Living Index (RNLI).

Descriptive statistics on the variables age, gender and medical diagnosis as well as scores of the various RNLI domains, subscales and the overall RNLI score are presented in graphs and tables. To determine if a relationship existed between the variables age, gender and medical diagnosis and levels of community integration, inferential tests (t-test and Kraskal-Wallis tests) were applied. A P-value of <0.05 was observed as statistically significant.

**Results:** Fifty-four percent of study participants were women. Participant's median age was 43 with an interquartile range of 35 to 57. The most common diagnosis was stroke (41%) and spinal cord injury (30%).

The median overall RNLI score for the study population was 71.30 with an interquartile range of 53.24 and 87.50. The RNLI items personal relationships and presentation of self-recorded the highest median scores (88.89). The RNLI items work and related activities scored the lowest median score of 55.56. Home mobility, community mobility, travel out of town and recreational activities also had median scores below 70.

No statistically significant differences could be found when examining the relationships between the variables age, gender and medical diagnosis and the domains, subscales and the overall RNLI scores.

**Conclusion:** The results of this study show that persons with disabilities, who received in-patient rehabilitation and were discharged into their home and community environments, achieve lower overall RNLI scores than persons with disabilities living in well-resourced countries such as the United States of America (USA) and Canada. Rehabilitation professionals may need to adjust rehabilitation programmes offered to improve community integration outcomes of clients. Low levels of integration in areas such as community mobility, and participation in social and meaningful work activities might be an indication that persons with disabilities still face many barriers in the communities. Persons who suffered a traumatic brain injury or a cerebrovascular accident (CVA) achieved lower levels of community integration in comparison to persons who suffered a SCI or have an impairment of the peripheral neural/muscular system(s).

**Key terms:** community integration, adults with disabilities, in-patient rehabilitation, Reintegration to Normal Living Index (RNLI)

## Abstrak

**Agtergrond:** Integrasie in die gemeenskap is een van die belangrikste uitvloeisels van rehabilitasie. Met rehabilitasiedienste moet gestreef word na die optimalisering van gemeenskapsintegrasie van mense met gestremdhede deur middel van funksionele herstel, die voorkoming van sekondêre komplikasies, die verskaffing van hulpmiddele en/of omgewingsveranderinge.

Navorsing in Suid-Afrika dui daarop dat rehabilitasiedienste in die land dikwels nie die mikpunt van die gemeenskapsintegrasie van mense met gestremdhede haal nie. 'n Behoefte om die vlakke van gemeenskapsintegrasie van mense met gestremdhede, wat as binne-pasiënte rehabilitasie ontvang het, te bepaal is ge-identifiseer.

**Doelwit:** Om die vlakke van gemeenskapsintegrasie van volwassenes met gestremdhede, wat rehabilitasie in 'n gespesialiseerde rehabilitasie-eenheid in die provinsie Wes-Kaapland ontvang het, te bepaal.

**Metodes:** 'n Kwantitatiewe, deursnee, beskrywende studieontwerp is gebruik. Die deelnemers het bestaan uit individue wat tussen 1 September 2012 en 30 November 2012 uit die rehabilitasiesentrum ontslaan is en aan die maatstawwe vir insluiting voldoen het. Altesaam 59 mense het aan die navorsing deelgeneem. 'n Demografiese en mediese data-vorm is gebruik om inligting van die deelnemers se mediese verslae te versamel. Die vlakke van gemeenskapsintegrasie is bepaal deur die Reïntegrasie tot Normale Lewe-indeks (RNLI) te gebruik.

Beskrywende statistieke van die veranderlikes ouderdom, geslag en mediese diagnose, asook die tellings van verskeie RNLI--domein subskale en die algehele RNLI-tellings word in grafieke en tabelle aangebied. Om te bepaal of die veranderlikes ouderdom, geslag en mediese diagnose 'n statisties beduidende impak op gemeenskapsintegrasie gehad het, is interferensietoetse (t-toetse en Kraskal-Wallis-toetse) aangewend. 'n P-waarde van  $<0.05$  is as statisties beduidend beskou.

**Resultate:** Vier en vyftig persent van die deelnemers was vroue. Die mediaan-ouderdom van die deelnemers was 43, met 'n interkwantiele bestek van 35 tot 57. Die algemeenste diagnoses was beroerte (41%) en rugmurgbeserings (30%).

Die mediaan- algehele RNLI-telling vir die navorsinggroep was 71.30, met 'n interkwantiele bestek van 53.24 en 87.50. Die RNLI-items persoonlike verhoudinge en self-presentasie het

die hoogste mediaantellings van 88.89 opgelewer. Die RNLI-items werk en verwante bedrywighede het die laagste mediaantelling van 55.56 gehad.

Mobilitiet tuis en in die gemeenskap, buitestedelike reis en rekreasiebedrywighede het ook mediaantellings van minder as 70 gehad. Geen statisties beduidende verskille kon gevind word toe die verhoudinge tussen die veranderlikes ouderdomme, geslag en mediese diagnoses en die domeine subskale en algehele RNLI-tellings ondersoek is nie.

**Bevinding:** Die resultate van dié navorsing toon dat mense met gestremdhede wat as binne-pasiënte rehabilitasie ontvang en ná hul ontslag na hul tuistes en gemeenskapomgewing terugkeer het laer algehele RNLI-tellings behaal het as mense met gestremdhede in lande soos die Verenigde State van Amerika en Kanada, waar goeie hulpbronne bestaan. Rehabilitasie diensverskaffers sal waarskynlik rehabilitasieprogramme wat aangebied word moet aanpas sodat die resultaat van kliënte se gemeenskapsintegrasië verbeter kan word. Lae vlakke van integrasië op gebiede soos mobiliteit in die gemeenskap en deelname aan sosiale en betekenisvolle werkbedrywighede kan dalk 'n aanduiding wees dat mense met gestremdhede steeds hindernisse in die gemeenskappe ervaar. Mense wat 'n traumatiese breinbesering opgedoen het of in 'n serebro-vaskulêre ongeluk (SVO) betrokke was, het laer vlakke van gemeenskapsintegrasië bereik vergeleke met mense wat rugmurgbeserings opgedoen het of wie se perifere senu/spierstelsel(s) aangetas was.

**Sleuteltermes:** gemeenskapsintegrasië, volwassenes met gestremdhede, binne-pasiënte-rehabilitasie, Reïntegrasië tot Normale Lewe-indeks (RNLI)

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## Glossary of Terms

**Activity:** “is the execution of a task or action by an individual” (WHO 2001).

**Barriers:** “Factors in a person’s environment that, through their absence or presence, limit functioning and create disability” (WHO 2001).

**Community integration:** “Community (re-) integration (after/with (physical) impairment or disability) is acquiring/resuming age-/gender-/culture-appropriate roles/statuses/activities, including independence/interdependence in decision making, and productive behaviours performed as part of multivariate relationships with family, friends, and others in natural community settings” (Dijkers 1998:5).

**Contextual factors:** “Factors that together constitute the complete context of an individual’s life, and in particular the background against which health states are classified in the ICF. There are two components of contextual factors: environmental factors and personal factors” (WHO 2001).

**Disability:** “An umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (WHO 2001).

**Function:** “An umbrella term in the ICF for body functions, body structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (WHO 2001).

**Facilitator:** “Factors in a person’s environment that, through their absence or presence, improve functioning and reduce disability” (WHO 2011).

**Impairment:** “Loss or abnormality in body structure or physiological function (including mental functions), where abnormality means significant deviation or loss” (WHO 2001).

**Participation:** “is involvement in a life situation” (WHO 2001).

**Quality of life:** “An individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept, incorporating in a complex way the person’s

physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to environmental factors that affect them” (WHO 2011).

**Rehabilitation:** “Appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life” (WHO 2010 (Health component):45).

**Specialised rehabilitation hospital:** “A specialised rehabilitation hospital caters for clients with severe disabling conditions and requires the services of rehabilitation personnel with specialist skills... Clients at this level undergo intensive rehabilitation to regain as many functional abilities and skills as possible to be able to go back and integrate into communities” (DoH 2013).

## Table of Contents

Declaration	i
Abstract	ii
Abstrak	iv
Acknowledgements	vi
Glossary of terms	vii
Table of Contents	ix
List of Tables	xii
List of Figures	xiii
List of Acronyms	xiv
<b>Chapter One</b>	<b>1</b>
Introduction to the study	1
1.1 Background to the study	1
1.2 Study problem	3
1.3 Study aim	3
1.4 Study objectives	4
1.5 Significance of the study	4
1.6 Motivation for undertaking the study	5
1.7 Summary of chapter	6
1.8 Outline of the study	6
<b>Chapter Two</b>	<b>8</b>
Literature review	8
2.1 Introduction	8
2.2 Disability	8
2.2.1 Individual approaches to disability	8
2.2.2 Societal/human rights approaches to disability	9
2.2.3 Bio-psychosocial approaches to disability	10
2.3 Community integration	11

2.4 Community integration and disability	13
2.5 Community integration outcome measures	14
2.5.1 Objective community integration outcome measures	14
2.5.2 Subjective community integration outcome measures	15
2.5.3 Other community integration outcome measures	16
2.6 Community re-integration of adults with physical disabilities	17
2.6.1 International studies in resourced countries	17
2.6.2 International studies in less resourced countries	21
2.6.3 Studies conducted in South Africa	22
2.6.4 Contextual factors that influence community integration	24
2.7 Comprehensive in-patient rehabilitation	26
2.8 Summary of chapter	27
<b>Chapter Three</b>	<b>29</b>
Methodology	29
3.1 Introduction	29
3.2 Study design	29
3.3 Study setting	29
3.4 Study population, sampling and participants	30
3.4.1 Inclusion criteria	31
3.4.2 Exclusion criteria	31
3.5 Data collection instruments	33
3.6 Research assistants	35
3.6.1 Identification and selection	35
3.6.2 Training of research assistants	36
3.7 Pilot study	37
3.8 Data collection	39
3.8.1 Identification of study participants and collecting data from folders	39

3.8.2 Telephonic data collection	40
3.8.3 Personal visits for data collection	42
3.9 Data analysis	43
3.9.1 Exploration and presentation of data	43
3.9.2 Analytical component of study	44
3.10 Ethical considerations	44
3.10.1 Autonomy	44
3.10.2 Confidentiality	45
3.10.3 Beneficence and Non-malficence	45
3.10.4 Justice	46
3.10.5 Approval of relevant authorities	46
3.11 Summary of chapter	46
<b>Chapter Four</b>	<b>48</b>
Results	48
4.1 Introduction	48
4.2 Demographic information	48
4.3 Medical diagnosis	49
4.4 Integration to normal living	50
4.5 Relationship between demographic variables and RNLI scores	52
4.5.1 Gender	52
4.5.2 Age	53
4.5.3 Medical diagnosis	55
4.6 Summary of chapter	57
<b>Chapter Five</b>	<b>58</b>
Discussion	58
5.1 Introduction	58

5.2 Profile of the study participants	58
5.3 Reintegration to Normal Living	59
<b>Chapter Six</b>	<b>68</b>
Conclusion and recommendations	68
6.1 Introduction	68
6.2 Study limitations	68
6.3 Conclusion	70
6.4 Recommendations for further research	71
6.5 Recommendations for service providers at WCRC	72
<b>References</b>	<b>74</b>
<b>List of Tables</b>	
Table 3.1: Reasons for exclusion	32
Table 3.2: Problems identified during pilot study and action plan for data collection	38
Table 3.3: Summary of item aggregation concerning reintegration to normal Living	43
Table 4.1: Descriptive statistics of the variable participant age	49
Table 4.2: Descriptive statistics according to RNLI scores	50
Table 4.3: Breakdown of RNLI scores per item and percentage of participants	51
Table 4.4: The differences in scores of the various domains, Daily Functioning and Perception of Self and the overall RNLI scores between males and females	53
Table 4.5: Comparison of scores of the various domains, Daily Functioning and Perception of Self and the overall RNLI scores between age categories	54
Table 4.6: Comparison of scores of the various domains, Daily Functioning and	

Perception of Self and the overall RNLI scores between diagnostic groups	55
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## List of Figures

Figure 2.1: Comparison between percentage of persons six months post stroke and age-matched controls experiencing any degree of difficulty in RNLI domains as found by Mayo et al. 2002.	18
Figure 2.2: Comparison between persons with CVA (Mayo et al. 2002) and Persons with traumatic brain injury (TBI) (Kim et al. 2013) experiencing any degree of difficulty on individual items as measured by RNLI	20
Figure 4.1: Age distribution of participants	48
Figure 4.2: Medical diagnosis of participants	49

## Appendices

Appendix 1: Demographic and medical data sheet	82
Appendix 2: The Reintegration to Normal Living Index	83
Appendix 3: Email to WCRC for recruitment of research assistants	86
Appendix 4: Participant information leaflet and consent form	88
Appendix 5: Research assistant confidentiality form	95
Appendix 6: Data sheet – excluded individuals	96
Appendix 7: Data sheet – eligible participants who declined participation	97
Appendix 8: Ethical approval	98
Appendix 9: Letter of approval Department of Health	99

## List of Acronyms

CEO: Chief Executive Officer

CHART: Craig Handicap Assessment and Reporting Technique

CVA: Cerebrovascular accident

DoH: Department of Health

DPOs: Disables People's Organisations

ICF: International Classification of Functioning, Disability and Health

NRP: National Rehabilitation Policy

RNLI: Reintegration to Normal Living Index

RVD: Retroviral Disease

SCI: Spinal cord injury

TBI: Traumatic brain injury

USA: United States of America

WCRC: Western Cape Rehabilitation Centre

WHO: World Health Organization

## Chapter One

### Introduction to the study

#### 1.1 Background to the study

While “community reintegration is the most meaningful outcome of rehabilitation as it relates to real life issues in the community” (Mothabeng, Eksteen & Westaway 2012:29), it is also one of the major challenges that persons with disabilities face. Authors and researchers in the field of disability and rehabilitation have attempted to accurately describe and define the concept community integration, using words and phrases such as ‘mainstreaming’ and ‘inclusion in everyday life’. As consensus has not been reached on the definition of this concept, many researchers fall back on the eloquent definition by Dijkers (1998) presented in the glossary of terms. This definition highlights that community integration is a multi-faceted phenomenon influenced by age, gender and culture/subculture as well as by various bio-psychosocial and environmental factors unique to every individual in his/her community setting. Each individual should be a visible and active member in his/her community through participating in community life, being involved, developing and growing as an individual and as part of the community, while contributing to the goals of the community. Reintegration into community life after acquiring a disability also includes the resumption of roles and relationships in the community that the individual enjoyed prior to being injured/impaired.

Despite efforts by the South African Government and Disabled Peoples Organisations, the majority of South Africans with disabilities still do not enjoy equal social and economic opportunities and rights, and are not integrated into their communities (Schneider & Nkoli 2011; Maleka, Stewart & Hale 2012; Heap, Lorenzo & Thomas 2009; Mudzi, Stewart & Musenge 2013). Participation of persons with disabilities in home, recreational, community and vocational activities generally continues to be poor and disappointing (Schneider & Nkoli 2011). Factors causing and/or contributing to the exclusion and marginalisation of persons with disabilities in South Africa include limited access to services such as education, housing, transport and health, poverty, lack of skills and basic education, poor physical assess of the environment, the cultural and social conceptualisation of disability, attitudes and lack of awareness of family, friends and community members and existing high levels of unemployment (Heap et al. 2009; StatsSa 2012, Mudzi et al. 2013; Schneider & Nkoli 2011).

Rehabilitation services should play an important role in addressing many of the above mentioned barriers, in an effort to promote community participation and inclusion of persons with disabilities in South Africa (WHO 2011). Health care professionals working in both

institution and community based rehabilitation settings should strive to influence and optimise the levels of community integration of their clients through the processes of functional restoration, prevention of secondary complications, provision of appropriate and affordable assistive devices and/or environmental modification (DoH 2013; Sekaran, Vijayakumari, Hariharan, Zachariah, Jospeh & Senthil Kumar 2010; Whiteneck, Tate & Charlifue 1999; DoH 2000; WHO 2011).

In the year 2000, the South African government committed itself to developing accessible, affordable and goal-orientated rehabilitation programmes designed to achieve equalisation of opportunities and integration for persons with disabilities living in our country (DoH 2000). The National Rehabilitation Policy (NRP) (2000) published by the Department of Health is one of the guiding documents in this regard. According to the NRP (DoH 2000), the following principles should form the foundation of rehabilitation services on primary, secondary and tertiary levels in South Africa:

- Achieving integration of persons with disabilities into society through full participation in community life;
- Facilitating active participation of persons with disabilities in the rehabilitation process;
- Promoting and protecting equal rights and dignity of and opportunities for persons with disabilities in all spheres of life; and
- Involving general systems of society, through policy development, intersectoral collaboration and environmental adaptation.

More recently the South African Department of Health published the “Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015 – 2020” (DoH 2013). This document built on the NRP and states that rehabilitation services for South Africans should “make the vital, practical link between medical treatment and the translation of a person’s restored capacity into a productive and health-promoting social and economic life” (DoH 2013:6).

However, studies recently conducted in various South African settings show that rehabilitation services in the country do not yet achieve these goals. Henn, Visagie and Mji (2012) identified in a study conducted at a private rehabilitation hospital in Gauteng that rehabilitation programmes at the institution did not sufficiently address the outcome of community integration post discharge. These results are in agreement with the findings by Fredericks and Visagie (2013) who reported that persons with lower limb amputations

received mainly impairment focused rehabilitation services with little attention being paid to activities of daily living, home and community environments, as well as the community integration and participation needs of the individuals in a Western Cape setting. Wasserman, de Villiers and Bryer (2009) found that stroke survivors in a remote rural setting of KwaZulu-Natal did not have access to rehabilitation services and were discharged directly into family care with little or no follow up by home-based carers or rehabilitation professionals. Study participants reported reduced levels of participation in activities such as housework, community, cultural and sporting activities as well as employment.

## **1.2 Study problem**

The studies referred to above indicate a lack of focus on community integration during rehabilitation. However, they did not quantify the problem. Hassan, Visagie and Mji (2012) did some quantification and showed that 58% of stroke survivors, dependent on a care giver, achieved community integration post discharge from a specialised, government funded rehabilitation centre in the Western Cape Metro Health District, the Western Cape Rehabilitation Centre (WCRC).

Adults with a range of physical impairments from diverse backgrounds and socioeconomic status are admitted to the Western Cape Rehabilitation Centre for in-patient rehabilitation. During the rehabilitation programme at the WCRC the multi-disciplinary rehabilitation team aims to assist each client to achieve optimal levels of functioning and participation and the highest possible level of community integration. However, except for the findings by Hassan et al. (2012) mentioned above, the levels of community integration achieved by adults with disabilities after completing their in-patient rehabilitation programme at the WCRC have, to date, not been assessed and recorded. As indicated above, Hassan and colleagues (2012) selected a very specific group of participants. Thus, there is still a need to further quantify community integration of persons with disabilities who received rehabilitation at the WCRC. The researcher thus posed the question: what levels of community integration do adults with disabilities reach after discharged from the WCRC?

## **1.3 Study aim**

Therefore, the aim of this study was to determine the levels of community integration of adults with disabilities post discharge from a specialised in-patient rehabilitation unit, the Western Cape Rehabilitation Centre.

#### **1.4 Study objectives**

- To establish the demographic profile of study participants;
- To determine the levels of community integration of adults with disabilities post discharge from the WCRC;
- To explore the domains of normal living that have the greatest positive and negative impact on the community integration of adults with disabilities post discharge from the WCRC;
- To determine the relationship of age, gender and medical diagnosis on levels of community integration achieved study participants.

#### **1.5 Significance of the study**

The findings of the study will add to and build on the findings by Hassan et al. (2012) as a more representative sample of the overall WCRC population will be studied and reported on and community integration will be assessed more comprehensively. This information should enable the rehabilitation team and management of the WCRC to determine whether they are successful in achieving their rehabilitation aim of assisting clients to achieve community integration.

Findings of the study will identify domains of community integration that most clients achieve and domains that a high proportion of clients struggle with. This information may help the rehabilitation team at WCRC to develop and focus their rehabilitation efforts towards improved community integration outcomes for clients. Findings could also assist the management of the WCRC with future planning with regards to programme/service development and delivery as well as resource allocation (Joubert & Ehrlich 2007). This may lead to the development of more appropriate and effective rehabilitation services at the WCRC, which in turn might lead to improved community integration outcomes for future clients.

