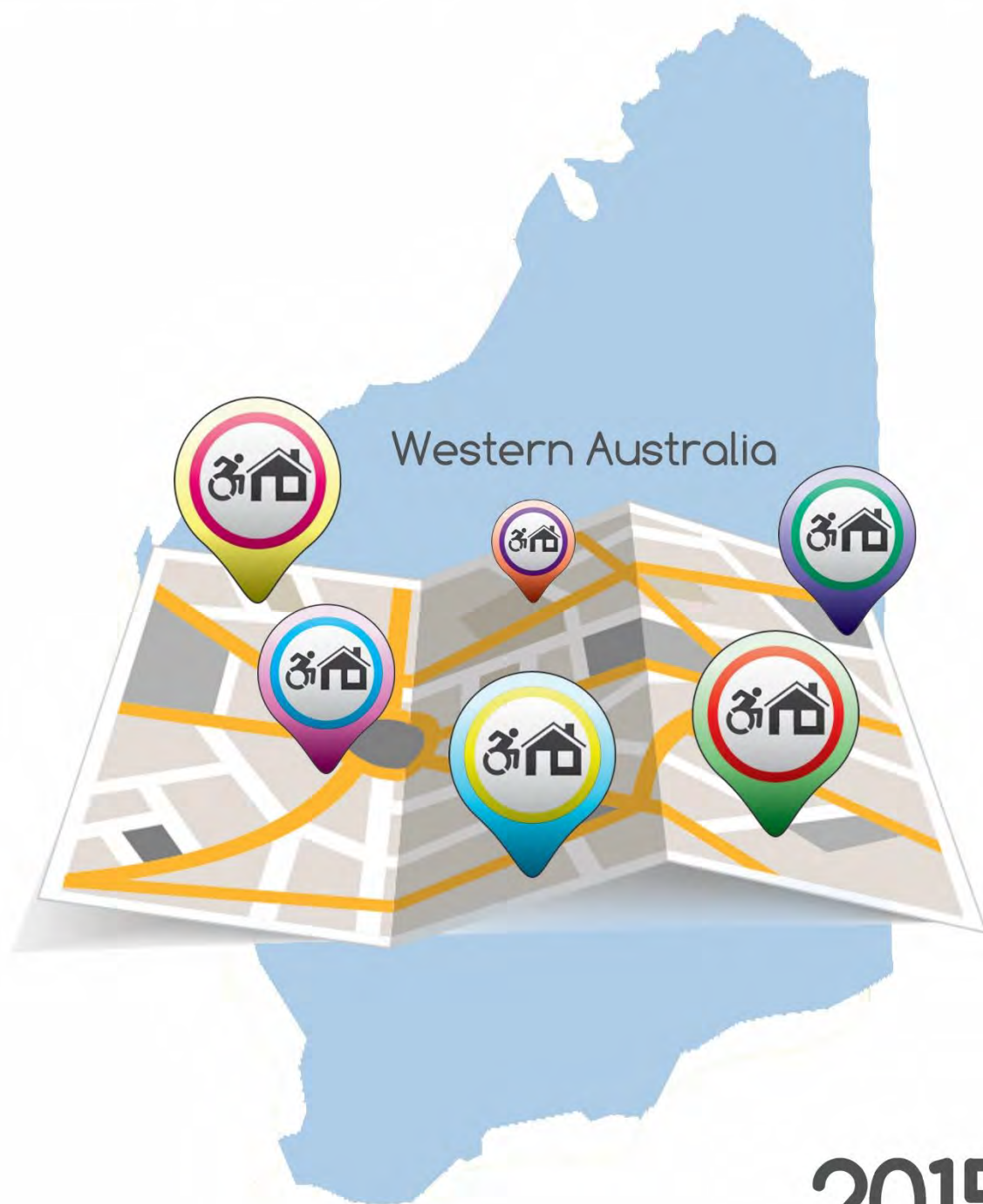


# An Enhanced Service Model For People With Spinal Cord Injury In Western Australia

Including Review Of State Quadriplegic Centre



2015

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## Similar beginnings...different journeys

The following stories are of two young men who both sustained a spinal cord injury in the same month, in the same year and have a very similar level of injury. However, their journeys to date have been quite different.