Findings of this study could thus allow future clients of the WCRC to achieve higher levels of community integration after discharge from their in-patient rehabilitation programme. This means that future clients could possibly enjoy greater independence and participation within their community allowing them to lead more productive and meaningful lives as integrated and equal members of our society. It may also be of benefit to family members as the person with a disability may require less care and may be able to engage in more meaningful and possibly income generating activities within the community.

In addition to the possible clinical significance this study also adds to the body of knowledge on community integration in South Africa. Few local studies in the field of disability and rehabilitation include participation outcome measures such as community integration and levels of employment (Henn et al. 2012; Wasserman et al. 2009; Hassan et al. 2012). Inglis, Faure & Frieg (2008) found that South African physiotherapists mainly used impairment based outcome measures with little attention being paid to participation and quality of life outcomes. This study should therefore add value to South African research literature on community integration of persons with disabilities, especially since the measuring instrument (the Reintegration to Normal Living Index (RNLI)) used has been found to be “a true measure of community integration” (Mothabeng et al. 2012:32) within the South African context.

## **1.6 Motivation for undertaking the study**

The researcher was employed as a physiotherapist at the Western Cape Rehabilitation Centre for six years between 2006 and 2012 and is passionate about rehabilitation and the rights of persons with disabilities. At the beginning of 2012 the researcher commenced her Masters Studies in the field of Rehabilitation and, during the first six months of her studies, was able to gain a tremendous amount of valuable knowledge about and insight into disability and disability rights, the rehabilitation and community integration of persons with disabilities as well as policy/programme evaluation and development.

Working in the out-patient department at the WCRC the researcher observed and assessed former in-patients returning for follow up appointments. She found that many clients had developed devastating secondary complications such as pressure sores, contractures and postural deformities after discharge. Few clients reported to be active members of their communities and few clients reported to be satisfied with their participation and involvement in community activities.

This prompted the researcher to think more critically about the rehabilitation programmes offered to persons with disabilities at the Western Cape Rehabilitation Centre. The researcher started raising the following questions:

- Are rehabilitation programmes, offered to persons with disabilities at the WCRC, focused enough on achieving participation and community integration?
- What are the levels of community integration of former in-patients of the centre some time after discharge?

- Where should rehabilitation programmes, offered by the multi-disciplinary team at the WCRC, focus to promote optimal community integration and improved quality of life of persons with disabilities?

For these reasons the researcher embarked on the current study, aimed at answering, in part, the above questions and contributing to the development and improvement of rehabilitation services offered to persons with disabilities at the Western Cape Rehabilitation Centre.

## **1.7 Summary of chapter**

Community integration has been termed one of the most important outcomes of rehabilitation of persons with disabilities. Although the South African Government has committed itself to delivering effective rehabilitation services to persons with disabilities living in South Africa, many persons with disabilities still face a wide range of environmental and societal barriers that prevent them from achieving full community integration. Research conducted in South Africa has found that rehabilitation programmes are mainly impairment focused and, as a result, do not sufficiently address barriers to community integration. However, studies quantifying community integration post rehabilitation were scarce.

Thus, the aim of this study was to determine the levels of community integration of adults with disabilities post discharge from a specialised in-patient rehabilitation unit, the Western Cape Rehabilitation Centre. The study also identified domains of normal living that had the greatest positive and negative impact on the community integration of study participants. This information can inform rehabilitation programmes at WCRC.

## **1.8 Outline of the study**

The literature review in Chapter 2 highlights and summarises findings from international and South African studies regarding community integration of persons with disabilities, barriers and facilitators to community integration and the role of rehabilitation services in enabling individuals with disabilities to achieve community integration. To set the stage for the current study, disability approaches and community integration outcome measures are summarised and discussed.

In Chapter 3 methodological choices such as the quantitative design, participant selection and using the Reintegration to Normal Living Index (RNLI) as measuring instrument are

explained. Descriptive statistics on demographic details of the study population and RNLI scores are presented in Chapter 4 by means of tables and figures. Some statistical analyses between demographic/medical information and RNLI scores are also presented. In Chapter 5 the researcher discussed the findings in the context of available literature and explored possible reasons for findings of the current study.

Finally, in Chapter 6 a conclusion is drawn from the findings of the study, study limitations are presented and recommendations for services and further research are given.

## Chapter Two

### Literature Review

#### 2.1 Introduction

This chapter takes a journey through the literature of recent and of past decades that has dealt with the concepts 'disability', 'community integration' and 'rehabilitation'. Various aspects and angles of these concepts are discussed to provide an overview of current trends on these concepts and how they pertain to the study.

#### 2.2 Disability

Rehabilitation professionals and researchers rely on conceptual frameworks of disability to provide a common language and help guide clinical care as well as disability research (Jette 2006). However, consensus regarding a definition and framework on the overall nature of disability has yet to be reached (Schneider 2009; McDermott & Turk 2011). Until the 1980s individual approaches were used to define disability and predominantly guided the management of persons with disabilities. In the past three decades the perspective of disability has shifted towards a more societal and human rights approach (Goodley 2011).

##### 2.2.1 Individual approaches to disability

Individual approaches to disability include models such as the moral model, medical model, personal tragedy model and individual pathology model (Jordan & Bryan 2001; Rothman 2010; Goodley 2011). Individual approaches locate disability in the person and see it as "...a characteristic or attribute of the person, which is directly caused by disease, trauma or other health conditions and requires some type of intervention provided by professionals to 'correct' or 'compensate' for the problem" (Jette 2006:727). It is characterised by the identification and measurement of bodily deficits to allow health care professionals to reach specific medical diagnoses (McDermott & Turk 2011; Jordan & Bryan 2001). This approach has created a world in which individuals are defined by their dysfunctional bodies (Hughes & Paterson 1997). The physical, cognitive, psychological and/or emotional impairment is seen as the cause of the person's functional limitations and limited participation (Raman & Levi 2002).

Defining disability using individual approaches may lead to the exclusion of persons with disability from their communities and society. As persons with disabilities are viewed as

being outside of what society considers the norm, having a deficit, not being worthy and requiring specialised care and attention, individuals with disabilities are often hidden from society. This approach can lead to persons with disabilities being placed in institutions which causes further isolation and exclusion from society (Jordan & Bryan 2001; Rothman 2010).

## **2.2.2 Societal/human rights approaches to disability**

From the 1960s the societal/human rights approaches to disability gained momentum. Contrary to individual approaches to disability, they saw disability as a socially created phenomenon (Jette 2006; Hughes & Paterson 1997). These approaches include models such as the social barriers model and the social oppression model. According to social approaches the deficit associated with disability is identified within societal attitudes and unaccommodating social, physical and political environments and not within the physical, psychological or cognitive impairments of the individual (Jette 2006; McDermott & Turk 2011; Hughes & Paterson 1997).

As the social approach has shifted the focus of disability from the impaired individual to social attitudes and environmental and political barriers, it “has succeeded in shifting debate about disability from biomedically dominated agendas to discourse about politics and citizenship” (Hughes & Paterson 1997:325). Managing and dealing with disability thus requires a political response or solution to help re-organise and re-build society to allow persons with physical, psychological and/or cognitive impairments to participate as equal members of society (Jette 2006; Hughes & Paterson 1997; Masala & Petretto 2008). Social approaches thus emphasise the importance of assessing environmental and attitudinal factors as well as economic and political barriers during the examination and management of disability (Raman & Levi 2002).

As social approaches to disability call for the removal of social barriers they facilitate inclusive practices within society to enable persons with disabilities to be fully integrated into community life (Jordan & Bryan 2001). To achieve this, the social approach for example promotes community based care for persons with disabilities instead of institutional care; employee accommodations within the workplace to allow the individual with a disability to return to the workplace and inclusion of children with disabilities in mainstream schools (Rothman 2010). This means that persons with disabilities become autonomous, visible and active members of their communities. Critics of the social approach point out that it does not incorporate the individual’s physical body; the experiences and the history of the individual. This may lead to inattention to personal functional goals and medical and rehabilitation

needs which may negatively affect the functional independence and community integration of persons with disabilities (Jordan & Bryan 2001; Rothman 2010; Hughes & Paterson 1997).

### **2.2.3 Bio-psychosocial approaches to disability**

Bio-psychosocial approaches to disability attempt to combine the individual approach to disability with the societal approach by acknowledging the roles of biological, personal and social factors in the creation of disability (Jette 2006; Levasseur, Desrosiers & St-Cyr Tribble 2007). These approaches to disability have been adopted widely amongst health care professionals, academics and other stakeholders in the disability field and have served as the dominant perspective behind current disablement frameworks utilised in the disability field (Jette 2006). The most prominent example of these approaches today is probably the International Classification of Functioning, Disability and Health (ICF) (WHO 2001).

The ICF aims to describe the complex and dynamic interaction between the individual, his/her health condition, his/her activities and social roles and various contextual factors. The ICF distinguishes between three domains of human functioning: body structures and functions, activities and participation. Illness or limitations in these three domains can lead to impairments, activity limitations and participation restrictions. The ICF framework describes activity limitations as the difficulties a person may experience when performing a specific task or action, while participation restrictions refer to the difficulties a person experiences while involved in life situations. The gap or difference a person experiences between the level of performance of an activity and the level of participation in life situations is then mostly attributed to the influence and impact of contextual factors (Masala & Petretto 2008; Levasseur et al. 2007; WHO 2001; Jette 2006).

Application of the ICF requires a detailed description of an individual's health condition, his/her impairments, activities, participation, and contextual factors (environmental and personal). Environmental factors include aspects of the physical, attitudinal and social environments in which an individual conducts his/her life while personal factors include personal features such as age, gender, coping styles, social background and educational level. Contextual factors, as well as their interaction with health characteristics, influence and ultimately determine an individual's experience of disablement and ultimate level of community integration (Raman & Levi 2002; Jette 2008; Masala & Petretto 2008; WHO 2001).

In this study disability was defined using the bio-psychosocial approach and the ICF was used as disability framework. Since it recognises both the individual and societal/contextual factors contributing to the disability experience, this approach should have the biggest positive impact on an individual's community integration.

### **2.3 Community integration**

Community integration has not only become the focus and ultimate goal of rehabilitation of persons with disabilities, but is also an important objective and aim of public policy and legislation (Yasui & Berven 2009, Dijkers 1998; Mothabeng et al. 2012). At the core of community integration lies the fact "that all people, including those who have disability, have a right to full community participation and membership" (Yasui & Berven 2009:761; Wong & Solomon 2002). While studying literature regarding the concept community integration, one repeatedly stumbles upon this simple yet effective description of the concept: "Community integration means having something to do; somewhere to live; and someone to love" (Jacobs 1993:226). Although Jacobs is able to explain this concept in such plain words, extensive effort has gone into the development of a comprehensive and consensual definition of community integration (Yasui & Berven 2009) and to date no universal definition has been agreed on (Dijkers 1988; McColl, Carlson, Johnston, Minnes, Shue, Davies & Karlovist 1998; Wolfensberger 1993; Salter, Foley, Jutai, Bayley & Teasell 2008; Yasui & Berven 2009; Parvaneh & Cocks 2012).

However, authors are in agreement that community integration is a multi-dimensional concept and includes common features or ideas such as inclusion into:

- A residential setting (Willer, Rosenthal, Kreutzer, Gordon & Rempel 1993; Dijkers 1998; Parvaneh & Cocks 2012);
- An appropriate social network (culturally, developmentally and sexually) (Willer et al. 1993; Corrigan 1994; Dijkers 1998; McColl et al. 1998; Yasui & Berven 2009; Parvaneh & Cocks 2012);
- Community activities and accepting responsibilities as an equal member of society (Ware, Hopper, Tugenberg, Dickey & Fisher 2007);
- Productive activity appropriate to the individual's developmental stage, for example employment, education or volunteer work (Willer et al. 1993; Corrigan 1994; Dijkers 1998; McColl et al. 1998; Parvaneh & Cocks 2012);
- Interactive relationships with family, friends and other community members (Dijkers 1998; Ware et al. 2007; Yasui & Berven 2009; Parvaneh & Cocks 2012).

Thus community integration includes elements of being part of, participating in and sharing responsibilities of family and community life; building and growing relationships with family, friends and community members; and being involved in meaningful activities as a contributing member of society as considered normal for someone of a specific age, gender and culture (Dijkers 1988; McColl et al. 1998; Wolfensberger 1993; Salter et al. 2008; Yasui & Berven 2009; Parvaneh & Cocks 2012).

Community integration includes relationships with others, independence in living situations and activities to occupy time meaningfully (McColl et al. 1998; Sander, Clark & Pappadis 2010; Parvaneh & Cocks 2012). As such, community integration has a physical, social and psychological component (Dijkers, 1998; Wolfensberger 1993; Sander et al. 2010; Parvaneh & Cocks 2012; Wong & Solomon 2002). Physical integration is the presence and participation in ordinary community settings and activities while social integration refers to the involvement of persons with disabilities in social interactions with family and community members (Wolfensberger 1993; McColl et al. 1998; Sander et al. 2010). To help define psychological integration researchers identified themes such as heightened risk and vulnerability, having new experiences, having the confidence to assume new and different social roles and the feeling of being acknowledged by others as an active family and community member (Parvaneh & Cocks 2012; Sander et al. 2010). Psychological integration can therefore be described as the sense of being an accepted member of the community. As community integration is distinguished by active contribution and participation within community settings (Dijkers 1998; Wolfensberger 1993), it is clear that all three components should form an integral part of a comprehensive definition of community integration (Dijkers 1998; McColl 1998; Sander et al. 2010).

In summary, community integration is a complex, multi-dimensional construct and a comprehensive definition should include aspects of physical, social and psychological integration. Community integration for the purpose of this study includes the three themes identified by the majority of researches in the field of disability and rehabilitation namely: relationships with others, independence in living situations and activities to fill time meaningfully as well as aspects of psychological integration such as the feeling of acceptance within the family and community and the ability to deal with life situations and changes.

The concept community integration can be considered equivalent to, or even interchangeable, with the concept 'participation' in the ICF (WHO 2001; Kim, Colantonio, Dawson & Bayley 2013). The ICF defines 'participation' as the involvement in life situations (Chang, Coster & Helfrich 2013). Involvement can be described as taking part in, engaging

in, being part of or being included in life situations, as well as having access to necessary resources (Chang et al. 2013).

## 2.4 Community integration and disability

While reviewing literature on the concept of community integration, one repeatedly reads about the importance of community integration of persons with disabilities. This is shown by the following statements:

- “Community integration has consistently been considered by many researchers as the ultimate goal of rehabilitation after traumatic brain injury” (Kim et al. 2013:50)
- “Community participation has been regarded as a key indicator of successful rehabilitation for people with disabilities” (Chang et al. 2013:771)
- “The emphasis on community integration has increased over time” (Sander et al. 2010:121)
- “(...) community integration is becoming an increasingly important area of clinical, policy and research interest” (Whiteneck, Tate & Charlifue 1999:1485)

Acquiring a disability is a life changing event and, once survival is certain, the individual's focus and goals usually shift towards integrating into former life roles and activities (Salter et al. 2008). This means that the disabled individual strives towards and hopes to succeed in returning to “what really counts in life: being part of natural groups and having ‘normal’ activities, roles, relationships, rights and responsibilities” (Dijkers 1998:2). Disability often limits people from fully participating in community life and former life roles (Minnes, Carlson, McColl, Nolte, Johnston & Buell 2003). Yet “individuals with disabilities have an inherent right and should be afforded the opportunity to live, study, work and recreate alongside and in the same manner as their peers without disabilities” (Wong & Solomon 2002:13; Yasui & Berven 2009).

Chun, Lee, Lundberg, McComick and Heo (2008), Charlifue and Gerhart (2004) and Mayo, Wood-Dauphinee, Côté, Durcan and Carlton (2002) showed that active engagement in community activities and life roles leads to higher quality of life and life satisfaction amongst persons with disabilities. According to a study conducted by Kwok, Pan, Lo and Song (2011) active participation in leisure activities, one aspect of community integration, in particular encouraged higher levels of quality of life. Levels of community integration of persons with disabilities can be recorded through outcome measures.

## **2.5 Community integration outcome measures**

A number of valid and reliable tools/instruments have been developed to determine and measure community integration of persons with disabilities (Yasui & Berven 2009; Mothabeng et al. 2012). These tools/instruments can be referred to as community integration outcome measures. To date there is no single measure that has been accepted as the most effective and preferred measure of community integration, both in resourced and less resourced settings (McColl et al. 1998; Baumgartner & Susser 2013). This is not surprising considering the greatly varying definitions of community integration, various types and complex nature of disabilities, and varying communities or environments that individuals with disabilities live in.

Community integration is most often described and measured from one of two main perspectives: that of the individual or that of society (Salter et al. 2008; Chang et al. 2013). A smaller number of outcome measures assess community integration from a service delivery or health care systems perspective (Minnes et al. 2003). The outcome measure used, in research and in clinical practice, is determined by the aspects of community integration that need to be investigated (Yasui & Berven 2009:769). Measures that assess community integration from the perspective of the person who is/was faced with the task of integrating into his/her community are referred to as subjective in nature and may take the form of a self-report tool such as the Short Form (36) Health Survey (SF36), whereas measures that assess community integration from the perspective of a service provider are referred to as objective community integration outcome measures.

### **2.5.1 Objective community integration outcome measures**

Objective measures of community integration evaluate and record indicators such as:

- Frequency of participation in certain activities or behaviours;
- Time spent engaging in specified activities and behaviours;
- Support required by the individual while performing said activities;
- Variety of activities carried out (Chang et al. 2013; Salter et al. 2008; Minnes et al. 2003; Yasui & Berven 2009).

Activities assessed by the above categories generally fall under the physical and social components of community integration focusing on participation in domestic activities, involvement in productive activities and social interactions with others (Minnes et al. 2003). The most commonly and widely used objective measures, as identified by Salter et al.

(2008), Minnes et al. (2003), Sander et al. (2010) and Walker, Mellick, Brooks and Whiteneck (2003) include the:

- Community integration Questionnaire;
- Craig Handicap Assessment and Reporting Technique (CHART);
- Participation Index of the Mayo-Portland Adaptability Inventory-4.

Objective measures describe community integration according to an individual's level of functional independence and participation (Minnes et al. 2003). As objective measures are based on the assumption that a higher frequency (more) and less support (higher level of independence) are better; individual and cultural differences and priorities are not taken into consideration (Chang et al. 2013; Salter et al. 2008; Sander et al. 2010). Another limitation of objective measures are that the activities and behaviours assessed are based on general population norms, in other words on activities and behaviours that are considered ordinary and standard by society (Chang et al. 2013; Salter et al. 2008; Sander et al. 2010). The subjective well-being of individuals and individual priorities are not addressed in the activities assessed by objective measures. Thus the psychological component of community integration is neglected.

## **2.5.2 Subjective community integration outcome measures**

When community integration is assessed from a subjective perspective the emphasis shifts from physical functioning to the individual's internal experiences and feelings (Yasui & Berven 2009; Chang et al. 2013). Subjective measures of community integration typically assess the individual's:

- Sense of belonging;
- Satisfaction with involvement in community activities;
- Attitudes, perceptions, experiences;
- Beliefs (Chang et al. 2013; Salter et al. 2008; Minnes et al. 2003; Sander et al. 2010; Yasui & Berven 2009).

This 'person-perceived' assessment of community integration does not make any assumptions about the relative importance of certain activities and relationships (Yasui & Berven 2009). The degree of community integration is not determined by societal norms but rather by the individual's self-reported experiences and feelings of and satisfaction with certain life situations and relationships (Minnes et al. 2003; Salter et al. 2008; Chang et al. 2013). Subjective measures assess participation within the domains of social relationships,

independent living, occupation and general integration (Minnes et al. 2003). The most common and widely used subjective measures, as identified by Salter et al. (2008), Sander et al. (2010) and Yasui & Berven (2009) include:

- The Reintegration to Normal Living Index (RNLI);
- The Community Integration Measure;
- The Sydney Psychosocial Reintegration Scale.

Salter et al. (2008), Hitzig, Esconbar, Noreau and Craven (2012) and Yasui and Berven (2009) found the RNLI to be the most widely used and most thoroughly evaluated subjective community integration measure. The current study uses the RNLI; a short, easy and validated outcome measure to rate participant's satisfaction regarding selected aspects of community integration from a subjective standpoint (Yasui & Berven 2009; Hitzig et al. 2012). The RNLI is described in more detail in Chapter 3.

### **2.5.3 Other community integration outcome measures**

The Assimilation Integration Marginalisation Segregation measure describes community integration in terms of support available to and participation of persons with disabilities in different community areas (Minnes et al. 2003; Yasui & Berven 2009). The community areas include access to medical services, education services, employment, social activity, community involvement, housing and spiritual activity. This outcome measure describes levels of community integration from a service delivery perspective, measuring "the extent to which a person with a disability encounters social responses that recognise and affirm the value of individual differences and value supporting those differences in the interest of increased participation in the life of the community" (Minnes et al. 2003:154).

The Participation Objective, Participation Subjective community integration measure looks at both subjective and objective indicators of participation (Sander et al. 2010; Yasui & Berven 2009). Using two separate scoring systems, the measure aims to rate both the individual's levels of participation in the community relative to societal norms and the individual's satisfaction and perceptions in areas considered priority to his/her personal well-being (Sander et al. 2010; Yasui & Berven 2009).

## **2.6 Community reintegration of adults with physical disabilities**

### **2.6.1 International studies in resourced countries**

A number of research studies that assessed the community integration of adults with physical disabilities have been conducted in resourced countries (Mayo et al. 2002; Carter, Buckley, Ferraro, Rordorf & Ogilvy 2000; Pang, Eng & Miller 2007; Kim et al. 2013; Whiteneck et al. 1999; Boschen, Tonack & Gargaro 2003). Three of these studies used the RNLI to assess community integration post stroke (Mayo et al. 2002; Carter et al. 2000; Pang et al. 2007). One of these studies was conducted in Canada (Mayo et al. 2002) with 434 community dwelling stroke survivors; and two in the USA by Pang et al. (2007) with 63 community dwelling older adults; and Carter et al. (2000) with 182 community dwelling individuals with previously treated aneurismal subarachnoid haemorrhage. According to these studies the following aspects of community integration, as measured by the RNLI, were most affected after suffering a stroke:

- Moving around in the community (Mayo et al. 2002)
- Travel (Mayo et al. 2002)
- Social activities (Mayo et al. 2002)
- Recreational activities (Mayo et al. 2002)
- Participating in work/meaningful activities (Mayo et al. 2002; Carter et al. 2000)

Mayo et al. (2002) compared RNLI scores of the participants with stroke (ischemic or haemorrhagic) to the scores of individuals without stroke. In their study, 365 stroke survivors and 486 individuals without stroke, of similar age and residing in the same city districts, completed the RNLI yielding the results presented in Figure 2.1. Figure 2.1 shows that 65% of community dwelling stroke survivors experienced limitations/restrictions in one or more items as measured by the RNLI compared to only 21% of their peers.

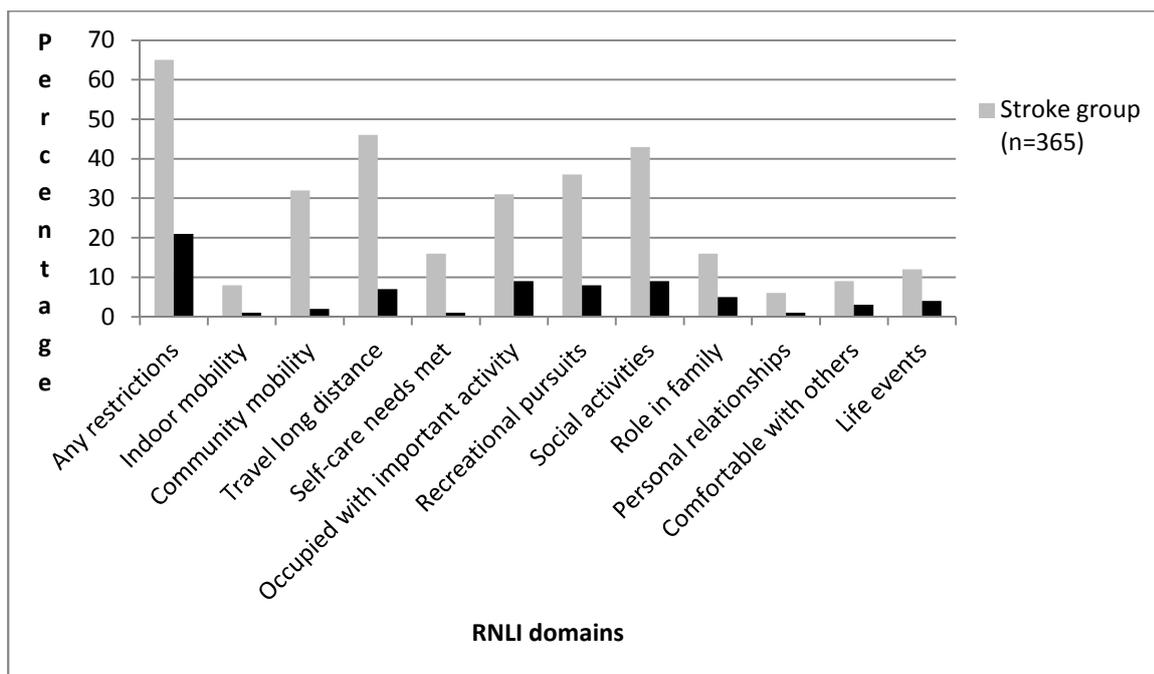


Figure 2.1: Comparison between percentage of persons six months post stroke and age-matched controls experiencing any degree of difficulty in RNLi domains as found by Mayo et al. 2002.

Pang et al. (2007) found that 89% of participants experienced limitations in one or more items as measured by the RNLi. Carter et al. (2000) on the other hand reported a much higher percentage of full reintegration into the community. Only 45% of participants stated that they experienced limitations in one or more RNLi items (Carter et al. 2000).

Reasons for the differences in the findings from the different studies might be related to the following factors:

- Stroke characteristics: Pang et al. (2007) and Mayo et al. (2002) both studied individuals who have suffered either an ischemic or haemorrhagic stroke. Carter et al. (2000), in contrast, only included individuals who suffered an aneurismal subarachnoid haemorrhage;
- Mean age of study participants: The mean age in the study conducted Carter et al. (2000) was lower (52 years) in comparison to the mean age in the Pang et al. (2007) and Mayo et al. (2002) studies which were 65 and 68 years respectively;
- Time since onset of stroke: While Mayo et al. (2002) interviewed participants six months after the onset of the stroke, Carter et al. (2000) and Pang et al. (2007) met

with and assessed study participants, on average, 2.75 and 5.5 years after the onset of the stroke respectively;

- Ability to ambulate: Pang et al. (2007) only included stroke survivors who were able to ambulate independently with or without an assistive device. Caution should thus be exercised when interpreting these findings and when wanting to generalise these to all community dwelling stroke populations. Many stroke survivors may require a wheelchair or motorised device for independent indoor and/or outdoor mobility.

Kim et al. (2013) assessed the community integration outcomes of 243 Canadians who suffered a traumatic brain injury. The majority of participants were between the ages of 30 to 34 years. Kim et al. (2013) found the following aspects of community integration, as measured by the RNLI, to be most affected:

- Travel
- Participation in work/meaningful activities
- Recreational activities
- Social activities
- Fulfilment of family roles

Figure 2.2 shows that participants with TBI in the study by Kim et al. (2013) experience greater limitations in and dissatisfaction with all items as measured by the RNLI, except for indoor mobility and self-care, in comparison to participants with stroke in the study by Mayo et al. (2002).

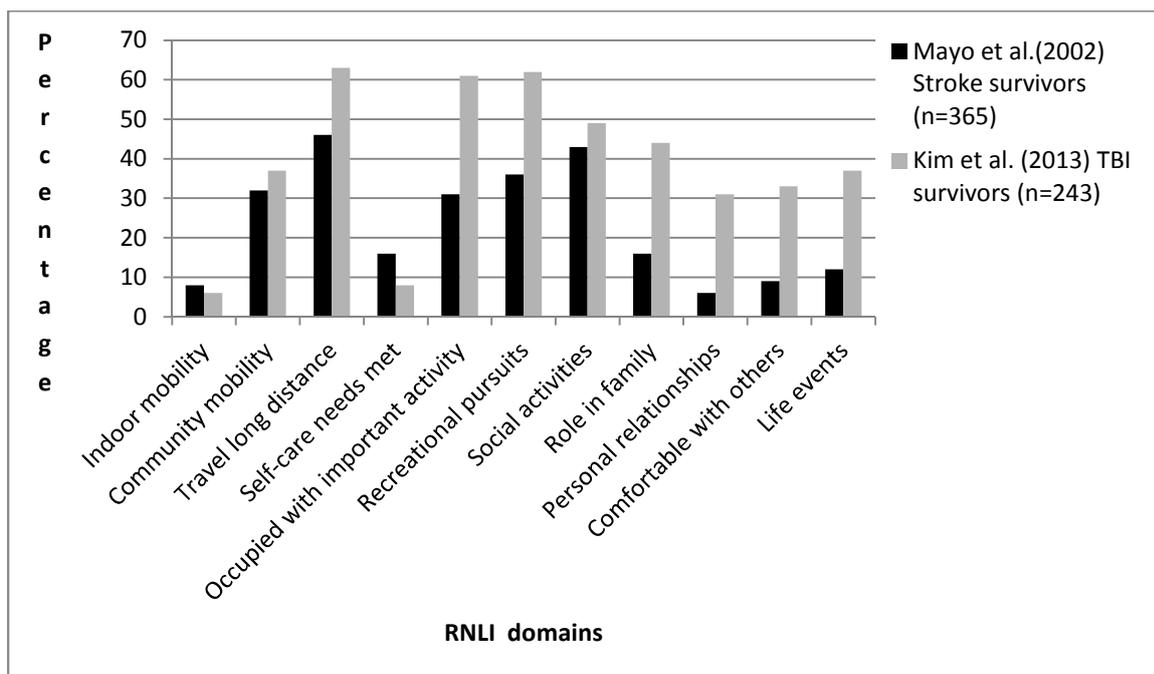


Figure 2.2: Comparison between persons with CVA (Mayo et al. 2002) and persons with TBI (Kim et al. 2013) experiencing any degree of difficulty on individual items as measured by RNLI

Both Mayo et al. (2002) and Kim et al. (2013) used a 3-point categorical scoring system (0-2 indicating the response categories: does not describe my situation, partially describes my situation and fully describes my situation). Mayo et al. (2002) did not comment on reasons why this brief scoring system was preferred over the original scale (1-10), Kim et al. (2013) report that the brief RNLI has been included in the Canadian National Rehabilitation Reporting System as “a single global assessment tool for community functioning” (Kim et al. 2013:52) since the year 2001 and that the brief system has been found to be equally valid and reliable when compared to the original scale. Kim et al. (2013) reported on RNLI scores captured on a database managed by the Canadian National Rehabilitation Reporting System.

Two studies, assessing community integration following spinal cord injury, were found (Whiteneck et al. 1999; Boschen et al. 2003). One of the studies was conducted in Canada with 100 community residing adults with spinal cord injury (SCI) (Boschen et al. 2003) and used the RNLI to determine community reintegration. The other was conducted in the USA with 3835 individuals with SCI (Whiteneck et al. 1999) using the CHART, an objective community integration measure. Whiteneck et al. (1999) found that persons who suffered a traumatic SCI experienced the biggest limitations in the domains physical independence,

mobility and occupation. Boschen et al. (2003) reported that participants expressed lower levels of participation in social and work-related activities. According to these studies the following variables affect community integration in individuals suffering from SCI:

- Age: younger individuals experienced higher levels of community integration (Whiteneck et al. 1999)
- Level of education: higher levels of education were indicative of higher levels of community integration (Whiteneck et al. 1999)
- Neurological level of injury: SCI sufferers with a lower neurological level of injury had higher levels of participation in community activities (Boschen et al. 2003; Whiteneck et al. 1999).

### **2.6.2 International studies in less resourced countries**

Samuelkamaleshkumar, Radhika, Cherian, Elango, Winrose, Suhany and Prakash (2010) and Sekaran et al. (2010) assessed community integration of persons with SCI in South India. Both studies used the CHART as outcome measure. Samuelkamaleshkumar et al. (2010) recruited 104 previously rehabilitated community residing persons with SCI. Sekaran et al. (2010) included 35 individuals with SCI discharged to a rural environment after completing rehabilitation. According to these two studies the following aspects of community integration were most affected after suffering a SCI:

- Occupation (Samuelkamaleshkumar et al. 2010; Sekaran et al. 2010)
- Mobility (Samuelkamaleshkumar et al. 2010; Sekaran et al. 2010)
- Social integration (Sekaran et al. 2010)
- Economic self-sufficiency (Samuelkamaleshkumar et al. 2010)

Both Sekaran et al. (2010) and Samuelkamaleshkumar et al. (2010) found that participants reported the lowest scores (lowest levels of integration) for occupation. The highest scores were recorded for the domains physical independence (Samuelkamaleshkumar et al. 2010; Sekaran et al. 2010) and cognitive independence (Samuelkamaleshkumar et al. 2010).

Samuelkamaleshkumar et al. (2010) commented that the majority of Southern Indian communities are located in rural areas that are generally inaccessible to wheelchair users and persons with disabilities are seldom presented with employment opportunities in these areas. Environmental barriers such as poor access to transportation, and quality health care as well as the attitudes of family were reported as great negative influences to community integration by participants (Sekaran et al. 2010). Similar to Boschen et al. (2003) and

Whiteneck et al. (1999) the researchers identified demographic variables such as younger age (Samuelkamaleshkumar et al. 2010), higher educational level (Samuelkamaleshkumar et al. 2010) and lower neurological level of injury (Sekaran et al. 2010) to be predictors of community integration in the study population.

Chau, Thompson, Twinn, Chang and Woo (2009) studied 188 stroke survivors, 12 months post discharge from rehabilitation hospitals in Hong Kong to determine factors influencing their community participation. The researchers used the London Handicap Scale to measure participation restrictions and the following outcome measures to determine which factors influenced participation: the State of Self-Esteem Scale, the Geriatric Depression Scale, the Social Support Questionnaire and the Modified Barthel Index to measure degree of independence. These researchers also found that the severity of injury leading to disability and age of participants predicted their level of community integration. The presence of depressive symptoms and female gender were found to be predictors of lower levels of community integration amongst the study population as measured by the London Handicap Scale.

### **2.6.3 Studies conducted in South Africa**

A number of studies discussing community integration, or concepts related to community integration, of persons living with disabilities in South Africa were identified.

Five studies, looking at the activity limitations and participation restrictions of community dwelling stroke survivors in South Africa (Rouillard, De Weerd, De Wit & Jelsma 2012; Cunningham & Rhoda 2014; Mudzi et al. 2013; Maleka et al. 2012; Wasserman et al. 2009), reported similar findings regarding participation restrictions experienced by their study participants. Rouillard et al. (2012) investigated 46 community dwelling stroke survivors six months post discharge from the WCRC, the setting of the current study; Cunningham and Rhoda (2014) reported on 24 stroke survivors who received treatment at and were discharged into the community from Uitenhage Provincial Hospital; Mudzi et al. (2013) established and discussed the levels of community participation of 114 stroke survivors 12 months post discharge from Chris Hani Baragwanath Academic Hospital situated in Soweto; Wasserman et al. (2009) assessed 30 stroke survivors discharged to the community from a district health facility in rural KwaZulu-Natal; while Maleka et al. (2012) interviewed 32 community dwelling stroke survivors and their caregivers from Soweto and the Limpopo province. Participants experienced the biggest challenges in:

- Participation in social and leisure activities (Rouillard et al. 2012; Cunningham & Rhoda 2014; Maleka et al. 2012; Mudzi et al. 2013; Wasserman et al. 2009);
- Participation in work activities/meaningful daily activities (Rouillard et al. 2012; Maleka et al. 2012; Wasserman et al. 2009);
- Assuming previous family roles and responsibilities (Rouillard et al. 2012; Cunningham & Rhoda 2014; Maleka et al. 2012; Wasserman et al. 2009);
- Their relationships with friends and family members (Rouillard et al. 2012; Cunningham & Rhoda 2014; Mudzi et al. 2013);
- Mobility within the home and community mobility (Cunningham & Rhoda 2014; Maleka et al. 2012; Mudzi et al. 2013);
- Accessing public transport which negatively affected activities such as shopping and independently attending social events in the community (Cunningham & Rhoda 2014).

Hassan et al. (2011) studied 57 stroke survivors dependent on a caregiver, discharged from the WCRC. They found that 60% of participants in their study was partially integrated into the community and former life roles (participated in social activities such as shopping, attending church and recreational activities in the community) or fully integrated (participated in the previous activities and engaged in work/educational activities appropriate to the individual's life stage and interests). Hassan et al. (2011) and Rouillard et al. (2012) commented that participants could have benefited from community based rehabilitation services to address environmental barriers within the home and community environments.

Henn et al. (2012) assessed rehabilitation outcomes of persons with complete paraplegia, who received rehabilitation at a private rehabilitation hospital in Gauteng, South Africa. Sixteen individuals participated in the study. The authors concluded that the rehabilitation process inadequately prepared participants for reintegration into community life. They postulated that this may be due to the rehabilitation programme mainly concentrating on and addressing activity limitations while including few efforts to prepare the individuals for active community participation and resumption of their previous social roles.

Fredericks and Visagie (2013) reported similar findings to Henn et al. (2012) after evaluating the outpatient amputee rehabilitation programme at a centre in the Western Cape Province. Findings revealed that rehabilitation efforts were mostly aimed at addressing impairments. The rehabilitation programme addressed aspects related to community mobility, environmental barriers in the community and visits to the home and work environments to a very limited extent. Fredericks and Visagie (2013) and Godlwana and Stewart (2013) found that lower limb amputees mainly experienced difficulties with:

- Outdoor mobility (Fredericks & Visagie 2013);
- Completing chores within the community such as shopping, going to the bank or post office (Fredericks & Visagie 2013; Godlwana & Stewart 2013);
- Pursuing hobbies and sporting activities (Godlwana & Stewart 2013);
- Visiting family and friends (Godlwana & Stewart 2013);
- Engaging in social and recreational activities with a partner or other family members (Godlwana & Stewart 2013);
- Securing gainful employment (Godlwana & Stewart 2013; Fredericks & Visagie 2013).

#### **2.6.4 Contextual factors that influence community integration**

Community integration achieved by persons with physical disabilities is influenced by an interaction of injury/disease-related impairments with the contextual factors (Sander et al. 2010; WHO 2001). The ICF groups contextual factors into two overarching categories namely environmental factors and personal factors. Environmental factors include aspects such as access to products and technology, including assistive devices, the natural environment and changes made to it, family structures and functioning, social support and attitudes, cultural belief systems, government policies, accessibility to community environments and services. Personal factors that impact community integration include features such as age, gender and socio-economic status (Godlwana & Stewart 2013; Rouillard et al. 2012; Chimatiro & Rhoda 2013; Øderud 2014; Munsaka & Charnley 2013; Chau et al. 2009; Whiteneck et al. 1999).