One was injured where there was good access to specialist multi-disciplinary community spinal cord injury services and one was injured where these services do not yet exist. These are their own words and have not been altered or edited.

“ *D's Story*

*On a Saturday in November 2010, I was involved in a motor vehicle accident which left me a complete T8 paraplegic. I was admitted to ICU and placed in an induced coma for a period of 6 weeks. During this period I developed pressure sores to my head, sacrum and heel and I was hospitalised for 10 months at the spinal unit in order for them to heal and to learn how to be paraplegic.*

*I then moved in with my girlfriend and was transferred to a local hospital for ongoing support. I soon developed issues with my cushion which was the beginning of all my problems. I got pressure sores on my trochanter and had to spend another 4 months in bed healing up my skin at home with no care except for my girlfriend and her mother. I was forced to stop work whilst I healed the area and the local nurse visited me at home 3 times a week. It was the nurse who attributed my cushion as the cause of my pressure sores. She issued me with a loan Roho Cushion while one was ordered for me in the long term.*

*Four months on my pressure sore healed, I was allowed to mobilise again but my new cushion popped and began to leak after 6 months of use. I was forced to purchase another cushion at my own expense but another 6 months on the same problem, the cushion popped and began to leak. So I contacted my OT to assess the situation as I was following the washing instructions and taking good care of my new cushion; again I had to purchase a third cushion at my own expense. Instead of a review being undertaken to assess why this was happening I received a phone call from the local OT stating that the supplier had told her that I was over inflating the cushion, so I proceeded to let air out of the cushion, little did I know what was to unfold next....*

“ *H's Story*

*I grew up in a small country town and after finishing school I moved to the city to chase a career in motocross. I raced for Team Yamaha in the National motocross and super cross series but at age 19 I had an accident while training. The accident left me with a*

*punctured lung, broken ribs, a bleed on my brain a broken C5, C6, T4 and T5, I was now paraplegic. I had a short stay in ICU and spent 2 months in the spinal unit where the nurses and physios taught me everything from skin care to getting in and out of a bed. It was hard at the start to get my head around the thought of being in a wheel chair for the rest of my life until I met the peer support team. They made me realize that life goes on normally after a spinal cord injury. Seeing how happy and positive the team were made the transition so much easier. After my rehab was finished I lived with Mum and Dad just outside of the city. Heading home was somewhat of a scary thing to do..... ”*

**D and H's stories will continue later...**

## **Acknowledgements**

The External Review Project Team would like to acknowledge the support and guidance of Dr Shane Kelly, Mr Wayne Salvage and Mr David Mulligan from North Metropolitan Health Services throughout this External Review. They have generously provided background information, valuable discussion and administration support and released staff to assist with focus groups. Without this level of support the review would not have been possible.

We also particularly valued the input from key stakeholders who completed surveys, attended interviews and focus groups. They have freely shared their valuable time, their views on current services in Western Australia (WA) for people who have a spinal cord injury and provided invaluable insights into potential future services that have contributed to the development of the recommendations contained within this report.

We would also like to acknowledge the individuals with disabilities, their families and carers who shared very personal stories of their journey since the time of their injury. These stories although extremely personal, have contributed greatly to the review process and to the final recommendations for future services for people who experience spinal cord injury in the state of Western Australia.

We are very also grateful for the cooperation, assistance and advice from Mr Shane Yensch, Chief Executive Officer, The Spine and Limb Foundation Incorporated; Ms Lynda Emersen, Director of Nursing, The Quadriplegic Centre; the Quadriplegic Centre Board of Management; People with Disabilities WA and Dr Hannah Seymour, Medical Co-Director, Fiona Stanley Hospital.