Environmental factors that can act as barriers and/or facilitators to community integration in less resourced settings include:

- Access or lack thereof to appropriate assistive devices (Sekaran et al. 2010; Chimatrio & Rhoda 2014; Cunningham & Rhoda 2014; Cawood & Visagie 2015);
- Poor/limited access to health care services including home based care services and appropriate medical equipment (Sekaran et al. 2010; Boschen et al. 2003; Chimatiro & Rhoda 2013; Wasserman et al. 2009; Øderud 2014; Cawood & Visagie 2015);
- Interventions by health care professionals (Cunningham & Rhoda 2014; Sekaran et al. 2010; Chimatrio & Rhoda 2014; Boschen et al. 2003; Cawood & Visagie 2015);
- Family support served as facilitators to community participation for persons with disabilities (Cunningham & Rhoda 2014; Sekaran et al. 2010; Chimatrio & Rhoda 2014; Boschen et al. 2003; Godlwana & Stewart 2013; Cawood & Visagie 2015);

- Accessibility of physical home environment including outdoor toilets (Cunningham & Rhoda 2014; Rouillard et al. 2012; Samuelkamaleshkumar et al. 2010; Øderud 2014; Cawood & Visagie 2015);
- Access to amenities such as running water (Cunningham & Rhoda 2014; Rouillard et al. 2012; Samuelkamaleshkumar et al. 2010; Øderud 2014);
- Accessibility of the community natural and built environments such as kerbs, stairs, uneven and sandy gravel roads (Cunningham & Rhoda 2014; Boschen et al. 2003; Chimatiro & Rhoda 2013; Banda-Chalwe, Nitz & de Jong 2012; Sekaran et al. 2010; Cawood & Visagie 2015);
- Accessibility of public buildings including school buildings (Samuelkamaleshkumar et al. 2010; Chimatiro & Rhoda 2013; Øderud 2014);
- Accessibility of public transport system (Rouillard et al. 2012; Samuelkamaleshkumar et al. 2010; Øderud 2014; Banda-Chalwe et al. 2012; Cawood & Visagie 2015);
- Negative attitude/stigma of person within the home and community, exclusionary practices (Sekaran et al. 2010; Chimatiro & Rhoda 2013; Øderud 2014; Banda-Chalwe et al. 2012; Munsaka & Charnley 2013; Cawood & Visagie 2015);
- Negative attitudes of employers (Chimatiro & Rhoda 2013; Ntsiea, Aswegen & Olorunju 2013);
- Lack of knowledge and awareness about disability (Chimatiro & Rhoda 2013; Øderud 2014; Banda-Chalwe et al. 2012);
- Social-cultural and religious beliefs (Banda-Chalwe et al. 2012; Munsaka & Charnley 2013);
- Development of appropriate legislation, systems and policies promoting accessibility and inclusion (Banda-Chalwe et al. 2012; Cawood & Visagie 2015);
- Accessibility to social security services and support (Cawood & Visagie 2015).

The provision of health care and rehabilitation services plays an important role in facilitating community integration of persons with disabilities (Mudzi et al. 2013). Comprehensive rehabilitation services should not only address the re-education and training of physical and functional abilities and assist with psychological and emotional adjustment to the disability; it should also attempt to influence barriers faced by persons with disabilities within the home and community environments.

## 2.7 Comprehensive in-patient rehabilitation

As stated earlier community integration is one of the main aims of rehabilitation. As such rehabilitation programmes should focus their efforts on assisting clients to become active and productive members of their communities and to help them to live with greater independence (DoH 2013; Parvaneh & Cocks 2012). Rehabilitation programmes should be designed to address barriers to community integration on both a personal and community level (Minnes et al. 2003). As community integration is influenced by personal factors such as age, gender and culture, as well as the physical and social environments (Dijkers 1988; McColl et al. 1998; Wolfensberger 1993; Salter et al. 2008; Yasui & Berven 2009; Parvaneh & Cocks 2012), rehabilitation programmes aimed at achieving community integration of persons with disabilities should be designed and implemented according to individual needs and priorities.

The WHO not only defines rehabilitation as presented in the glossary of terms, but also explains that rehabilitation should be a time-limited and goal oriented process that involves single or multiple interventions. According the WHO disability report rehabilitation should include modification of the impairment, compensation for loss of function and modification of the environment (WHO 2011).

In South Africa rehabilitation should be provided through a continuum of care from community and district level through to tertiary level (DoH 2013). District level services must be supported by in-patient facilities that provide comprehensive rehabilitation to those whose needs cannot be met by community based services (DoH 2013). Typically individuals with multiple or severe impairments who require the input from a number of professionals and can actively participate in a rehabilitation programme for at least three hours per day should be admitted to in-patient rehabilitation facilities (DoH 2013). Specialised in-patient rehabilitation facilities should be dedicated to rehabilitation service provision, be well equipped and have professionally trained rehabilitation staff (DoH 2013; Lightfoot 2004). Multi- or interdisciplinary rehabilitation teams offer intensive rehabilitation programmes aimed at improving an individual's health, function and community integration (Stucki, Ewert & Cieza 2002). Rehabilitation goals and realistic time frames to attain these goals are set by the individual with a disability in consultation with the rehabilitation team. Rehabilitation professionals should make use of a disability framework, such as the ICF for example, to allow for multidisciplinary assessments, goal setting and management of the rehabilitation process and ensure that all aspects from impairments to the environment are addressed (Stucki et al. 2002).

However, in many instances rehabilitation teams working at in-patient rehabilitation facilities still view disability and health as a medical problem (Lightfoot 2004; Stucki et al. 2002; Larrson Lund & Tamm 2001) and, due to this approach, rehabilitation programmes and treatment goals are largely focused on addressing impaired body structures and improving functioning and health (Lightfoot 2004; Stucki et al. 2002; Larrson Lund & Tamm 2001). This is also true for South Africa where rehabilitation service provision often follows a medical approach and is aimed primarily at modification of bodily impairments and improving and normalising body function and structures (DoH 2013; Mji, Chappell, Statham, Mlenzana, DeWet & Rhoda 2013; Chappell & Johannsmeier 2009). Little attention is paid to environmental, economic and political barriers that affect and hinder community integration and the performance of persons with disabilities within former life roles (Mji et al. 2013; Chappell & Johannsmeier 2009; Kahonde, Mlenzana & Rhoda 2010).

According to policy these environmental barriers should be addressed at community level. Rhoda, Mpofu and DeWeerd (2009) investigated the rehabilitation services available to stroke survivors at community health centres in the Western Cape Province and found poorly coordinated services and a lack of therapy staff at primary health care facilities. This means that persons with disabilities are often discharged from in-patient rehabilitation services without access to follow up rehabilitation services at primary health care level to help facilitate and achieve community integration (Rhoda et al. 2009; Hassan et al. 2012; Cawood & Visagie 2015; Wasserman et al. 2009).

## **2.8 Summary of chapter**

The bio-psychosocial approach to disability includes aspects of both individual and societal approaches to disability as it acknowledges the influences of biological, individual and societal factors in the creation of disability. This approach to disability is used in the current study. While community integration is one of the main focus areas of rehabilitation services for persons with disabilities, it is difficult to achieve.

Community integration is a multifaceted concept that takes into account inclusion into residential and family life, community and social activities, productive activity relevant to an individual's life stage, social and interactive relationships with family, friends and members of the wider community. Community integration of persons with disabilities can be determined by means of objective or subjective outcome measures. This study will use a subjective measure, the RNLI.

Literature from Canada, the USA, India and South Africa indicates that areas which negatively impact on community integration of persons with disabilities include community mobility, long distance travel, participation in social and recreational activities, relationships with family members and friends, fulfilment of family roles and engaging in daily meaningful/productive activities. A wide variety of environmental and personal barriers and facilitators influencing community integration of persons with disabilities have been identified by researchers such as access to services and assistive devices, family support, physical home and community environments, access to public buildings and public transport systems, attitudes of family and community members and potential employers, and cultural and social beliefs regarding disability. Comprehensive rehabilitation services should endeavour to address these barriers.

## **Chapter Three**

### **Methodology**

#### **3.1 Introduction**

Chapter 3 provides a detailed description of the methodology of the study. All aspects related to study design, study setting, sampling, measurement tools, data collection and analysis, and ethical considerations are explained.

#### **3.2 Study design**

A quantitative, cross-sectional, descriptive study design was used. Descriptive studies can portray the characteristics of a selected population and can quantify and describe the burden of disease and/or disability in a population (Joubert & Ehrlich 2007). A descriptive design was thus deemed suitable for this study with the aim of describing the levels of community integration achieved by adults with disabilities after completing in-patient rehabilitation.

Quantitative data is obtained through the measurement and observation of facts and occurrences of interest (Carter, Lubinsky & Domholdt 2011). It provides numerical data which can be used to inform service providers of the extent of a problem. Quantitative data from this study provided information to managers and members of the WCRC rehabilitation team on the levels of community reintegration achieved by former patients. The study also identified domains of community reintegration that posed the greatest challenges to persons with disabilities after rehabilitation at the WCRC.

Cross-sectional studies describe the current state of a selected group of people at a certain point in time, can explore the prevalence of an occurrence and can identify associated factors and variables (Joubert & Ehrlich 2007; Carter et al. 2011). A cross-sectional design was therefore selected for this study as it set out to describe the levels of community reintegration of persons with disabilities at a given point in time and to identify if the variables age, gender and medical diagnosis can possibly be associated with community reintegration achieved after discharge from in-patient rehabilitation.

#### **3.3 Study setting**

The study was conducted at the Western Cape Rehabilitation Centre (WCRC), located in Mitchell's Plain, Cape Town (Cape Town Metro Health District). The WCRC is a government

funded, specialised rehabilitation unit (Joseph, Mji, Statham, Mlenzana, De Wet & Rhoda 2013; Rouillard et al. 2012, WCRC 2007) that provides high-intensity in-patient rehabilitation services and community integration programmes for adults and children with physical disabilities. The centre accepts appropriate referrals from all levels of health care (tertiary, secondary, district and primary) within the province as well as from neighbouring provinces. Clients treated at the centre mainly fall within one of the following medical diagnostic categories: traumatic brain injury, spinal cord injury, cerebral vascular accident, lower limb amputation, neuropathy, muscular dystrophy, cerebral palsy or a combination of the above mentioned medical diagnoses. Rehabilitation professionals work in inter-disciplinary teams to provide outcome-based rehabilitation programmes aimed at improving the functional independence of persons with disabilities (Joseph et al. 2013; WCRC 2007). Rehabilitation goals are set collaboratively by the inter-disciplinary rehabilitation team and the client's progress is reviewed and discussed on a weekly basis during team discussions. The team aims to work according the bio-psychosocial approach to disability.

The WCRC has 156 in-patient beds. Rehabilitation services are rendered to each in-patient for at least five days a week with an average of four to six hours of active rehabilitation per patient per day, offered by various members of the inter-disciplinary team (Provincial Government of the Western Cape 2007). Interventions and rehabilitation programmes focus on promoting functional independence and community reintegration of persons with disabilities by addressing activity limitations and participation restrictions as well as environmental barriers within home and community environments. Family members and care givers are encouraged to play an active part in the rehabilitation process. To evaluate and facilitate community reintegration, clients spend a number of weekends at home during their rehabilitation programme. This allows the rehabilitation team and the client to identify activity limitations to be addressed and environmental modifications required to help achieve optimal community reintegration after discharge from the unit. If indicated, home, school and/or work visits are conducted by relevant team members. Statistics drawn from the electronic database of the WCRC show that the length of stay for in-patients varies from an average of 28 days (e.g., traumatic brain injury or stroke) to 90 days or longer (e.g., for patients with a high level spinal cord injury).

### **3.4 Study population, sampling and participants**

The study population consisted of the 188 persons with disabilities who were, according to the WCRC electronic data base, discharged from the Western Cape Rehabilitation Centre between 01 September 2012 and 30 November 2012. This time frame was selected to

ensure that study participants would have been home between seven and nine months at the time of data collection in July and August 2013. Individuals discharged in December 2012 were not selected for the study as rehabilitation programmes of in-patients at the WCRC are often interrupted and/or fast tracked due to a great number of public and religious holidays in December.

#### **3.4.1 Inclusion criteria**

- Individuals 18 years and older;
- Individuals discharged from the WCRC to the community after intensive in-patient rehabilitation by an inter-disciplinary team.

#### **3.4.2 Exclusion criteria**

- Individuals discharged to a care facility or nursing home;
- Individuals who have had more than one period of admission of in-patient rehabilitation at the WCRC i.e., individuals who were discharged after a readmission to the WCRC. These individuals were given a second/multiple chance/s to address domains of reintegration together with their rehabilitation team to improve their participation and level of community reintegration. The majority of individuals complete one period of in-patient rehabilitation at the WCRC. The researcher therefore wanted to determine the levels of community reintegration achieved by adults with disabilities who have completed only one period of admission of in-patient rehabilitation;
- Individuals who were unable to complete a questionnaire in English, Afrikaans or Xhosa, the three languages most commonly spoken in the Western Cape Province;
- Individuals residing outside the Cape Town Metro Health District who did not have access to a telephone to allow completion of a telephonic questionnaire. Individuals residing outside the Cape Town Metro Health District could not be visited at their home for data collection due to the financial and time constraints experienced by the researcher;
- Individuals residing outside the Cape Town Metro Health District, who were unable to verbally complete a telephonic questionnaire due to speech-language (communication) difficulties and/or cognitive disorders;
- Individuals who died prior to data collection;

- Individuals not competent to give informed consent or unable to give accurate reports of their own functioning and satisfaction regarding community integration. Competence to give informed consent was determined by the researcher during the file audit. Notes made by the rehabilitation team, in particular the occupational therapist, social worker and the psychologist were studied in detail. Any indication that the individual might not be competent to give informed consent or accurate reports of their own functioning were noted and then followed up with a phone call to the individual's family. Proxy participants were not used as the RNLI showed poor reliability between individuals with a disability and significant others (Tooth, Mckenna, Smith & O'Rourke 2003). Tooth et al. (2003) found that proxies had a tendency to underrate an individual's perception and performance of activities related to community reintegration.

Of the 188 individuals in the study population 76 had to be excluded based on the exclusion criteria (See Table 3.1 for details).

Table 3.1: Reasons for exclusion

Number of individuals	Reason
17	Younger than 18 years
7	Deceased prior to data collection
40	More than one period of in-patient admission at the WCRC
1	Unable to complete questionnaire in English, Afrikaans or Xhosa
6	Unable to give accurate verbal report of their own functioning and satisfaction regarding community reintegration, as identified during rehabilitation at the WCRC
5	Discharged to a care facility

The study proposal called for 80 participants, a sample that was thought to be convenient for the completion of the research assignment taking time and resource constraints into consideration while still big enough to allow statistical analysis. The researcher planned to perform proportional stratified random sampling with medical diagnosis as strata. However, since only 112 participants were left after implementing exclusion criteria and others might decline participation in the study or the research team may not be able to locate/contact

some of the individuals, the researcher decided to include all 112 individuals in the study sample and do no further sampling.

Of the 112 eligible participants four individuals declined participation and 49 individuals could not be located either telephonically or by means of a home visit if the individual resided within the Cape Metro Health District. Thus 59 individuals participated in the study.

### **3.5 Data collection instruments**

Data was collected from the WCRC electronic database, patient folders and study participants. Two data collection instruments were used:

- A demographic and medical data sheet (Appendix 1)
- The Reintegration to Normal Living Index (RNLI) (Appendix 2)

Demographic and medical details were gathered by the researcher from the WCRC electronic database and the medical folders on a data sheet (Appendix 1) designed by the researcher.

Community reintegration post discharge was measured with the Reintegration to Normal Living Index (RNLI) (Appendix 2). The RNLI is an 11-item index. Each item is rated on a scale of 1-10 or a visual analogue scale that allows participants to express the extent to which each statement describes his/her current situation (Wood-Dauphinee & Williams 1987). The number 1 on the scale represents minimal reintegration (does not describe my situation) and the number 10 represents complete reintegration (fully describes my situation). The 11 items collate to a total score of 110, but for ease of interpretation, “the scores can be proportionately converted to a 100 point system” (Wood-Dauphinee & Williams 1987:495).

Wood-Dauphine, Opzoomer, Williams, Marchand and Spitzer (1988) reported on the development of the RNLI and its validity when tested with individuals suffering from cancer, myocardial infarction, central nervous system or orthopaedic impairments, living in Canada. According to Wood-Dauphine (1988) and colleagues the RNLI showed high internal consistency and was responsive to changes in the clinical condition/circumstances of individuals. As part of testing the validity of the index, the researchers found the index to be related, to some extent, to work status and disease status (criterion validity). It also showed construct validity, both convergent and discriminant, when compared to a quality of life

measure, namely the Quality of Life Index. The 11 items of the RNLI was found to be representative of the construct 'reintegration to normal living'.

Hitzig et al. (2012) also validated the RNLI, interviewing 618 community dwelling individuals with SCI in Canada. Their findings support the findings by Wood-Dauphine et al. (1988), showing that the RNLI has high internal consistency (Cronbach  $\alpha$  of 0.87). Hitzig et al. (2012) performed a regression analysis showing that the RNLI "is sensitive to factors that may affect participation for persons with SCI" (Hitzig et al. 2012:112). Hitzig et al. (2012) also confirmed the construct and concurrent validity of the RNLI: the RNLI was compared with the Satisfaction with life scale by means of confirmatory factor analysis to confirm construct validity while a generalised linear model approach was selected to confirm concurrent validity. These findings were also applicable when the questionnaire is administered telephonically (Hitzig et al. 2012).

Mothabeng et al. (2012) determined the psychometric properties of the RNLI in a group of persons living with SCI in South Africa. The researchers demonstrated that the RNLI is a reliable measure for satisfaction with community reintegration (Cronbach  $\alpha$  of 0.974) for persons living with SCI in South Africa and the RNL Index is therefore suitable for use in the South African context. Mothabeng et al. (2012) were also able to establish:

- Content validity;
- Construct validity (item loadings ranged from 0.86 to 0.93 (>0.71) on all items);
- Item convergent validity (corrected RNLI item-total correlation coefficients ranged from 0.73 to 0.91); and
- Item discriminant validity (Fisher's z value was 4.45 which is >1.96, the criterion for z) for the RNLI.

Time dependent aspects of validity, for example predictive validity and reliability, for example test retest reliability, could not be determined due to the cross sectional nature of their study (Mothabeng et al. 2012).

The original questionnaire is in English. It was translated into Afrikaans and Xhosa as these are the three languages most commonly spoken in the Western Cape. The researcher consulted translators at the Language Services of the Western Cape Department of Health (Directorate: Communications, Language Unit) to perform the translations from English to Afrikaans and Xhosa. To ensure that the translation process was accurate, i.e., information or the meaning of phrases were not changed, the questionnaire was translated back into English by translators at the Language Services University of Stellenbosch. Inconsistencies between the original questionnaire and the back translated document were then compared

and discussed by the researcher with a Xhosa and an Afrikaans mother tongue speaking individuals. To ensure consistency between the three questionnaires, the most appropriate and accurate wording and phrasing was then decided upon by the researcher and the Xhosa/Afrikaans speaking individuals.

### **3.6 Research assistants**

#### **3.6.1 Identification and selection**

The researcher identified and recruited three research assistants from the staff of the WCRC to assist with data collection. An email (Appendix 3) describing the study and the role of research assistants in the study was sent to all therapy assistants and therapy administration clerks employed at WCRC. The email contained the following information on the requirements for research assistants:

- Three research assistants were needed;
- Mother tongue/home language – an English, Afrikaans and Xhosa speaking individual were needed to allow the data collection to be conducted in the three languages most commonly spoken in the Western Cape;
- Willingness to participate in training sessions prior to data collection to ensure equal application and interpretation of the data collection instruments;
- Willingness to telephonically administer the RNLI;
- Willingness to accompany the researcher on visits to study participants' homes within the Cape Town Metro Health District for data collection purposes should the individual not have access to a telephone;
- Willingness to administer questionnaires for data collection outside of official working hours;
- Availability during the months of July and August 2013 during which the pilot study as well as the data collection for the main study were scheduled to take place.

A number of staff members indicated their interest. The researcher met with all interested staff to provide them with a background and summary of the proposed study and to clarify the researcher's expectations of a research assistant. Following this meeting, two individuals indicated that they were no longer interested. The researcher then held individual interviews and discussions with each of the remaining interested staff members. The three most suitable individuals were selected by the researcher based on the following criteria:

- Mother tongue/home language – fluency of spoken language and ease of communication;
- Availability during the months of July and August 2013;
- Level of confidence and presentation when interacting with in-patients at the WCRC.

### **3.6.2 Training of research assistants**

The researcher trained the three research assistants in all aspects of the data collection process for the pilot and the main study. Terminology and concepts were clarified and the assistants were taken through each step of the data collection process. An information package was provided to each assistant that included:

- The synopsis of the research study (as written for the research proposal);
- The methodology of the research study (as written for the research proposal);
- The RNL Index;
- The Participant information leaflet and consent form;
- A map showing the Cape Metro Health District;
- A flow diagram showing the steps of the data collection process;
- An example of the demographic and medical data sheet;
- An example of a log sheet to capture and track information of participants that could not be contacted/located or that needed to be contacted at an alternative day and time;
- The confidentiality form to be completed by research assistants.

The following aspects were covered in a 4 hour training session:

- Introduction to the study;
- Familiarising research assistants with the Information Leaflet and Consent Form (Appendix 4);
- Data collection process
  - Introduction to the participant
  - Verification of personal and medical data
  - Completion of the RNLI – to ensure uniformity and to limit interator bias, items on the RNLI could only be repeated. Items could not be rephrased or explained to participants by means of alternative wording
  - Management of questions or concerns raised by the participant during the interview process – information as set out in the Information Leaflet and Consent Form could be

repeated to participants. Any further questions had to be recorded in writing and referred to the researcher for further management

- Management of concerns or problems identified by the research assistant during the interview process with the study participant – any concerns identified by the assistants needed to be clearly recoded in writing and referred to the researcher for further follow-up and investigation.