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## Executive Summary

In early 2015, the North Metropolitan Health Service, Western Australia commissioned a team from the Queensland Spinal Cord Injuries Service (QSCIS), Princess Alexandra Hospital, Brisbane and Spinal Injuries Australia, (based in Queensland) to conduct an independent External Review of the Quadriplegic Centre (The Centre), Perth.

The purpose of the External Review was to assess the Centre's adequacy for the purpose of providing contemporary models of care to people with quadriplegia and to assess the current clinical service model for people living with quadriplegia at the Centre. This was undertaken in the context of the whole of life continuum of services experienced by people with quadriplegia and other spinal cord injury (SCI) in Western Australia (WA). Recommendations were to be made in a number of areas including; the optimum service model and service demand for quadriplegic patients within WA, inclusive of the Ventilator Dependant Quadriplegic Community Care Program, considering a whole of life approach and transition from acute care to rehabilitation to supported community living.

SCI is an extremely complex and lifelong condition that requires support and health interventions at many stages throughout a person's life beyond primary rehabilitation. In WA it is estimated that there are more than 1,100 people living with a SCI and almost 70 people sustain a new SCI each year. However, due to the relatively small incidence and prevalence of SCI, generalist health professionals of all disciplines rarely see a large number of people with SCI. For this reason, best practice health and rehabilitation services for people with SCI have traditionally always been provided by specialist multi-disciplinary SCI teams.

The External Review included two onsite visits to the Centre and other organisations involved in the delivery of services to people with SCI in WA to facilitate an assessment of the current state of services for people with SCI including the Spinal Rehabilitation Ward (SRW), State Rehabilitation Service, the Ventilator Dependent Quadriplegic Community Care Program (VDQ-CCP), Paediatric SCI Services (briefly), the Quadriplegic Centre and the Spine and Limb Foundation Inc. The Project Team undertook an extensive consultation process with key stakeholders from the government, health and hospital, and community and disability sectors. Methods of consultation included focus groups, surveys and face to face meetings with multiple groups. In all, approximately 118 stakeholders provided feedback to the Project Team that helped to formulate the final recommendations in this report.

An extensive review of current models of SCI service provision in Australia and a search of peer-reviewed and other literature on national and international best practice services across the SCI continuum of care was performed. In most states dedicated specialist, multi-disciplinary SCI outreach services and some form of specialist support during the period of transition from hospital to community is now becoming commonplace. Similarly, well developed peer support services that are available not only in the Spinal Injuries Units but in the community are becoming the norm.

High quality research on this topic was relatively scant; however the available literature confirmed that SCI rehabilitation is not complete at the end of inpatient rehabilitation. There is a great need for goal based, multi-disciplinary, specialised SCI community services that

are available to assist people with SCI, both during the very challenging community reintegration period immediately following discharge from primary rehabilitation but also on an ongoing basis throughout their life. The literature also confirms that the models used and the philosophies that underpin service delivery to people with SCI have changed dramatically over the past 50 years. In 2011, the World Health Organisation's groundbreaking World Health Report on Disability stated that barriers to service delivery such as inadequate policy, lack of funding, physical access barriers, negative community attitudes and a lack of knowledge undermines quality of life for people with disability requiring supports and services. However, it also provides evidence that innovative policies and programs can improve the lives of people with disabilities.

The consultation process was generally well received by all stakeholders and enabled the development of six Key Findings and Themes. These were: 'There are Gaps in Spinal Rehab Services', Barriers to Timely Discharge Home, Quality of Services at the Quadriplegic Centre, Better Peer Support Services, Information and Advocacy for People with Spinal Cord Injury, What do the Current Residents of the Quadriplegic Centre Say.

The majority of people reported that services for people with SCI in WA are somewhat fragmented and in any future service model, services and systems need to work much more cohesively. There was general consensus that the addition of specialist SCI transition and outreach teams to the SCI continuum of care would be highly beneficial and would be a major step towards closing the existing gaps in the service model.

The major barriers to discharge included lack of personal care funding and appropriate housing available at the time of discharge from SRW.

There was a consensus that historically, services provided by the Quadriplegic Centre were highly valued by both past and current service recipients and other organisations that provide services and support to people with SCI. Overwhelmingly, the feedback received also confirmed the current facilities and resources at the Centre were in desperate need of upgrading and this provided an opportunity for a new and contemporary service model for people transitioning from primary rehabilitation at the SRW and for those already living in the community to be considered.

It was universally agreed that the development of enhanced peer support services would assist greatly in increasing the support for people with SCI.

While there have been many advances in the acute medical and inpatient rehabilitation management of SCI in Australia over the past five decades, unfortunately the development and appropriate funding of services and support for people with SCI returning to community living has often lagged behind other advances. In many areas, there is still a situation where adequate and necessary equipment and support services for people living with SCI are insufficient and not available when and where they are needed. Too often, people with a disability are without the services and equipment that are necessary to enable full participation in social, work and family life. These gaps in services for people with SCI were clearly identified by participants of the consultation process for the External Review.



The Recommendations made by the External Review Project Team are summarised below:

1. Development of an enhanced three-stage SCI Continuum of Care (The Western Australia Spinal Cord Injuries Service – WASCIS) for the treatment of people with spinal cord injury in WA and specifically the development of multi-disciplinary transitional rehabilitation and outreach teams (see Diagram 3).
2. Development of a peer support program to deliver services across the spinal cord injury continuum (see Diagram 3).
3. Strong collaboration with Rehabilitation in the Home (RITH) services for appropriate patients discharging from the SRW.
4. The use of the existing tele-health services by all components of the new SCI model as an adjunctive method of delivering services in more rural or remote regions.
5. The Quadriplegic Centre be devolved through offering the current residents a range of choices in accommodation options; wherever possible this needs to be a community based living arrangement (see Diagram 4).
6. A Reference Group / Steering Committee is formed inclusive of a consumer representative to drive the implementation of the recommendations in this report.
7. The formation of a dedicated suitably resourced Project Team to establish and implement the Quadriplegic Centre Devolution and Transition Project.
8. A co-ordinated whole of government approach to providing personal care, housing and home modifications, health related services and equipment to all people with a new SCI discharging from the SRW, SRS.
9. A Clinical Nurse Consultant or other Senior Nursing position is created within the new spinal outreach service to provide services to people on the VDQ–CCP across all components of the WASCIS continuum.
10. Consideration be given to providing early intervention, vocational rehabilitation services across the SCI continuum of care.
11. That the VDQ-CCP program be reviewed particularly in relation to current funding eligibility and the need for a primary carer to reside with individuals requiring mechanical ventilation.
12. That consideration should be given to undertaking discussions with NDIS / My Way to include the devolution of appropriate residents from the Quadriplegic Centre as a “pilot program” for NDIS implementation in WA.
13. A comprehensive review of rehabilitation services for children with SCI in WA be undertaken..
14. Consideration is given to assisting community based personal care agencies to develop the necessary competencies to be able to perform invasive procedures such as bowel therapy.

15. Further consideration is given to the interim accommodation needs of people with SCI and in addition, that the WA Patient Assisted Travel Scheme (PATS) is reviewed to ensure that funding allowances under that scheme are sufficient to support the requirements of people with SCI.
16. Further consideration is given to an appropriate future model for the provision of respite services for people with SCI in WA.
17. The initial work being undertaken by the Spinal WA group, to ensure that specialised information and education is available to individuals with SCI, their families and service providers be encouraged and supported and that other key SCI service providers review their own methods of communication and websites to ensure that they are providing the information that people with SCI need.