The research assistants were informed that all participant information and data related to and collected during the study had to be treated as confidential. Assistants signed a confidentiality form (Appendix 5) confirming that they would not disclose any information related to the study participants. The signed forms were kept in a secure location by the researcher.

The WCRC management granted permission that the research assistants could perform all telephonic interviews and home visits during official working hours. Thus the researcher and the research assistants agreed that the honorarium set aside for the research assistants will be paid to the research fund of the WCRC Facility Board.

### **3.7 Pilot study**

The researcher obtained a list of individuals discharged from the WCRC during the month of August 2012 from the WCRC electronic database. From the medical folders, the researcher identified 12 possible participants for the pilot study who met all the inclusion criteria of the study. Using the demographic and medical data sheet, the researcher captured the required demographic and medical data. The researcher then identified four suitable participants for the pilot study ensuring that the population was as diverse as possible, i.e., that both male and female participants from various age and language groups and from different diagnostic groups were included.

The trained research assistants then conducted telephonic interviews and one home visit to practice the data collection process. The researcher was present during these interviews to help identify problems with regards to:

- The data collection instruments;
- The research assistants' accuracy during the data verification and collection processes;
- The logistics of the data collection process.

Additional purposes of the pilot process included determining:

- The time required to complete an interview;
- Whether the data collected would enable the researcher to answer the study aims and objectives.

Each research assistant conducted one telephonic interview in their respective language. During these interviews, a speaker telephone was used to allow the conversation to be recorded using an audio recorder. The following process was followed during each interview:

- Research assistant briefly introduced herself to the participant;
- Concise background to the research study, as set out in the Participant information Leaflet and Consent Form (Appendix 4), was read to the participant;
- Informed consent was then obtained from the participant;
- If the individual declined to participate, his/her details were captured on a spread sheet;
- If the individual consented to participation, the research assistant would proceed with the interview, first checking the captured demographic and medical data for correctness, followed by the RNLI;
- The participant was then thanked for his/her time and willingness to answer all relevant questions.

One home visit was conducted by the research assistants and the researcher. Due to time constraints only one interview was carried out with all three research assistants and the researcher present. This allowed both the researcher and research assistants to observe the data collection process by means of a personal visit. The same process, as set out above for the telephonic interviews, was followed. Table 3.2 describes the problems identified during the pilot study and how they were addressed.

Table 3.2: Problems identified during pilot study and action plan for data collection process

<b>Problem identified during pilot study</b>	<b>Changes/improvements made to data collection process</b>
<ul style="list-style-type: none"> <li>• Contact telephone numbers in patient folders were often no longer valid or incorrect</li> </ul>	<ul style="list-style-type: none"> <li>• As many contact phone numbers as possible of the patient and his/her relatives were entered into the data sheet from the folder</li> <li>• Research assistants checked the ward 'patient contact books' in which nursing staff record contact numbers of patients and next of kin prior to a patient's weekend leave</li> <li>• If family members of the eligible participant answered the phone,</li> </ul>

	alternative and updated contact details were requested and documented for follow up to assist in successfully reaching the participant
<ul style="list-style-type: none"> <li>Participants, with cognitive involvement as identified during the rehabilitation process by health care professionals, struggled to complete the questionnaire telephonically. Mainly individuals who suffered a CVA or a head injury fell into this category.</li> </ul>	<ul style="list-style-type: none"> <li>Participants, with cognitive involvement as identified during rehabilitation, and who resided within the Cape Town Metro Health District were interviewed in person by means of a home visit by the research assistant</li> </ul>
<ul style="list-style-type: none"> <li>Some participants experienced difficulty scoring the 'example of the question format' of the RNLI (The weather today pleases me) and this resulted in poor understanding of the scoring process for the 11 questions of the index</li> </ul>	<ul style="list-style-type: none"> <li>Research assistants took care to ensure that the example question and the scoring was well understood by means of rephrasing the example question and, at times, using a different/alternative example for this question</li> </ul>
<ul style="list-style-type: none"> <li>Some participants experienced difficulty understanding some items/statements on the RNLI due to unfamiliar wording and expressions</li> </ul>	<ul style="list-style-type: none"> <li>All statements/items of the translated documents (Xhosa and Afrikaans) were reviewed and adapted to ensure that simple and understandable language was used while at all times ensuring consistency and accuracy of phrases and their meaning between the documents in the various languages</li> </ul>

### 3.8 Data collection

Data was collected from 59 participants of whom 31 (53%) completed the RNLI telephonically and 28 (47%) were visited at their home to complete the Index by means of a personal interview.

#### 3.8.1 Identification of study participants and collecting data from folders

The researcher obtained a list of all individuals discharged from the WCRC, between 01 September 2012 and 31 November 2012, from the WCRC electronic database. The folders of these 188 individuals were drawn from the medical records department. 27 folders were not available at medical records. These 27 folders were located over the following two weeks

by the researcher with the help of a staff member from the medical records department and the Chief Occupational Therapist of the centre. Most of these 27 folders were located either in the in-patient wards, the out-patients department or with therapy staff responsible for the individual during his/her in-patient stay at the WCRC.

The researcher completed the demographic and medical data sheet (Appendix 1) from information in the folder. Each study participant's demographic and medical information was recorded directly into an Excel spreadsheet on the researcher's laptop and each participant was allocated a random number which was used for identification on the RNLI data collection tool. The researcher worked from a vacant office at the WCRC for three days to complete this first step of the data collection process. Where the medical notes of the various health care professionals or the discharge notes indicated that a participant might be unable to give accurate and reliable responses due to speech-language (communication) difficulties and/or cognitive disorders, the researcher contacted the participant and/or his/her closest family members to confirm this. Based on the medical notes and the information given by the participant and/or family members, the researcher determined if the participant met the inclusion criteria of the study.

The data of all individuals who did not meet the inclusion criteria was captured on a separate data sheet (Appendix 6) indicating only the individual's name, contact telephone number and the reason for exclusion from the study.

### **3.8.2 Telephonic data collection**

The telephonic data collection process took place over a six week period from mid July 2013 to the end of August 2013. The completed Excel spreadsheet, detailing the demographic and medical data of all eligible participants, was provided to the each of the three research assistants.

The research assistants divided the eligible participants into three groups according to probable language preference. Study participants were then contacted telephonically by the respective research assistants. To ensure that the individuals received all relevant information regarding the study and the terms of informed consent in their home language, research assistants first asked each individual which of the three languages he/she would prefer. If the English speaking assistant, for example, contacted a participant and he/she indicated that he/she would prefer having the interview in Afrikaans, the English speaking assistant arranged a follow up date and time for an Afrikaans interview with the participant.

All relevant information was then passed on to the respective research assistant. Also, if participants indicated that the telephone call was at an inconvenient time, the research assistant confirmed a date and time for a follow up phone call to conduct the interview. Research assistants kept a log sheet capturing the date and time of each telephone call and also indicated if and when a follow up call was required to complete data capturing.

On making telephonic contact, the research assistants introduced themselves and, explained the aim and objectives of the study as well as its benefits and social implications to the study participants. Informed consent was then obtained telephonically by the research assistant and all conversations were audio recorded as proof of informed consent.

The actual interview was started by verifying the demographic and medical data obtained from the WCRC electronic database with the individual. Thereafter the RNLI was completed. The research assistant recorded the responses given by the participants (a score between 1 and 10 for each of the 11 items of the index) on the questionnaire sheet. Research assistants made detailed notes if any questions were raised by participants during an interview or if the assistant identified any concerns or problems regarding the participant's health or rehabilitation management. This information was passed onto the researcher to follow up with the participants after the completion of data collection to make appropriate recommendations and referrals.

Many of the eligible participants could not be reached telephonically on the first attempt. Often, the research assistants found that telephones would simply ring with no answer or a voicemail message activating. In these instances the research assistants phoned the particular telephone number three more times, at three different times during the day and early evening in an attempt to contact the participant. Other telephone numbers recorded for a participant were also dialled following this routine in an attempt to contact the individual. If the additional attempts to contact the participant were unsuccessful, the participant's information was added to the spread sheet of excluded participants, indicating that the participant could not be contacted for participation in the research study.

All telephone costs related to data verification and collection were carried by the WCRC and the researcher. The WCRC agreed to carry all telephone costs incurred by the research assistants during working hours from their office telephones. All telephone costs incurred by the research assistants after hours, while using their home telephones or their mobile phones, were covered by the researcher.

The data of all individuals who could not be located or who declined to participate in the study was transferred and captured on a separate data sheet (Appendix 7).

### **3.8.3 Personal visits for data collection**

The data collection process by means of a personal visit to participants' homes took place over a one week period, from 05 to 08 August 2013.

Eligible study participants residing within the Cape Town Metro Health District who could not be contacted telephonically due to invalid telephone numbers or due to not having access to a telephone, were visited at their home address by the researcher and a research assistant. In addition to this, participants, where cognitive involvement was identified during rehabilitation (as indicated in the medical folder), and who resided within the Cape Town Metro Health District, were interviewed in person by means of a home visit.

Only the research assistant was present during the interview. The interview commenced with the information leaflet being read to the participant explaining the aim and objectives of the study as well as its benefits and social implications. Research assistants answered any questions the study participant had regarding the study before obtaining written informed consent.

If the participant indicated that the day and time of the home visit was not convenient for him/her and his/her family, the research assistant made an appointment for a follow up visit on a suitable day. If the individual consented to participating in the study the research assistant proceeded with verifying all medical and demographic data as captured by the researcher (Appendix 1). The research assistant continued the interview, completing the RNLI with the participant. The research assistant recorded the responses given by the participant on the questionnaire sheet. Any questions raised by the participant or any concerns identified by the research assistant during the interview were noted by the assistant and passed on to the researcher for follow up.

In some cases the residential address provided in the medical folder was incorrect or the individual had, since discharge from the WCRC, moved to an alternative address. The research team then asked the current residents if they could provide updated contact details for the participant. The researcher and research assistant would then contact the participant by visiting the provided updated residential address or by phoning the participant using the updated telephone details. If these additional attempts to contact the participant were unsuccessful, the participant's information was added to the spread sheet of excluded participants, indicating that the participant could not be contacted for participation in the research study. All costs, related to home visits were carried by the researcher.

### 3.9 Data analysis

#### 3.9.1 Exploration and presentation of data

Both demographic data and findings from the RNLI were captured and combined on an Excel spreadsheet by the researcher. An independent individual, not involved with the research, checked all data captured for correctness.

The 11 items of the RNLI were grouped into nine domains and two subscales according to the item aggregations concerning reintegration to normal living patterns as described by Wood-Dauphinee & Williams (1987) and presented in table 3.3.

Table 3.3: Summary of item aggregation concerning reintegration to normal living

RNLI item	Domains	Subscales	Overall index score
Home mobility	Mobility	Daily functioning	Reintegration to Normal Living Index score
Community mobility			
Travel out of town			
Self-care activities	Self-care activities		
Daily meaningful activities	Daily meaningful activities		
Recreation activities	Recreation activities		
Socialising	Socialising		
Assuming family roles	Assuming family roles		
Personal relationships	Personal relationships	Perception of self	
Presentation of self	Presentation of self		
General coping skills	General coping skills		

Item, domain and subscale scores are presented by descriptive statistics and were also used for some statistical analysis. The scores of the two subscales were then summated to calculate the overall score for the RNLI. To allow presentation of the findings, scores of the various domains, subscales and the overall score were converted to a score out of 100 using the following formula:  $(\text{Average of related items or domains} - 1) \times \frac{100}{9}$

### **3.9.2 Analytical component of study**

An analytical component was added to the descriptive study to determine the relationship between the demographic and medical variables age, gender and medical diagnosis and the levels of community integration achieved. The researcher consulted a statistician who applied inferential tests (t-tests and Kruskal-Wallis tests) to determine if a statistically significant relationship exists between these variables and the levels of community integration achieved. A P-value of  $<0.05$  was observed as statistically significant.

### **3.10 Ethical considerations**

#### **3.10.1 Autonomy**

In order to acknowledge and protect the autonomy of all study participants the researcher took the following steps:

- At the start of each interview, the research assistants disclosed all relevant information and knowledge about the proposed study. The purpose, benefits and the social implications were explained telephonically or in person to each study participant in English, Afrikaans or Xhosa (according to his/her language of preference). Using the language preferred by the participant and using layman's terms should have ensured that all research participants understood the information given to them regarding the proposed study. The research assistants read the information, as set out in the Information Leaflet and Consent Form (Appendix 4), to the participants and answered any questions participants had regarding the study and their participation in the project;
- Participants were informed that involvement in the study was completely voluntary and that declining participation would not impact negatively on future health care provision at the Western Cape Rehabilitation Centre or any other health care facility. Participants were also made aware that they had the right to withdraw at any stage of the study. Withdrawal from the study would also not impact negatively on future medical and health care provision at the WCRC or any other health care facility;
- Informed consent was obtained from all study participants by the research assistants prior to completing the RNLI questionnaire. Although informed consent should preferably be obtained in writing, telephonic informed consent was collected from all study participants who complete the data verification and collection interview telephonically. All telephonic conversations were recorded by means of an audio recorder and serve as proof of informed consent. Information such as place, date and time of the phone call, participant particulars and questions asked were clearly recorded on the consent form;

- Consent forms and audio recordings are being kept in a secure research file in an access controlled location (lock-up cupboard) by the researcher.

### **3.10.2 Confidentiality**

Stringent steps were followed by the researcher and research assistants to ensure the confidentiality of all participants. Each research assistant signed a confidentiality form (Appendix 5) confirming that she will not disclose any information related to study participants and will treat all information related to and collected during the study as confidential. The signed forms are kept in a secure and access controlled location by the researcher.

All information collected during the study is treated as confidential and protected. Only the researcher and the research assistants had access to participants' medical records and personal information. No personal data such as names and contact details will be used during dissemination.

Following the recruitment of study participants, a random number was allocated to each participant on the data spread sheet. Once all study participants had been recruited and personal information had been verified, participant names and personal information were hidden on the spread sheet. RNLI questionnaires only indicate the assigned participant number. Hard copies of all the documents are kept in a secure research file in an access controlled location (lock-up cupboard) by the researcher and data captured on the researcher's computer has been secured by means of a password.

The WCRC is a unique facility as it is the only specialised, in-patient rehabilitation facility in the Province of the Western Cape, South Africa. Due to this fact, the author decided to name the study setting in this research report as readers would have been able to derive which facility is being referred to had it not been named.

### **3.10.3 Beneficence and Non-malificence**

Participants did not stand to benefit directly from the study. The knowledge gained from the study may however be helpful to and inform future rehabilitation practices at the Western Cape Rehabilitation Centre. Anticipated results justified the performance of the study. The researcher hopes that knowledge gained from the study might lead to more effective management of persons with disabilities during their in-patient rehabilitation at the WCRC. This may allow future clients of the WCRC to achieve improved levels of community

reintegration post discharge from the rehabilitation facility. The researcher will present the results and recommendations to staff and the management of the WCRC.

Any problems or concerns regarding a participant's health or rehabilitation management identified by the research assistants during data collection were followed up by the researcher. The researcher attempted to make appropriate recommendations and/or referrals to relevant health care professionals or health care institutions to help facilitate the provision of appropriate and relevant health care and rehabilitation services. This possibly helped improve participants' level of community reintegration and quality of life.

The researcher and research assistants at all times strived to remain professional and sensitive to ensure no harm is brought upon study participants.

#### **3.10.4 Justice**

All study participants were treated equally during the recruitment process as well as the data collection process of the study. Each participant was dealt with in an equal and fair manner by the researcher and the research assistants.

#### **3.10.5 Approval from relevant authorities**

Ethical approval was obtained prior to commencing the study from the Health Research Ethics Committee of the University of Stellenbosch (Appendix 8). Permission to access data related to study participants was sought from relevant authorities prior to commencing the recruitment of study participants. As the study was conducted in the Western Cape permission from the Western Cape Department of Health and the Chief Executive Officer (CEO) of the Western Cape Rehabilitation Centre was obtained (Appendix 9).

#### **3.11 Summary of chapter**

A quantitative, cross-sectional, descriptive study design was chosen for this study investigating the levels of community integration of adults with disabilities. The study was conducted at the Western Cape Rehabilitation Centre, a government funded, specialised rehabilitation unit that offers high intensity, in-patient rehabilitation services by inter-disciplinary teams. Interventions are generally focused on promoting the functional independence and community integration of persons with disabilities.

Of 188 individuals in the identified study population, 76 had to be excluded as they did not meet the inclusion criteria of the study. Finally 59 individuals could be located and consented to participate in the study. To ensure a large enough study sample the researcher decided to perform no further sampling. To gather data needed to meet the objectives of the current study, two data collection instruments were used namely a demographic and medical data sheet and the RNLI, a reliable and valid instrument measuring community integration. Three research assistants were chosen and trained by the researcher, each speaking one of the three most commonly spoken languages in the Western Cape Province. A pilot study was conducted followed by the data collection for the study through telephonic interviews or home visits with face to face interviews. During all steps of the study the researcher and research assistants at all times adhered to ethical considerations such as autonomy, confidentiality, beneficence and non-maleficence and justice. Approval to conduct the study was obtained from the Health Research Ethics Committee of the University of Stellenbosch as well as from the Western Cape Department of Health and the CEO of the Western Cape Rehabilitation Centre.

## Chapter 4

### Results

#### 4.1 Introduction

The demographic details of the study participants, and RNLI scores are presented in Chapter 4. Some statistical analyses between demographic information and RNLI scores are also presented. While both mean and median scores are presented median scores are referred to in the text since high standard deviations for many variables and domains shows that data is skewed.

#### 4.2 Demographic information

The age of the 59 participants ranged from 19 to 82 years of age at the time of data collection. Figure 4.1 shows that ages are relatively evenly distributed between the age groups 19 – 29, 30 – 39, 40 – 49, 50 – 59 with a slight drop in the 40 – 49 group and a bigger drop after 59.

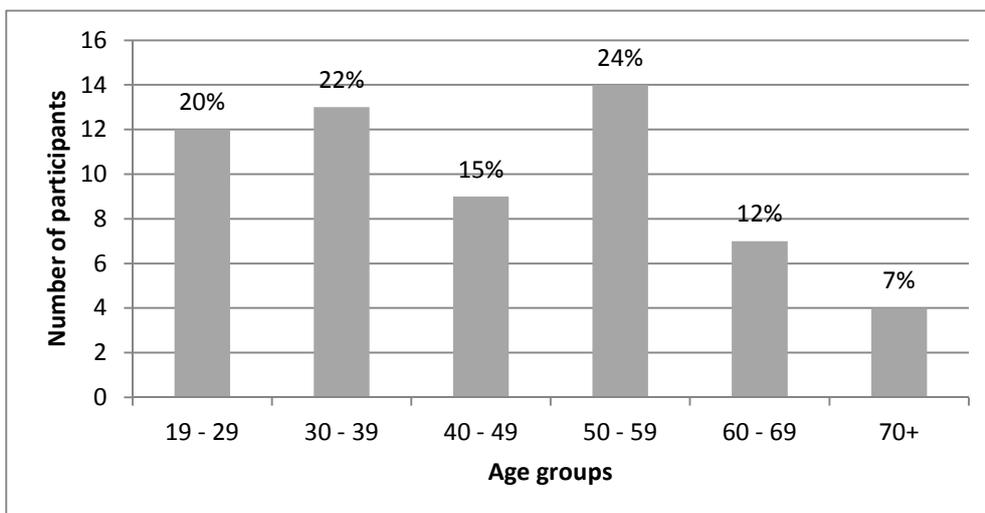


Figure 4.1: Age distribution of participants

Descriptive statistics on age is presented in Table 4.1 which shows a median age of 43 and an interquartile range of 35 to 57.

Table 4.1: Descriptive statistics of the variable participant age

<b>Mean</b>	44.98	<b>Median</b>	43
<b>S.D.</b>	15.92	<b>Quartile 1</b>	34.00
<b>Minimum</b>	19.00	<b>Quartile 3</b>	57.00
<b>Maximum</b>	82.00		

There were slightly more female (54%) than male (46%) participants in the study.