Three key themes have also emerged:

- a) A Whole of Government Approach and Coordinated SCI Program is essential and must be established as soon as possible.
- b) An Enhanced Continuum of Care for the clinical management of people with SCI in WA - the Western Australia Spinal Cord Injury Service (WASCIS) is required and specifically the development of transitional rehabilitation and community outreach services.
- c) The Devolution of the Quadriplegic Centre and Transition of Current Residents to Other Community Living Arrangements is required.

While a detailed implementation plan is outside the scope of this review, the External Review Project Team have indicated some key features (please see Diagram 5) which they believe are worth specific mention. Firstly, the new WASCIS community based SCI clinical teams need to be established first as they will become an essential element of the Quadriplegic Centre Devolution and Transition Project when the actual transition of residents commences. Secondly, negotiations between departments to establish the Whole of Government Co-ordinated SCI Program and the relationship to current and future NDIS services are likely to be complex and need to commence early as a functioning collaborative model will also need to be in place to enable residents to be re-located as part of the Quadriplegic Centre Devolution and Transition Project.

The External Review Project Team hope that this report and the implementation of its recommendations will, not only provide a blue print for the development of future services that will enhance health and lifestyle outcomes for people with SCI living in WA but also position the state as a future leader in the provision of services to people with SCI, not only in Australia but internationally.

## Introduction

Spinal Cord Injury (SCI) is an extremely complex and lifelong condition that requires support and health interventions at many stages throughout a person's life beyond primary rehabilitation. It has major personal, psychosocial and financial impacts on the individual and family involved but is also very costly, from an economic perspective for the community as a whole. The lifetime cost per incident case of SCI has been estimated to be \$5.0 million per case of paraplegia and \$9.5 million per case of quadriplegia, across Australia.<sup>1</sup>

In Western Australia it is estimated there are more than 1,100 people living with a SCI. There are on average 66 people who sustain a SCI each year. Of those 66 people admitted to the Spinal Rehabilitation Ward (SRW) each year, on average 30 will have an injury resulting in quadriplegia.

Due to the relatively low incidence and prevalence of SCI, generalist health professionals of all disciplines rarely see a large number of people with SCI and therefore have difficulty developing and maintaining the clinical skills required to confidently manage the rehabilitation and complications related to SCI, especially the more complex aspects. For this reason, best practice health and rehabilitation services for people with SCI have traditionally always been provided by specialist multi-disciplinary SCI teams.

Management of SCI requires high quality clinical inpatient health services to support the individual in the acute stages of the injury and provide primary rehabilitation in a specialist SCI unit. Western Australia has been at the forefront of this type of service provision since 1954 when Sir George Bedbrook (who many consider to be the "father" of the modern management of SCI in Australia) established Australia's first spinal unit as part of the Royal Perth Hospital and commenced revolutionising the management of SCI in WA and Australia. The recent opening of the Fiona Stanley Hospital, with its State Rehabilitation Service and "state of the art" Spinal Rehabilitation Ward continues this leadership in the field.

The aim of primary rehabilitation is to assist an individual to reach their full potential and return to the highest level of participation in life that their level of impairment will allow. The literature confirms that better outcomes occur for people when specialist SCI services are provided. A study by Parent et al, in 2011 found that "specialized centres of care consistently reduce length of stay and complications, and improve neurological recovery".<sup>2</sup> Similarly, Donovan et al noted that "At present the ideal scenario for modern SCI care is purported to be treatment in specialised integrated centres with an interdisciplinary team of health care professionals providing care as early as possible following injury and throughout the rehabilitation process with appropriate discharge to the community characterised by ongoing outpatient care and follow up".<sup>3</sup>

More recently the importance of the transition phase (when people with SCI are first discharged from a Spinal Unit and are re-integrating back into their families and communities) and of ongoing rehabilitation and outreach services for people with SCI has been recognised. Most states of Australia have now established, in various forms, specialist multi-disciplinary SCI community rehabilitation and outreach services to better provide services to people with SCI and assist with activities such as promoting self-management,

prevention, monitoring and early detection and management of complications and education and training of individuals, their families and service providers.

A comprehensive, effective and efficient approach to the management of people with SCI also requires the various government departments involved (e.g. Health, Disability Services, Housing and possibly others) to work together beyond traditional departmental boundaries to ensure that there is a co-ordinated approach to the provision of necessary services e.g. health and equipment, personal care provision, home modifications and social housing. This will ensure that discharge of people from the Spinal Injuries Unit is not delayed with the aim of avoiding the psychosocial and financial costs associated with such delays. Even more importantly, it will ensure that all necessary services are available to enable all people with SCI to live in the community, either alone or with their families, with the same degree of safety, comfort and choice (of accommodation types) as any able bodied member of the community would expect.

It is the considered opinion of the External Review Project Team that formal support systems for people with SCI in Western Australia have become somewhat fragmented over time. Personal care support funding for people with disabilities is often insufficient to meet their needs and is not available at the time of discharge from primary rehabilitation, when the person is required to take the next step of reintegration into their own community. The individual's family and informal networks are frequently required to "fill the gaps" left by insufficiencies in the formal disability service sector. Currently, if an individual is unable to access family and informal networks then centre based care may be their only option thus resulting in a delay to resumption of one's previous lifestyle and return to community living. Since the 1960's, the Quadriplegic Centre (The Centre), Perth has been filling such a role in WA, offering specialist residential services to people with quadriplegia for whom return to community living is not possible following primary rehabilitation.

The aim of this External Review is to now look to the future and carefully consider a model of service in WA that is best practice, evidenced based and contemporary and that will meet the needs of people with SCI well into the future.

## **Background to the External Review**

In early 2015, the North Metropolitan Health Service, WA commissioned a team from the Queensland Spinal Cord Injuries Service (QSCIS), Princess Alexandra Hospital, Brisbane and Spinal Injuries Australia, (based in Queensland) to conduct an independent External Review of the Quadriplegic Centre.

The Quadriplegic Centre is a partnership between the Spine and Limb Foundation (incorporating the Paraplegic and Quadriplegic Association of WA and the Civilian Maimed and Limbless Association) and the Government of WA; and is a publicly funded hospital governed by an Independent Board of Management. Its vision is the creation of a centre of excellence in the provision of spinal cord injury management, care and rehabilitation in Western Australia, and its mission; to provide a centre of best practice in the provision of spinal cord rehabilitation that is both innovative and responsive in the services it provides to the community. The Centre provides long term residential care, slow stream rehabilitation and respite to approximately 51 residents (number at the time of the External Review) with spinal disabilities. The majority of residents have a high level SCI and are long term occupants.

The WA Department of Health, as part of their upgrading of health services recognised that, while services at the Centre had expanded over the years, the built environment had not kept pace and is currently in a poor state of repair. The current facility has been described as outdated, not fit for purpose and not supportive of safe, high quality, contemporary service delivery models.

In addition, the current contractual arrangements, clinical patient management and governance arrangements are not compliant with government and WA Health policy.

A number of previous reviews of the Quadriplegic Centre have been conducted, in particular a feasibility study in 2005 and most recently, a review of clinical services undertaken in 2008. A previous proposal suggested that redevelopment of a new 85 bed facility be undertaken, however documents provided to the External Review Project Team at the commencement of the project indicated that this proposal was not considered current.

The stated objective of the WA Department of Health is to ensure that the government responds to the needs of existing and future Quadriplegic Centre residents by ensuring the model of care moving forward is contemporary and complies with government policy and standards.

Future funding sources and partnerships also need to consider the changing landscape of disability service delivery, in particular the impact of the National Injury Insurance Scheme (NIIS) and the National Disability Insurance Scheme (NDIS).

## Terms of Reference of the External Review

The purpose of this External Review was to assess the adequacy of the Centre's facilities to provide contemporary models of care to people with SCI and to assess the current clinical service model for people living with quadriplegia at the Centre.