### 4.3 Medical diagnosis

Figure 4.2 shows that the most common diagnosis amongst participants was stroke (41%) and spinal cord injury (30%).

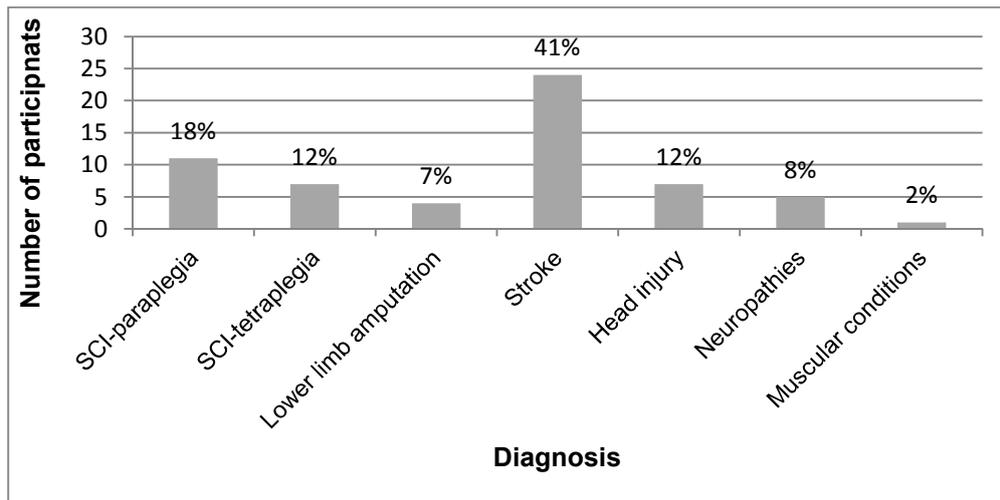


Figure 4.2 Medical diagnosis of participants (Neuropathies include Guillian Barre and retroviral disease related neuropathies; Muscular conditions include muscular dystrophy)

One participant had a head injury and an amputation of the lower limb. This participant was included under head injury, as this was indicated as the individual's primary diagnosis by the medical practitioner at the WCRC.

#### 4.4 Integration to normal living

Scores were converted to scores out of 100 as described in Chapter 3. The median overall RNLI score for the study population was 71.30 with an interquartile range of 53.24 to 87.50 (Table 4.2).

Table 4.2: Descriptive statistics according to RNLI scores (n = 59)

		Mean	S.D.	Minimum	Quartile 1	Median	Quartile 3	Maximum
<b>Item 1</b>	Indoor mobility	63.67	32.71	0.00	44.44	66.67	100.00	100.00
<b>Item 2</b>	Community mobility	59.89	34.56	0.00	33.33	66.67	94.44	100.00
<b>Item 3</b>	Travel out of town	62.00	35.25	0.00	33.33	66.67	100.00	100.00
<b>Combined score</b>	Mobility	61.83	27.71	0.00	38.89	62.96	85.19	100.00
<b>Item 4</b>	Self-care	64.97	37.01	0.00	38.89	77.78	100.00	100.00
<b>Item 5</b>	Work activity	52.54	35.25	0.00	22.22	55.56	88.89	100.00
<b>Item 6</b>	Recreation	57.25	37.19	0.00	22.22	66.67	88.89	100.00
<b>Item 7</b>	Social activities	64.97	34.39	0.00	33.33	77.78	100.00	100.00
<b>Item 8</b>	Family role	69.30	32.71	0.00	44.44	77.78	100.00	100.00
<b>Item 9</b>	Personal relationships	73.45	31.63	0.00	61.11	88.89	100.00	100.00
<b>Item 10</b>	Presentation of self	72.13	35.40	0.00	55.56	88.89	100.00	100.00
<b>Item 11</b>	Manage life events	65.16	36.53	0.00	33.33	77.78	100.00	100.00
<b>Subscale</b>	Daily Functioning	61.81	25.24	7.41	45.06	63.58	83.33	100.00
<b>Subscale</b>	Perception of Self	70.24	29.61	0.00	55.56	77.78	94.44	100.00
<b>Overall Score</b>		66.03	25.51	5.56	53.24	71.30	87.50	99.07

The RNLI items 9 and 10, personal relationships and presentation of self, recorded the highest median scores of 88.89. Item 5, work and related activities showed the lowest

median score 55.56. Home mobility (66.67), community mobility (66.67), travel out of town (66.67) and recreational activities (66.67) also had median scores below 70. The combined mobility scores had a mean of 62.96<sup>1</sup>.

Table 4.3: Breakdown of RNLi scores per item and percentage of participants (n = 59)

Item	1	2	3	4	5	6	7	8	9	10
<b>RNL 1</b> Home mobility	7%	2%	10%	5%	8%	15%	10%	7%	3%	32%
<b>RNL 2</b> Community mobility	10%	5%	8%	3%	12%	10%	5%	14%	7%	25%
<b>RNL 3</b> Travel out of town	12%	3%	7%	5%	8%	8%	8%	8%	12%	27%
<b>RNL 4</b> Self-care activities	12%	5%	7%	2%	7%	8%	7%	8%	5%	39%
<b>RNL 5</b> Daily/work activities	14%	8%	10%	5%	12%	3%	10%	8%	15%	14%
<b>RNL 6</b> Recreational Activities	12%	10%	10%	3%	7%	5%	5%	8%	19%	20%
<b>RNL 7</b> Socialising	7%	7%	8%	7%	3%	5%	5%	17%	14%	27%
<b>RNL 8</b> Family roles	5%	3%	8%	7%	5%	3%	8%	15%	8%	36%
<b>RNL 9</b> Personal relationships	7%	2%	5%	5%	5%	2%	3%	19%	19%	34%
<b>RNL 10</b> Presentation of self	12%	3%	3%	2%	0%	8%	2%	14%	17%	39%
<b>RNL 11</b> General coping skills	14%	5%	3%	5%	2%	7%	5%	15%	15%	29%

<sup>1</sup> The reason the combined mobility score has a lower median than the three separate scores is because the item medians are not calculated with a mathematical formula but depend on the distribution of the data. The domain median (combined score) is calculated using a mathematical formula.

With regard to the subscale scores, daily functioning (63.58) recorded a lower median value than perception of self (77.78) as illustrated in Table 4.2. Table 4.3 shows that 72% and 70% of participants, respectively, scored personal relationships and presentation of self an 8 or more. In comparison 37% of participants scored work activities an eight or higher.

#### **4.5 Relationships between demographic variables and RNLI scores**

No statistically significant differences could be found when examining the relationships between various demographic variables and the domains, subscales or the overall RNLI scores. This might be due to the small sample size or a true reflection of the situation. Interesting trends could however be observed and are presented below.

##### **4.5.1 Gender**

Table 4.4 shows that the mean scores between male and female participants were very similar with the exception of social activities where males scored 8 points lower and presentation of self where males scored 10 points higher. While the mean values of Daily Functioning were very similar between the two gender groups, Perception of Self shows some difference with females scoring slightly lower in comparison to their male counterparts. No statistically significant difference could be found between the two groups in any of the domains with the t-test.

Table 4.4: The differences in scores of the various domains, Daily Functioning and Perception of Self and the overall RNLI score between males and females

Domain		Male (n = 27)		Female (n = 32)		Mean Diff. Male – Female	T	p (df=57)
		Mean	S.D.	Mean	S.D.			
<b>Domain 1</b>	Mobility (Combined score of three mobility domains)	63.65	25.08	60.30	30.06	3.35	0.46	.648
<b>Domain 2</b>	Self-care	65.43	36.89	64.58	37.70	0.85	0.09	.931
<b>Domain 3</b>	Work activity	49.79	36.38	54.86	34.67	-5.07	-0.55	.587
<b>Domain 4</b>	Recreation	55.97	38.43	58.33	36.69	-2.37	-0.24	.810
<b>Domain 5</b>	Social activities	60.91	35.99	68.40	33.17	-7.50	-0.83	.409
<b>Domain 6</b>	Family role	70.37	33.19	68.40	32.80	1.97	0.23	.820
<b>Domain 7</b>	Personal relationships	74.07	30.82	72.92	32.78	1.16	0.14	.890
<b>Domain 8</b>	Presentation of self	77.78	32.61	67.36	37.43	10.42	1.13	.264
<b>Domain 9</b>	Manage life events	67.90	34.36	62.85	38.66	5.05	0.53	.601
<b>Subscale</b>	Daily Functioning	61.02	25.75	62.48	25.19	-1.46	-0.22	.827
<b>Subscale</b>	Perception of Self	73.25	24.87	67.71	33.28	5.54	0.71	.479
<b>Overall Score</b>		67.14	22.72	65.09	27.97	2.04	0.30	.762

#### 4.5.2 Age

To determine if age had an impact on the levels of community reintegration achieved by study participants, various age groups were joined to form two age categories, namely 19-49 and 50-82. These two categories provided large enough sample sizes to allow for statistical analysis.

The only domain that shows noticeable difference between the two age categories is work activities. Participants aged between 50 and 82 years scored this domain higher in comparison to participants in the age category 19 to 49 years. The mean scores for the constructs Daily Functioning and Perception of Self, and the overall RNL Index score show little difference between the two age categories. No statistically significant difference was found when comparing the mean values of the domains and the overall RNLI score of the two age categories, as illustrated in table 4.5.

Table 4.5: Comparison of scores of the various domains, Daily Functioning and Perception of Self and the overall RNLI scores between age categories

Domain		19 - 49 (n = 34)		50 - 82 (n = 25)		Difference	T	p (df=57)
		Mean	S.D.	Mean	S.D.			
<b>Domain 1</b>	Mobility (Combined score of three mobility domains)	61.66	28.66	62.07	26.95	-0.42	-0.06	.955
<b>Domain 2</b>	Self-care	66.01	36.79	63.56	38.02	2.46	0.25	.804
<b>Domain 3</b>	Work activity	48.04	35.42	58.67	34.77	-10.63	-1.15	.256
<b>Domain 4</b>	Recreation	55.88	37.95	59.11	36.81	-3.23	-0.33	.745
<b>Domain 5</b>	Social activities	63.40	36.75	67.11	31.51	-3.71	-0.41	.686
<b>Domain 6</b>	Family role	68.63	33.22	70.22	32.67	-1.59	-0.18	.855
<b>Domain 7</b>	Personal relationships	71.57	33.63	76.00	29.17	-4.43	-0.53	.599
<b>Domain 8</b>	Presentation of self	70.59	37.59	74.22	32.82	-3.63	-0.39	.700
<b>Domain 9</b>	Manage life events	66.99	36.85	62.67	36.69	4.33	0.45	.657
<b>Subscale</b>	Daily Functioning	60.60	28.40	63.46	20.63	-2.85	-0.43	.672
<b>Subscale</b>	Perception of Self	69.72	31.38	70.96	27.65	-1.25	-0.16	.875
<b>Overall Score</b>		65.16	28.45	67.21	21.37	-2.05	-0.30	.763

### 4.5.3 Medical diagnosis

To provide sample sizes large enough to allow statistical analysis, some of the diagnostic categories were combined to create the following:

- SCI: including SCI paraplegia and tetraplegia;
- Brain injury: including CVA (intracranial bleed non-traumatic) and head injury;
- Peripheral: including participants with lower limb amputation, neuropathies (including GuillianBarre, Retroviral Disease (RVD) related neuropathies) and muscular dystrophies (and other muscular diseases).

The researcher acknowledges the literature finding by Mayo et al. (2002) and Kim et al. (2013) as discussed in Chapter 2, showing that individuals with TBI (Kim et al. 2013) experienced greater limitations in most items of the RNLI in comparison to individuals with stroke (Mayo et al. 2002). While taking cognisance of this finding, the researcher decided to combine the CVA and the head injury groups for statistical analysis as these two groups are more comparable to each other than to any of the other diagnostic groups due to possible cognitive involvement.

Table 4.5 shows that individuals with SCI had higher community integration scores in all the individual domains as well as subscales and total scores. While the SCI group achieved an overall mean score of 75.15, participants of the brain injury and peripheral groups had overall mean scores of 60.91 and 65.46 respectively. No statistical difference was found when comparing the mean values of the domains, subscales and the overall RNLI score of the SCI, brain injury and peripheral diagnostic groups.

Table 4.6: Comparison of scores of the various domains, Daily Functioning and Perception of Self and the overall RNLI scores between diagnostic groups

		Group	Mean	SD	Median	Mean Rank	Test-statistic	p-value
<b>Domain 1</b>	Mobility (Combined score of three mobility domains)	SCI (n= 18)	73.46	25.60	77.78	37.47	5.22	0.074
		Head Injury (n= 31)	57.83	27.19	59.26	27.55		
		Peripheral (n= 10)	53.33	28.96	40.74	24.15		
<b>Domain 2</b>	Self-care	SCI	74.69	35.71	94.44	34.67	3.85	0.146
		Head Injury	56.27	37.73	55.56	25.97		
		Peripheral	74.44	33.56	88.89	34.10		

<b>Domain 3</b>	Work activity	SCI	57.41	35.60	55.56	32.53	0.87	0.648
		Head Injury	48.75	34.15	44.44	28.06		
		Peripheral	55.56	40.23	72.22	31.45		
<b>Domain 4</b>	Recreation	SCI	67.28	35.85	88.89	34.83	2.18	0.335
		Head Injury	51.25	38.35	44.44	27.42		
		Peripheral	57.78	35.45	66.67	29.30		
<b>Domain 5</b>	Social Activities	SCI	74.69	31.84	88.89	35.03	2.30	0.317
		Head Injury	60.22	36.04	77.78	27.65		
		Peripheral	62.22	33.21	77.78	28.25		
<b>Domain 6</b>	Family role	SCI	74.07	30.96	83.33	32.28	0.52	0.770
		Head Injury	66.67	33.21	77.78	28.69		
		Peripheral	68.89	36.59	83.33	29.95		
<b>Domain 7</b>	Personal Relationships	SCI	83.95	20.60	88.89	34.31	2.16	0.340
		Head Injury	67.74	34.47	77.78	27.13		
		Peripheral	72.22	36.76	88.89	31.15		
<b>Domain 8</b>	Presentation of self	SCI	78.40	37.63	100.00	35.17	2.63	0.269
		Head Injury	70.61	34.49	77.78	28.23		
		Peripheral	65.56	36.08	77.78	26.20		
<b>Domain 9</b>	Manage life Events	SCI	77.78	33.44	88.89	37.31	5.19	0.075
		Head Injury	56.63	38.42	66.67	25.92		
		Peripheral	68.89	31.34	77.78	29.50		
<b>Subscale</b>	Daily Functioning	SCI	70.27	24.00	75.31	35.94	3.88	0.144
		Head Injury	56.83	24.11	58.64	26.05		
		Peripheral	62.04	29.15	70.68	31.55		
<b>Subscale</b>	Perception of Self	SCI	80.04	22.19	88.89	35.44	2.72	0.257
		Head Injury	64.99	31.80	70.37	27.16		
		Peripheral	68.89	32.58	83.33	29.00		
<b>Overall Score</b>		SCI	75.15	20.34	81.17	36.11	3.79	0.150
		Head Injury	60.91	25.84	65.74	26.23		
		Peripheral	65.46	30.45	77.93	30.70		

Domains that showed noticeable difference include:

- Domain 1 Mobility: A large difference in the mean scores between participants in the SCI group (highest) and participants in the peripheral group (lowest) was observed (18.52 higher than for those with head injuries and 37.04 higher than for those with peripheral conditions);
- Domain 2 Self-Care Activities: In this domain participants in the SCI and peripheral groups achieved higher mean scores (74.69 and 74.44 respectively) than participants in the brain injury group (56.27);
- Domain 3 Work shows low mean scores amongst all three diagnostic categories;
- Domain 4 Recreational Activities was scored the lowest by participants in the brain injury diagnostic group. Their mean score of 51.25 is more than 15 points lower than the mean score of 67.28 of the SCI group;
- Domain 5 Social Activities: As in domain 4, participants of the head injury diagnostic group achieved the lowest mean score of 60.22;
- Domain 7 Personal Relationships showed a high mean score across all four diagnostic groups. The head injury group achieved the lowest mean score of 67.74;
- Domain 8 Presentation of Self: Participants in the peripheral diagnostic group achieved a mean score visibly lower than their counterparts in the SCI and head injury groups.

#### **4.6 Summary of chapter**

The median age of the study population was 43 years with ages ranging from 19 to 59 years of age. There were more female than male participants. Forty-one percent of study participants had suffered a stroke while 18% and 12% of participants fell into the diagnostic categories SCI paraplegia and tetraplegia respectively.

The median overall RNLI score of the study population was 71.30. Participants scored the subscale 'perception of self' higher than the 'daily functioning' subscale. The RNLI items personal relationships, presentation of self and family roles were the highest scoring items while travel out of town, community mobility, participation in recreational activities and participation in daily/work activities were scored the lowest by study participants.

None of the demographic/medical variables showed a statistically significant impact on the level of community integration achieved by participants.

## Chapter Five

### Discussion

#### 5.1 Introduction

The aim of this study was to determine the levels of community reintegration of adults with disabilities post discharge from a specialised in-patient rehabilitation unit in the Western Cape. In this chapter the study findings are discussed and compared to findings from similar studies from various parts of the world. The RNLI results are compared to four international studies which used the RNLI to assess the levels of community reintegration of adults with acquired physical disabilities after having suffered a CVA or a traumatic brain injury. The researcher acknowledges that the differences in medical diagnosis of participants in these studies and the current study could have a bearing on the findings explored in this discussion. The differences in environment and environmental barriers might also have played a role as one would expect fewer environmental barriers in the better resourced countries in which the four above mentioned studies were done. Comparisons to findings from various studies that explore community integration with other tools were also made.

#### 5.2 Profile of the study participants

It is difficult to compare the profile of the study participants to that of other studies using the RNLI to determine levels of community integration as all other studies reviewed included persons with disabilities from one specific medical diagnostic group only. Persons with various medical diagnoses were included in the current research study. The profile of the study sample is therefore somewhat unique.

The finding of an almost equal percentage of male and female participants is in agreement with the gender distribution in South Africa and the Western Cape Province (StatsSa 2012). Census figures showed that the South African population consists of 48.2% of men and 51.7% women. A fairly similar gender distribution was found in the Western Cape Province with 49.09% of men and 50.91% of women. The current study findings are also similar to results of other studies conducted in South Africa (Rouillard et al. 2012; Hassan et al. 2011; Ntsiea et al. 2013; Hilton et al. 2013; Rhoda, Mpofu & De Weerd. 2011; Maart & Jelsma 2014; Cawood & Visagie 2015) but contrasts with the findings of Fredericks and Visagie (2013), Henn et al. (2012) and Hastings et al. (2015). The last three studies had a considerably higher percentage of male participants, namely 66%, 81% and 80%

respectively. While the study participants in the studies by Rouillard et al. (2012), Hassan et al. (2011), Ntsiea et al. (2013) and Hilton et al. (2013) had suffered a CVA, Fredericks and Visagie (2013), Henn et al. (2012) and Hastings et al. (2015) looked at persons with lower limb amputations and spinal cord injuries. The incidence of both spinal cord injuries and amputations is higher in men than women. Henn et al.'s (2012) and Hastings et al.'s (2015) findings are supported by results of Samuelkamaleshkumar et al. (2010) and Sekaran et al. (2010) who investigated the community reintegration of persons with spinal cord injury residing in South India. Both researchers described a study sample with a considerably higher percentage of male than female participants. The majority of participants in the current study have suffered a CVA. That might explain why the study population reflects a more equal ratio of female to male participants similar to other South African studies investigating persons with CVA (Rouillard et al. 2012; Hassan et al. 2011; Ntsiea et al. 2013; Hilton et al. 2013).

The current study findings on age are similar to results from other South African studies in the field of disability and community reintegration (Rouillard et al. 2012; Hassan et al. 2011; Ntsiea et al. 2013; Hilton et al. 2013; Fredericks & Visagie 2013). While most papers reported the average age of their study sample to be between the ages of 40 to 60 years, Henn et al. (2012) reported a much younger average age (32 years). This difference in average age can possibly be attributed to the fact that Henn et al. (2012) found traumatic accidents and injuries such as motor vehicle accidents, violent attacks, industrial accidents and falls to be the main cause of SCI in her study population. Other South African studies revealed chronic conditions such as diabetes mellitus, hypertension and HIV to be the main causing factors of disability (Rouillard et al. 2012; Hassan et al. 2011; Ntsiea et al. 2013; Hilton et al. 2013; Fredericks & Visagie 2013).