This report was to make recommendations on key issues including:

- The optimum service model and service demand for quadriplegic patients within WA, inclusive of the Ventilator Dependant Quadriplegic Community Care Program, that considers a whole of life approach for all ages and transition from acute care to rehabilitation to supported community living.
- Key Performance Indicators for performance reporting and management purposes.
- Governance and management arrangements that should underpin the service model.
- Facility based options that support the recommended service model beyond just the redevelopment of the Centre on its current site.
- Other significant issues as identified.

The scope of the review included:

- Review of the current Centre's service model, including all aspects of service delivery and quality, inclusive of the patient experience.
- Consultation with appropriate key stakeholders as required to facilitate the review.
- Research on national and international contemporary best practice service models for whole of life clinical care, rehabilitation and support from acute care to rehabilitation to supported community living, for people with quadriplegia and their families/carers.
- Recommending a detailed whole of life model of care for post-acute quadriplegic patients.
- Consideration of alternative sites and supported living models including consultation with the Department of Housing and the Disability Services Commission, beyond just the redevelopment of The Centre on its current site.
- Contractual arrangements between the service provider (Quadriplegic Centre) and the predominant funder (WA Health).

Reviewing the model of acute care and sub-acute rehabilitation at the State Rehabilitation Service (SRS) at Fiona Stanley Hospital was not in scope except where the model transitions to the next stage of rehabilitation for people with quadriplegia beyond that provided by the SRS. The deliverable from the External Review was to be a report outlining the methodology applied during the review, a summary of the key findings and the provision of a range of recommendations for future service delivery and governance arrangements. This is that Report.

## The External Review Project Team

The multi-disciplinary External Review Project Team is highly experienced in the management and provision of services for people with SCI including in the health and disability sectors. The team includes senior clinicians / managers from the Queensland Spinal Cord Injuries Service, Division of Rehabilitation, Metro South Health and from Spinal Injuries Australia, Queensland's peak non-government, member based organisation, for people with SCI.

The team consists of:

**Professor Tim Geraghty:** Consultant Physician in Rehabilitation Medicine, Queensland Spinal Cord Injuries Service (QSCIS) and Medical Chair, Division of Rehabilitation, Princess Alexandra Hospital, Metro South Health

**Dr Sridhar Atresh:** Consultant Physician in Rehabilitation Medicine and Director, Queensland Spinal Injuries Service

**Mr Greg Ungerer:** Manager Transition Services and Rehabilitation Program, Queensland Spinal Cord Injuries Service

**Ms Donna Harre:** Project Manager, Queensland Spinal Cord Injuries Service

**Ms Francis Porter:** General Manager Client and Member Services, Spinal Injuries Australia

**Mr Peter Harre:** Senior Peer Support Coordinator, Spinal Injuries Australia

## Approach and Methodology

The composition of the External Review Project Team was carefully considered to ensure a breadth of experience in the management of people with SCI across the health and community sectors. Collectively the review team has significant knowledge and skills including from the perspective of the lived experience; and have been responsible for the development of key and innovative services for people with SCI in Queensland.

The approach to the External Review ensured representation of views from across the entire continuum of care for people with SCI in WA. Every effort was made to ensure past and present residents of the Quadriplegic Centre had the opportunity to provide input; services from the point of primary rehabilitation through to community living were contacted and relevant government departments approached.

The External Review was divided into three phases: (see Diagram 1).

During **Phase One** a comprehensive literature review on national and international best practice models for services delivered across the continuum to people with SCI was undertaken. Site visit schedules and materials were prepared and surveys were developed and distributed during phase one.

**Phase Two** included two site visits to the Quadriplegic Centre, the State Rehabilitation Service, community-based organisations and government departments.