### **5.3 Reintegration to Normal Living**

The mean overall RNLI score for the study population was 66.03. This score cannot be compared to the overall RNLI scores determined by Mayo et al. (2002) and Kim et al. (2013) as both studies made use of the brief RNLI Scoring (as described in Chapter 2). Carter et al. (2000) and Pang et al. (2007) reported higher overall mean RNLI scores of 83.3 and 83.1 respectively (they did not report median scores). Apart from the differences in setting and medical diagnosis the following differences in methodologies can also possibly explain the almost 20 point difference in overall scores between the current study and two above mentioned studies:

- Pang et al. (2007) made use of 4-point ordinal scale to rate individual RNLI items. To obtain the overall score, summated item scores were normalised to 100. The current study used a 10 point scale to rate RNLI items. Using a 4-point scale could lead to obtaining higher item scores and a higher overall score as a smaller variation between the highest and the lowest score exists;
- Pang et al. (2007) only included stroke survivors able to ambulate independently, with or without an assistive device for at least 10 months. Excluding individuals who are dependent on assistance to ambulate or are dependent on a wheelchair for indoor and outdoor mobility could have led to better results;
- Seventy seven percent of the study participants included in the study by Carter et al. (2000) were stroke survivors who reported no residual physical limitations/disability as measured by the Barthel Index. Carter et al. (2000) reported that higher levels of physical disability, as measured by the Barthel Index, were significantly associated with poor community integration as measured by the RNLI. Thus, having a study population consisting mainly of stroke survivors with no residual physical limitation could have resulted in a higher mean overall RNLI score in comparison to the current study results.

Even so an average community integration score below 70% indicates that current study participants experienced challenges in this regard and the possibility exists that their rehabilitation did not prepare them optimally for community re-integration.

The RNLI items that were found to be most problematic by current study participants were participation in meaningful activities such as employment, participation in recreational activities, mobility, community mobility and travel out of town. Similarly Mayo et al. (2002), Carter et al. (2000) and Kim et al. (2013) found: community mobility, travel out of town, participation in social and recreational activities and participation in meaningful activities/return to employment to be most affected after stroke. Although study participants included in the Carter et al. (2000) and Mayo et al. (2002) studies were limited to persons with CVA or traumatic brain injury and the studies were conducted in the USA and Canada, the results are in agreement with current study findings. It must also be noted that the average age of the study population in the studies by Carter et al. (2000) and Mayo et al. (2002) was considerably higher (52 years and 68.8 years respectively) in comparison to the mean age of the current study population (44.9 years). Unfortunately it is not possible to explore the findings in more detail as none of the two studies mentioned above provided median or mean scores for individual RNLI items. Both Mayo et al. (2002) and Kim et al.

(2013) also made use of the brief RNLI, employing a 3-point scoring system, and thus more detailed comparison and exploration of these results are not possible.

In contrast to current study findings Kim et al. (2013) found that participants scored their satisfaction with fulfilment of family roles very low. Possible reasons provided by the authors for this finding included cause and nature of the injury (traumatic brain injury), and factors such as pre-injury personality, alcohol and drug abuse or employment status post discharge from rehabilitation. Rouillard et al. (2012), Maleka et al. (2012), Mudzi et al. (2013) and Cunningham and Rhoda (2014), who conducted studies in South Africa, similarly reported that a large percentage of stroke survivors were dissatisfied with their relationships with friends and family members and their ability to fulfil previous family roles. Cunningham & Rhoda (2014) postulated that a lack of social support post stroke was a possible cause of these findings. While the findings reported by Kim et al. (2013), Rouillard et al. (2012), Mudzi et al. (2013) and Cunningham and Rhoda (2014) are in agreement, participants in the current study were rather satisfied with assuming family roles and their relationship with family members according to RNLI scores. Involvement of the central nervous system and possible cognitive challenges experienced by study participants in the studies conducted by Kim et al. (2013), Rouillard et al. (2012) and Cunningham and Rhoda (2014) could have contributed to lower levels of satisfaction with personal relationships, the fulfilment of family roles and perception of self. This theory is supported by the current study finding that participants in the diagnostic category head injury achieved a lower mean score for the subscale perception of self than the SCI and peripheral diagnostic groups (Table 4.5). It could be postulated that participants with possible cognitive impairments might experience greater social isolation than persons with disabilities who present with physical impairments only.

The hypothesis that participants with possible cognitive and perceptual impairments experience lower levels of satisfaction with personal relationships, the fulfilment of family roles and perception of self, and therefore greater social isolation also supports findings of the current study that show that participants from the head injury group experienced greater dissatisfaction with their participation in both domain 4 (recreation) and domain 5 (social activities), than participants from the SCI and peripheral diagnostic groups. It appears as if persons who suffer from cognitive and perceptual impairments as well as physical impairments experience greater challenges with assuming family roles, their relationship with family members and others, and do not feel as comfortable in the company of others than those with only physical impairments.

The results of the current study were also compared to results from studies investigating community integration of persons after spinal cord injury (Whiteneck et al. 1999; Samuelkamaleshkumar et al. 2010; Sekaran et al. 2010). As presented in the literature review the CHART was used as a measuring instrument in all three studies; one study was performed in the USA (Whiteneck et al. 1999) while the other two were performed in Southern India (Samuelkamaleshkumar et al. 2010; Sekaran et al. 2010). All three studies agreed and concurred with current study findings that participants experienced the greatest challenges in the areas of occupation and mobility. The CHART categories occupation can be related to the RNLI item of: participation in meaningful activities during the day (including employment) (item 5), while mobility can be related to indoor mobility, outdoor/community mobility and travel out of town (items 1, 2 and 3).

Additionally Whiteneck et al. (1999) found that participants experienced challenges in the area of physical independence. This might include the self-care domain of the RNLI which current participants scored fifth highest, according to median scores, together with participation in social activities. The difference might be due to the difference in tools. The RNLI asks about satisfaction with how 'self-care needs are met'. 'Adaptive equipment, supervision and/or assistance may be used'. Thus even participants who were physically completely dependent, but were satisfied that caregivers meet their self-care needs could score a 10 on this question. Whiteneck et al. (1999) commented that the more severe the neurological level of injury the lower the physical independence rating. The neurological level of injury or the severity of the injury/impairment were not established in the current study but scores of the various diagnostic groups for the self-care domain shows that participants in the head injury group scored this domain considerably lower (mean 56.27) than participants in the SCI and peripheral groups. Individuals with cognitive impairments may not only be dependent on assistance to complete these daily tasks but may also be less likely to willingly accept help from a family member or care giver due to the presence of cognitive and perceptual impairments. This may help explain why individuals in the head injury group scored this domain lower than participants in the SCI and peripheral groups, who generally do not suffer from cognitive and perceptual impairments.

Lastly, the results of the current study need to be examined in relation to the results of similar studies conducted in South Africa. The aspects of community reintegration identified by participants of the current study to be the most challenging and difficult are very similar to the results found by Rouillard et al. (2012), Cunningham and Rhoda (2014), Hassan et al. (2011), Mudzi et al. (2013), Maleka et al. (2012) and Wasserman et al. (2009), who looked at community integration and/or related concepts such as activity limitation and participation restrictions, caregiver strain, quality of life and return to work. These studies reported on

community dwelling stroke survivors living in different areas of South Africa. The studies identified participation in social, leisure and community activities; participation and return to work activities; and community mobility as being most challenging. The results of the current study are also mirrored by the findings of Fredericks and Visagie (2013) and Godlwana and Stewart (2013) who found that community mobility, shopping, working and pursuing hobbies and sporting activities were the most challenging for persons with lower limb amputations.

Taking a closer look at the aspects of community integration that were found to be most problematic for study participants could provide valuable information to help guide and focus rehabilitation services for persons with disabilities. The aspects of normal living that seem to have the biggest impact on community integration, as identified by the current study and similar studies conducted in South Africa and internationally, include:

- Mobility in the house, community and long distance travel/travel out of town;
- Participation in recreational activities; and
- Participation in meaningful activities/work during the day.

In an effort to understand why the above mentioned aspects of community integration are experienced as the most problematic by the study participants, the researcher looked at other researchers' work to gain an understanding of the most common barriers to community reintegration faced by persons with disabilities.

Many South Africans are dependent on public transport for community mobility and long distance travel. Trains, taxis and buses are often inaccessible for persons with a mobility impairment and private transport is expensive or unavailable (Rouillard et al. 2012; Samuelkamaleshkumar et al. 2010; Øderud 2014; Banda-Chalwe et al. 2012; Mudzi et al. 2013; Cawood & Visagie 2015). Participants in the study by Mudzi et al. (2013) reported that using a taxi as a wheelchair user was very problematic as taxi drivers were not willing to stop long enough to allow wheelchair users to embark and disembark the vehicle or, taxi drivers charged an additional fee for transporting the wheelchair inside the taxi. This attitude displayed by taxi operators and financial constraints limiting the use of public transport are a major barrier to community integration of persons with disabilities, especially for individuals who require a wheelchair for personal mobility. Limited community mobility may impact on many areas of a disabled person's life such as accessing medical or rehabilitation services, accessing community or religious activities or gatherings, seeking and accepting employment and attending sports or recreational activities.

The researcher found it surprising that mobility was scored the highest by the SCI group. One associates wheelchair mobility with being less functional than ambulation. However, the

findings from the current study showed that persons with SCI, of whom the majority would use a wheelchair for personal mobility, have higher levels of mobility than both persons with impairments of the brain or the peripheral nervous and muscular skeletal systems. Central nervous system involvement brings with it cognitive and perceptual challenges that can negatively impact on mobility. However, one would expect persons with peripheral conditions and thus no central nervous system and, in some instances no involvement of the trunk musculature, to be more mobile than those with spinal cord injuries. There is a possibility that some of the participants suffering from conditions other than SCI, who would have benefitted from a wheelchair to optimise mobility, especially for travel within the community and out of town, did not receive one. Wheelchairs can open opportunities to community integration which might not be open to those who walk with difficulty.

Together with a lack of transport, physical environments, buildings and facilities where recreation and sport activities are offered are often inaccessible (Cunningham & Rhoda 2014; Boschen et al. 2003; Chimatiro & Rhoda 2013; Samuelkamaleshkumar et al. 2010; Øderud 2014; Cawood & Visagie 2015). In addition ignorance on the side of sports coaches and programme leaders on how to adapt activities for persons with disabilities might hamper participation in recreational activities (Rimmer & Rowland 2008). Personal factors such as depression or shyness might also prevent person with disabilities from accessing and participating in recreational activities within the community (Rimmer & Rowland 2008). Rehabilitation personnel should introduce persons with disabilities to a range of possible sporting and recreational activities during their rehabilitation programme and should provide information regarding available recreational centres or sports clubs within communities which are accessible and offer activities and sports for persons with disabilities. This might empower and encourage individuals to take part in sports or recreational activities after discharge from their rehabilitation programme.

Employment of persons with disabilities remains a big challenge in South Africa with multiple factors interacting and influencing the current employment situation of persons with disabilities (Chimatiro & Rhoda 2013; Ntsiea et al. 2013; Schneider & Nkoli 2011). Schneider and Nkoli (2011:103) reported “a high level of underemployment, unemployment and economic inactivity” of persons with disabilities in South Africa and found that persons with disabilities often earned less in comparison to their non-disabled counterparts. Hassan et al. 2011 and Rouillard et al. (2012) also reported low levels of participation in economic activities amongst persons with disabilities after discharge from rehabilitation. Barriers to employment of persons with disabilities include general high unemployment rates in South Africa, poor physical access to environments and transportation, negative attitudes of others and negative assumptions regarding the costs associated with employing persons with

disabilities, poor reasonable accommodation, lack of skills and low levels of education, and limited access to information regarding employment opportunities and skills training due to high levels of social isolation experienced by persons with disabilities (Chimatiro & Rhoda 2013; Ntsiea et al. 2013; Schneider & Nkoli 2011). Intersectoral collaboration, policy implementation and efforts by rehabilitation professionals are necessary to increase the levels of employment of persons with disabilities as employment brings many advantages including improved levels of self-esteem and confidence, reduced levels of social isolation, economic independence and the ability to support ones family, and the sense of being a contributing and meaningful member of society (Schneider & Nkoli 2011).

In the current study men scored their satisfaction regarding their participation in meaningful daily activities (domain 3) and their engagement in social activities (domain 5) lower in comparison to female participants. The traditional and cultural role of men as breadwinners in the South African society could have led to men experiencing the lack of employment and meaningful activity more acutely than women. Women might have been able to continue with their daily activities such as managing the household and related family activities especially since enabling women to perform their household roles and the provision of assistive devices to assist with various household tasks seem to be addressed during rehabilitation at the WCRC (Cawood & Visagie 2015).

Participation in meaningful daily activities also showed the biggest difference between the two age groups. The younger age group scored 10.63% lower than the older group in this area. Unemployment might have a bigger impact on the younger age group since their economically active years were, to a large extent, still lying ahead of them. Persons aged between 19 and 49 years should ideally be employed, building a career and actively contributing to society. Cramm, Nieboer, Finkenflügel and Lorenzo (2013) found that a lack of skills, social attitudes, lack of job availability and poor health were the main barriers to employment of persons with disabilities aged between 18 and 35 years in South Africa.

Participation in meaningful activities also showed the lowest mean score across all diagnostic groups, with participants in the brain injury diagnostic group scoring the lowest in this domain in comparison to the other groups. Determining employment figures was outside the scope of this study, thus we do not know how many participants became economically inactive due to the disability.

The overall RNLI scores of participants of the current study between the two age categories (19 – 49 and 50 – 58 years) show little difference (2.05%). This finding is in contrast with the

findings of Whiteneck et al. (1999) who reported that younger individuals experienced higher levels of community integration.

The finding that women and men had very similar levels of community integration is in contradiction to the findings by Chau et al. (2009) who reported that community dwelling women who had suffered a stroke experienced lower levels of community participation than men. Chau et al. (2009) found that female stroke survivors achieved lower self-esteem scores as measured by the State of Self-Esteem Scale (SSES) in comparison to male stroke survivors and were also less likely to participate in social and recreational activities. Chau et al. (2009) argue that this finding might be influenced by the large value placed on appearance and body image by women. The current study found that women scored their participation in recreational and social activities higher than male participants. Domain 8, 'being comfortable with self in company of others', showed the greatest difference in mean values (10.42%) between the two gender groups. Men indicated higher levels of satisfaction in this domain than women. The current study did not explore reasons behind the findings thus it is difficult to provide possible explanations for this finding. However, it might be possible that poor self-esteem and/or not feeling comfortable with one's appearance can result in a low score for this RNLI item.

All three diagnostic groups scored the subscale 'perception of self' higher than the 'daily functioning subscale'. The researcher believes that barriers to community integration, as identified by other studies, have a greater impact on the items in the subscale 'daily functioning'. Barriers such as poor access to transport, poor access to the physical environment and buildings, negative attitudes towards disability by community members and employers, low levels of skills and education and poor access to services such as health care, schooling and housing have the greatest impact on RNLI items such as community and long distance travel, participation in social and recreational activities and performing daily meaningful or work activities. In many South African families and cultures immediate and extended family forms a very close and supportive unit. This could have a positive influence on RNLI items in the subscale 'perception of self' such as assuming family roles, personal relationships and managing life events.

When comparing the overall score of the various diagnostic groups, participants in the SCI group showed notably higher overall RNLI scores compared to participants in the peripheral and brain injury groups. This result indicates that participants falling within the SCI group achieve higher levels of community integration as measured by the RNLI following in-patient rehabilitation in comparison to participants from the brain injury and peripheral diagnostic groups. Although the influence of length of stay in in-patient rehabilitation on levels of

community integration achieved was not determined in the current study, the researcher postulates that an increased length of stay may result in higher levels of community integration of persons with disabilities. Individuals with SCI of the current study sample spent an average of 90 days or longer in in-patient rehabilitation while individuals who suffered a traumatic brain injury or stroke only spent an average of about 28 days in in-patient rehabilitation. This hypothesis is supported by the findings by Pezzin, Dillingham and MacKenzie (2000) and Hastings, Ntsiea and Olorunju (2015) which show that an increase in in-patient days resulted in increased functional ability, improved health and better prospects of employment post discharge. Pezzin et al. (2000) interviewed 78 individuals who sustained a traumatic lower limb amputation in the USA, using the SF-36 to determine the health status and level of functioning of study participants. The researchers determined that a longer length of stay in in-patient rehabilitation resulted in improved health outcomes and significantly increased return to work of individuals with a lower limb amputation. Hastings et al. (2015) showed similar results when investigating 50 individuals with SCI who received in-patient rehabilitation at a private or a government funded rehabilitation unit in Gauteng, South Africa. The researchers found that “for every additional day spent in rehabilitation, an increase of 0.06% in the Spinal Cord Independence Measure could be expected” (Hastings et al. 2015:5). These results support the researcher’s speculation that participants in the SCI group of the current study may have achieved higher overall RNLI scores as individuals with SCI on average spend a considerably longer period of time in in-patient rehabilitation at the WCRC in comparison to individuals from the brain injury or peripheral groups.

## Chapter 6

### Conclusion and recommendations

#### 6.1 Introduction

The study limitations which need to be taken into consideration when reading and interpreting results, drawing conclusions and making recommendations, are presented. Thereafter conclusions are drawn and recommendations made to service providers at the WCRC and for further research.

#### 6.2 Study limitations

The researcher identified the following limitations to the study:

- Individuals who were unable to give accurate and reliable responses to questions asked due to speech-language (communication) difficulties and/or cognitive disorders were excluded from the study. Persons with severe cognitive and/or speech-language difficulties may struggle more with various aspects of community integration. The exclusion of these individuals needs to be considered when interpreting the results as their inclusion may have led to lower community integration scores;
- A quantitative, cross-sectional, descriptive study design was used. A mixed method design including interviews or focus groups discussions would have permitted the researcher to explore and gain an in-depth understanding of the reasons for the challenges and barriers faced by participants;
- Further demographic data such as socio-economic status and educational levels that might have impacted community integration were not collected;
- The number of study participants was low (59). This impacted negatively on statistical analysis and the interpretations of findings such as the relationship between levels of community integration and demographic and medical variables;
- Due to monetary and time constraints the researcher was not able to perform home visits for data collection from participants residing outside of the Cape Town Metro Health District. Individuals residing outside the Cape Town Metro Health District who could not be reached telephonically or who presented with cognitive involvement and were therefore unable to complete the questionnaire telephonically, were therefore excluded from the study. This could have led to the under-representation of

individuals residing in more rural settings of the Western Cape Province as well as of individuals with more severe cognitive problems;

- Instrumentation/measurement bias:
  - Although the RNLI has been found to be a reliable and valid measurement tool (Wood-Dauphinee & Williams 1987; Hitzig et al. 2012, Mothabeng et al. 2012), caution had to be exercised during the translation of the tool into Afrikaans and Xhosa. Validity and reliability had only been established for the English Index. To minimise instrumentation/measurement error, the Afrikaans and Xhosa questionnaires were translated and back-translated into English to ensure consistency and accuracy of phrases and their meaning.
- Selection/recruitment bias: As the RNLI questionnaire was administered telephonically, the researcher needed to ensure that clients who did not have access to a telephone were not excluded from the study. This could have resulted in the study population being systematically different from the target population of interest where the poorest individuals might have been excluded from the study which would pose a threat to the internal validity of the study. The researcher attempted to control this by conducting home visits where individuals could not be contacted telephonically and resided in the Cape Town Metro Health District. These strategies assisted towards limiting the threat to the internal validity of the study due to recruitment bias;
- Bias introduced due to data collection by means of both telephonic and personal interviews: The researcher acknowledges that utilizing two different interview methods (telephonic and personal) during data collection may have influenced ratings of items on the RNLI by participants. The possible impact on responses due to the interview method has been considered:
  - Arriving at participants' houses unannounced to request a personal interview and participation in the research study may have led to bias. Although participants had the right to decline participation in the study, the physical presence of the researcher and research assistance might have made it more difficult for the participant to exercise that right.
  - The presence of the research assistants, all employees of the WCRC, during the interview may have influenced the answers and scores given by the participants during the completion of the questionnaire. Participants might not have felt at ease to provide low item scores during the interview.

- Participants completing the telephonic questionnaire may have felt more at ease providing honest and accurate answers including low item scores, due to not being face to face with the research assistant during the interview.
- Interator bias: Thorough training was conducted with the research assistants to minimise interator bias. The training focused on the uniform and equal application of the data collection instruments by the three assistants in the various languages. Items in the RNLI could not be explained or rephrased using different wording. This limited bias introduced due to the interpretation and opinion of the research assistants. The researcher performed spot checks of the audio recordings of the interviews conducted by the assistants. These spot checks showed that the interviews were conducted in a consistent and uniform manner; only the sample question was rephrased to ensure that participants clearly understood the format of the questionnaire. Item questions of the RNLI were strictly only repeated to ensure consistency;
- External validity: It needs to be considered that the population of the study is not representative of all individuals with disabilities that received in-patient rehabilitation at the Western Cape Rehabilitation Centre. Caution needs to be exercised when generalizing the results of the study to adults with disabilities who received intensive in-patient rehabilitation at the WCRC in the Western Cape as the researcher selected three months for the identification and recruitment of study participants. This may result in the study population being systematically different from the target population of interest.

Due to these limitations the results of the study should be considered with caution.

### **6.3 Conclusion**

Keeping all study limitations in mind, the study showed that persons with disabilities, who received in-patient rehabilitation at the WCRC and were discharged into their home and community environments, achieve lower overall RNLI scores than persons with disabilities living in well-resourced/developed countries such as the USA and Canada. The median overall RNLI score of 71.30 indicates that some aspects of community integration might be lacking. Rehabilitation professionals may need to adjust rehabilitation programmes offered at the WCRC to improve community integration outcomes of clients.

Personal relationships, presentation of self (feeling comfortable in the company of others) and fulfilling family roles were the areas in which study participants achieved the highest

levels of participation and felt the most satisfied with. Study participants experienced the greatest challenges with participation in social and meaningful work activities, mobility, community mobility and travel out of town. Low levels of integration in these specific areas of community integration might be an indication that study participants still face many barriers in their communities.

Although age, gender and medical diagnosis were found to not be indicators of the level of community integration achieved, persons who suffered a traumatic brain injury or a CVA achieved lower levels of community integration in comparison to persons who suffered a SCI or have an impairment of the peripheral neural/muscular system(s). The presence of cognitive and perceptual impairments seems to impact not only on participation in social, recreational and work activities, and mobility, but also on satisfaction with relationships, family roles and presentation of self. These challenges in both the 'daily functioning' and the 'perception of self' subscales of community integration might lead to persons who suffered a traumatic brain injury or a CVA experiencing overall lower levels of community integration.

Although no statistical difference could be observed, clinically persons who suffered a SCI achieved higher levels of community integration than persons who suffered a CVA/traumatic brain injury or have impairment of the peripheral neural/muscular system(s). Longer average length of stay may be a contributing factor to persons with SCI achieving higher overall levels of community integration.

#### **6.4 Recommendations for further research**

There is a need to further research the levels of community integration achieved by persons with disabilities in South Africa as the current study only gathered quantitative data from one specific group and did not investigate qualitative aspects or barriers and facilitators to community integration. Insight into the predictive factors of community integration of persons with disabilities living in South Africa would be valuable to assist the development and improvement of rehabilitation services offered in our country. The researcher further recommends that a study, looking at the community integration outcomes of persons with disabilities accessing different types and levels of rehabilitation service provision (for example institution based rehabilitation, community based rehabilitation, out-patient rehabilitation services), is conducted. This could reveal which type of rehabilitation is the most effective in enabling persons with disabilities to achieve community integration. As community integration is seen as the ultimate goal of rehabilitation services, further and

more detailed information on this topic may allow service providers to render more comprehensive and effective rehabilitation services to persons with disabilities.

A follow up study consisting of a larger study population is recommended to determine if and how variables such as age, gender, socio-economic circumstances, educational level or medical diagnosis influence levels of community integration achieved by persons with disabilities. This information would be valuable to rehabilitation professionals and service managers as it could assist in the planning and structuring of rehabilitation services.

A qualitative study to gain an in-depth understanding of the daily challenges to community integration, faced by persons with disabilities, is also recommended as further research. This would provide much needed information on why persons with disabilities experience greater difficulties in certain areas of community integration. Barriers and facilitators to community integration could be explored in more detail. This information is vital to help advances towards an environment and a society that enables persons with disabilities to be fully integrated and productive community members.

A study investigating the impact of length of stay in in-patient rehabilitation on community integration scores is recommended. The current study found that persons living with SCI achieved higher overall RNLI scores compared to other study participants falling within the brain injury and peripheral diagnostic groups. The researcher could only speculate that the longer average length of stay of persons with SCI allowed these individuals to reintegrate better and participate more effectively within their community environments.

## **6.5 Recommendations for service providers at WCRC**

To help improve the levels of community integration of persons with disabilities after discharge from in-patient rehabilitation at WCRC, rehabilitation personnel should adapt current in-patient rehabilitation programmes to place additional focus on the areas of normal living experienced as most challenging by persons with disabilities, namely, participation in the domains social and meaningful work activities, community mobility and travel out of town. In addition to functional restoration and prevention of secondary complications, addressing the physical and attitudinal barriers faced by persons with disabilities on a daily basis within their home and community environments must be included in the focus of rehabilitation programmes. To achieve this rehabilitation staff of the WCRC need to collaborate with other rehabilitation services, including community based rehabilitation services, and various other sectors, such as social services, DPOs, and the labour sector, to

work towards and achieve inclusive environments and communities. Rehabilitation staff should also ensure that all individuals who require a wheelchair/mobility assistive device for community mobility and long distance travel receive the relevant device before/on discharge from the rehabilitation facility.

To help improve the participation of persons with disabilities in sporting and recreational activities, rehabilitation teams should introduce individuals to a range of available sporting and recreational activities during their rehabilitation programme. Prior to discharge the rehabilitation teams should provide individuals with information regarding available recreational centres or sports clubs within their communities which are accessible and offer activities and sports for persons with disabilities. This might empower and encourage individuals to take part in sports or recreational activities after discharge from rehabilitation.

Rehabilitation staff need to become active role players in intersectoral collaboration and policy implementation to help increase the levels of employment of persons with disabilities. Emphasis must be placed on liaison with employers, work visits and referral to vocational rehabilitation as required as part of rehabilitation.

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## Appendix 1

### Demographic and medical data sheet

No.	Participant name	Contact telephone number	Residential address	Date of Birth	Ethnic group					Gender		Diagnostic category **	Date of onset	Length of stay at WCRC (in days)
					A	C	I	W	O*	M	F			
1														
2														
3														
4														
5														
6														
7														
8														
9														
10														

\* African, Coloured, Indian, White, Other

\*\* Diagnostic category will be divided into:

1. SCI – paraplegia
2. SCI – tetraplegia
3. Amputee – lower limb
4. CVA – intracranial bleed non-traumatic
5. Head Injury
6. Neuropathies – including GuillianBarre, RVD related neuropathies
7. Muscular dystrophies and other muscular diseases
8. Other

## Appendix 2

### The Reintegration to Normal Living Index

Participant number:

This questionnaire asks about how you manage activities, roles and relationships on a day-to-day basis. This information will keep track of how well you are doing and feeling since your illness or injury.

Your reply to this questionnaire is confidential. Your identity will be known only to members of the research team, and the information you provide will not be able to be traced back to you. It is important that you answer every question by giving a score between 1 and 10. If you are unsure what answer to give, please do the best as you can. There is no incorrect answer.

Here an example of the question format:

The weather today pleases me.

Does not describe my situation 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Fully describes my  
situation

You are required to give a number between 1 and 10 to describe how you feel about the statement on today's weather.

Are there any questions?

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Please provide a number between 1 and 10 indicating how each of the statements apply to you.

1. I move around my living quarters as I feel is necessary. (Wheelchairs, other equipment or resources may be used.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

2. I move around the community as I feel is necessary. (Wheelchairs, other equipment or resources may be used.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

3. I am able to take trips out of town as I feel is necessary. (Wheelchairs, other equipment and resources may be used.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

4. I am comfortable with how my self-care needs are met (dressing, feeding, toileting, bathing). (Adaptive equipment, supervision and/or assistance may be used.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

5. I spend most of my days occupied in a work activity that appears to be necessary or important to me. (Work activity could be paid employment, housework, volunteer work, school etc.)

(Adaptive equipment, supervision and/or assistance may be used.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

6. I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to.

(Adaptive equipment, supervision and/or assistance may be used.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

7. I participate in social activities with family, friends, and/or business acquaintances as is necessary or desirable to me.

(Adaptive equipment, supervision and/or assistance may be used.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

8. I assume a role in my family which meets my needs and those of the other family members.

(Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis.)

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

9. In general, I am comfortable with my personal relationships.

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

10. In general, I am comfortable with myself when I am in the company of others.

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

11. I feel that I can deal with life events as they happen.

Does not describe my situation 1----2----3----4----5----6----7----8----9----10 Fully describes my situation

Thank you very much for your time.

## Appendix 3

### Email to the WCRC for recruitment of research assistants

Sent on 12 June 2013

Dear all

As some of you already know, I have proposed to do a research study at the WCRC (as part of my Masters degree) looking at the levels of community reintegration clients have reached 6 months after discharge from rehabilitation at WCRC.

I am now looking for 3 research assistants to help with the data collection – 1 English, 1 Afrikaans and 1 Xhosa speaking individual.

What will be asked of you as a research assistant?

- Obtain informed consent from each participant – telephonically
- Administer the Reintegration to Normal Living Index (RNL Index) with each participant – telephonically. The RNL Index is made up of 11 questions which the participant will have to answer while you will be required to note the response (takes +/- 10 - 15 minutes).
- Take down any questions or concerns that the participants might have – I will then follow these up with the participant.
- Home visits are planned to some participants living in the Cape Town Metro Health District for data collection. You will be asked to accompany me on these home visits to complete the RNL Index with the participants.

When will you have to be available?

- I would like to do train the research assistants either in the last week of June or in the first week of July.
- Training will take about 4 hours.
- During that week we will also complete the pilot study – each assistant will have to complete 2 telephonic interviews and you will be required to accompany me on 1 or 2 home visits for data collection.
- Data collection is scheduled for the rest of July and first week of August: you will be asked to do all the telephonic interviews (each of you will have to do +/- 25 calls) early in the morning (8h00 – 9h00) or later in the afternoon (15h00 – 17h00) so that it does not interfere with therapy time and client management of your in-patients. You

will be allowed to do the phone calls during work time but may be asked to do some after hours.

- Some participants will be visited at their home- I am planning to be in Cape Town at the beginning of August to do the home visits with you. Home visits will be done during the week but could also be done on a Saturday. You may be asked to make some time available on a Saturday for some home visits.

All costs of the study will be paid for by myself. You will not have any expenses if you volunteer to be a research assistant. I have set aside R500 for each research assistant. If you are required to do data collection in your own time (after hours or on a Saturday) then that money will be paid to you as a token of appreciation for your time. If all data collection is done during official working hours then the money will have to be paid to the WCRC facility board.

If you are interested in assisting me please remember to discuss this with your supervisor so that they know that you would like to be part of the research team. Make sure you get their approval. Please get back to me by next week Wednesday 19 June.

Looking forward to hearing from you.

Dietlind

083 310 6649

## Appendix 4

### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

#### TITLE OF THE RESEARCH PROJECT:

Levels of community integration achieved by adults with disabilities post discharge from a specialized in-patient rehabilitation unit in the Western Cape

**REFERENCE NUMBER: S12/11/293**

**PRINCIPAL INVESTIGATOR:** Dietlind Gretschel

#### ADDRESS:

44 Walter Road

PO Box 15094

Charlo, Port Elizabeth

Emerald Hill, Port Elizabeth

6070

6011

**CONTACT NUMBER:** 083 310 6649/(041) 368 4992

You are being invited to take part in the above mentioned research project. Please take note that our conversation is being recorded and will be used as proof of consent given by you if you agree to take part in this research study.

Please take some time to listen to/read the information presented to you, which will explain the details of this project. Please ask me (the principal researcher/research assistant) any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. For example, declining to participate will not have a negative impact on any future health care provision at the Western Cape Rehabilitation Centre or any other health care facility. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

## **What is this research study all about?**

The researcher wants to find out if adults with a new disability are able to take part in activities of community life after they had treatment at the Western Cape Rehabilitation Centre.

The main reason the researcher wants to do this study is that at the moment therapists, nurses and doctors at the WCRC do not have much information about how well patients are managing/coping within the community after they were discharged from their rehabilitation programme.

For that reason we want to know more about how happy you are with your participation and involvement in your community six months after you were discharged from the WCRC. This information can then be used to help the therapists, nurses and doctors at the WCRC to give better and more effective treatments to future patients.

About 90 – 100 ex-patients of the WCRC will take part in this project. All patients that were discharged home from the WCRC during the months of September to November 2012 are being asked to participate.

If you agree to take part in the project, these steps will be followed:

### **1. Telephonic interview**

- You will be asked for a date and a time when a research assistant will phone you back for an interview in English, Afrikaans or Xhosa.
- The researcher has looked at your medical folder and wrote down your personal information including your age, gender, ethnicity, medical diagnosis, the date when you had your injury/incident and the number of days you stayed at the WCRC as an in-patient.
- The research assistant will phone you on the set date.
- First the research assistant will make sure that the personal information we wrote down from your medical folder is correct.
- The assistant will then ask you 11 questions over the phone. You will need to answer all 11 questions, with each question saying how happy you are with your participation and performance in a certain area of your life. The research assistant will write down your answers.
- The telephonic interview will take about 15 minutes of your time.
- It is a once off telephonic interview and you will only be phoned back/contacted again by the researcher if answers on the questionnaire are missing or unclear.

### **2. Face-to-face interview**

- The researcher will ask you if you are able to take part in the interview now or which day and time she and the research assistant should come back to your home for the interview. If necessary, the researcher and the research assistant will come back to your home on the day and time that is best for you and your family.
- You will then tell the researcher if you want to complete the interview in English, Afrikaans or Xhosa.
- When the interview takes place, the researcher will first ask you for some personal information including your age, gender, ethnicity, medical diagnosis, the date when you

had your injury/incident and the number of days you stayed at the WCRC as an in-patient.

- The research assistant will then make sure that the all the information you gave has been written down correctly.
- The assistant will then ask you 11 questions. You will need to answer all 11 questions, with each question saying how happy you are with your participation and performance in a certain area of your life. The research assistant will write down your answers.
- The face-to-face interview will take about 15 minutes of your time.
- The researcher will then draw your medical folder to check and correct all the personal information you gave during the interview.

### **Why have you been invited to participate?**

- You are being asked to take part in this project because you were discharged from your in-patient rehabilitation programme at the Western Cape Rehabilitation Centre six (6) months ago. All adults discharged from the WCRC during the months of September to November 2012 have spent the last 6 months at their home and in their community. We now want to find out how happy you have been with your involvement and participation in your community over the last six (6) months.

### **What will your responsibilities be?**

#### 1. Telephonic interview

- If you agree to take part in the project a research assistant will phone you back on a set date. You will be responsible to make sure that you are available on that day to complete the telephonic questionnaire. The phone call will take about 10 – 15 minutes and you will need to answer all questions to the best of your ability.

#### 2. Face-to-face interview

- If you agree to take part in the project and ask the researcher to come back to your house on another day for the interview, you will be responsible to make sure that you are at home on that day to complete the face-to-face questionnaire. The interview will take about 10 – 15 minutes and you will need to answer all questions to the best of your ability.

### **Will you benefit from taking part in this research?**

- You will not directly benefit if you take part in this research project.
- Future patients of the Western Cape Rehabilitation Centre may benefit from this research.
- Knowledge gained from this project will allow therapists, nurses and doctors of the WCRC to provide better and more effective rehabilitation programmes to future patients. This may help future patients to manage and function better within their community and have a better quality of life after discharge from in-patient rehabilitation.

**Are there any risks involved in your taking part in this research?**

- No risks have been identified in taking part in the research project.

**Who will have access to your medical records?**

- All personal information collected during the research project will be treated as confidential and protected.
- Only the researcher and the research assistants will see your medical folder in order to write down personal information such as your age, gender, ethnicity, medical diagnosis and length of stay at the WCRC.
- A research assistant will complete the telephonic questionnaire/interview with you.
- No personal information will reflect on the questionnaire sheet. Only a number, randomly given to each participant, will show on the questionnaire sheet.
- No personal information will be used in the thesis or in a publication.

**Will you be paid to take part in this study and are there any costs involved?**

- No, you will not be paid to take part in the study. There will be no costs involved for you, if you do take part. All costs related to this project such as telephone calls/home visits and postage will be carried by the researcher.

**Is there anything else that you would like to know about this research project?**

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You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints regarding this research project that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form by post for your own records.

Postal address:

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### Declaration by participant

Mr/Mrs/Ms \_\_\_\_\_ agrees to take part in a research study entitled: **'The levels of reintegration achieved by adults with disabilities six months post discharge from a specialized in-patient rehabilitation unit in the Western Cape'**.

Yes:

Mr/Mrs/Ms \_\_\_\_\_ declares that:

- I have had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished if the researcher feels it is in my best interests.

Yes:

Conversation held at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2013 at  
(*time*) \_\_\_\_\_.

\_\_\_\_\_  
**Signature of participant**

\_\_\_\_\_  
**Signature of witness**

### Declaration by investigator

I (*name*) \_\_\_\_\_ declare that:

- I explained the information in this document to \_\_\_\_\_.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2013 at  
(*time*) \_\_\_\_\_.

\_\_\_\_\_  
**Signature of investigator**

\_\_\_\_\_  
**Signature of witness**

### Declaration by interpreter (if applicable)

I (*name*) \_\_\_\_\_ declare that:

- I assisted the investigator (*name*) \_\_\_\_\_ to explain the information in this document to (*name of participant*) \_\_\_\_\_ using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was relayed to me.

- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2013 at  
(*time*) \_\_\_\_\_.

\_\_\_\_\_  
**Signature of interpreter**

\_\_\_\_\_  
**Signature of witness**

\_\_\_\_\_  
**Signature of investigator**

\_\_\_\_\_  
**Signature of witness**

**Appendix 5**

**RESEARCH ASSISTANT CONFIDENTIALITY FORM**

**TITLE OF THE RESEARCH PROJECT:**

Levels of community integration achieved by adults with disabilities post discharge from a specialized in-patient rehabilitation unit in the Western Cape

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** Dietlind Gretschel

**ADDRESS:**

44 Walter Road	PO Box15094
Charlo	Emerald Hill
Port Elizabeth	Port Elizabeth
6040	6011

**CONTACT NUMBER:** (041) 368 4992 / 083 310 6649

I (*name*) \_\_\_\_\_ herewith declare that I will treat all participant information and data related to and collected during the study as confidential and protected. I will not disclose any information or data that I obtain from study participants or the researcher as part of the above mentioned research study. I will uphold each participant's right to confidentiality and to be treated in a fair and just manner at all times.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2013.

\_\_\_\_\_  
**Signature of research assistant**

\_\_\_\_\_  
**Signature of witness**

\_\_\_\_\_  
**Signature of investigator**

\_\_\_\_\_  
**Signature of witness**

**Appendix 6**

**Data sheet – excluded individuals**

No.	Participant name	Reason for exclusion from research study
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

## Appendix 7

### Data sheet – eligible participants who declined participation

No.	Participant name	Contact telephone number
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

## **Appendix 8**

### **Ethical approval**

## Appendix 9

### Letter of approval Department of Health



#### STRATEGY & HEALTH SUPPORT

healthres@pgwc.gov.za  
tel: +27 21 483 9907; fax: +27 21 483 9895  
5th Floor, Norton Rose House., 8 Riebeeck Street, Cape Town, 8001  
[www.capegateway.gov.za](http://www.capegateway.gov.za)

REFERENCE: RP 018/2013  
ENQUIRIES: Ms Charlene Roderick

PO Box 15094  
Emerald Hill  
6011  
Port Elizabeth

For attention: Dietlind Gretschel, Surona Visagie, Martha Geiger

Re Levels of community reintegration achieved by adults with disabilities six months post discharge from a specialized in-patient rehabilitation unit in the Western Cape

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries.

Western Cape Rehab Centre

Jenny Hendry

Contact No. 021 370 2313

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za)).
3. The reference number above should be quoted in all future correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'NT Naledi', written over a blue horizontal line.

DR NT Naledi  
DIRECTOR, HEALTH IMPACT ASSESSMENT

DATE: 21/4/2013