During **Phase Three** the information gathered during Phases One and Two was closely examined by the review team with deliberations occurring across a number of meetings and team workshops. Following a review of the data and information gathered, a list of key recommendations was made in relation to future services for people with SCI in WA.

Consultation with key stakeholders used a variety of interactions including multimodal surveys, teleconference interviews, semi-structured face to face individual and small group interviews, and a number of focus groups across a variety of stakeholders were held over the course of both site visits.

The project ran between April and August 2015.



**Diagram 1: Project Phases**



## Key Stakeholders

To ensure the review team captured a whole of life approach for people with SCI, a wide variety of stakeholders were engaged from across the continuum of care. Engaging people who currently used or had previously used the services of the Quadriplegic Centre was a priority.

The list of stakeholders consulted includes:

- Current residents of the Quadriplegic Centre and their families
- Past residents of the Quadriplegic Centre and their families
- Quadriplegic Centre Executive and Senior Staff
- Quadriplegic Centre Board
- Senior Executives Fiona Stanley Hospital
- Spinal Rehabilitation Ward Interdisciplinary Team
- Spinal Rehabilitation Ward Rehabilitation Medicine Consultants
- Disability Services Commission
- Department of Health Executives
- Department of Housing
- National Disability Insurance Scheme
- Paraplegic Benefit Fund – Peer Support
- People With Disabilities WA (PWDWA)
- Spinal WA
- Community Aids and Equipment Program (CAEP)
- Rehab In the Home Program (RITH)
- Princess Margaret Childrens Rehabilitation Program
- Ventilator Dependent Quadriplegic Program (VDQ)
- Spine and Limb Foundation Community Services Program
- Community Nursing Service – The Quadriplegic Centre

In total, approximately 118 stakeholders provided opinions and suggestions during the course of the project.

## **Current State of Spinal Cord Injury Services in WA**

### ***Spinal Rehabilitation Ward, State Rehabilitation Service***

The Spinal Rehabilitation Ward (SRW) is a 35 bed unit offering a state-wide service to people undergoing primary rehabilitation following a SCI as well as people who are readmitted with secondary complications of their SCI. The SRW, originally located at Royal Perth Hospital's Shenton Park campus was transferred to the Fiona Stanley Hospital (FSH) in October 2014. The SRW is part of the 140 bed State Rehabilitation Service (SRS) and is located next to the main hospital. The Fiona Stanley Hospital is operated by the South Metropolitan Health Service (SMHS).

The SRW has a multidisciplinary team, consisting of rehabilitation medicine specialists, nursing and allied health staff, and rehabilitation technology services which are overseen by the Director of Rehabilitation Services.

The SRW provides individualised goal based rehabilitation programs for inpatients as well as outpatient services for ongoing post-discharge follow up. The ward accepts people whose SCI is traumatic or non-traumatic in aetiology and there are approximately 66 new admissions and 107 readmissions for secondary complications each year.

With respect to discharge planning, the inpatient team works with individuals and their families to explore appropriate discharge accommodation options which may be determined by factors such as medical status, personal resources, psychosocial needs, degree of family support and compensation status.

Usual discharge accommodation options include:

- Home with or without outpatient therapy and/or Rehabilitation in The Home Program (RITH)
- Transfer to a regional / rural hospital
- Referral to the Quadriplegic Centre to access transition care while awaiting compensation, community funding and housing or long term residential care.
- Residential care placement for those unable to return home

Staff of both the Quadriplegic Centre and SRW interviewed during the consultation process indicated there had been a reduction in the number of referrals to the Quadriplegic Centre in the previous 12 months.

### ***Ventilator Dependent Quadriplegic Community Care Program***

The Ventilator Dependent Quadriplegic Community Care Program (VDQ-CCP) commenced in 2007 and is based at the Fiona Stanley Hospital under the governance of the SMHS. The program supports people with quadriplegia who are non-compensable and require permanent mechanical ventilation to maintain their respiratory function. The program came

to fruition because of the determination of people with SCI and staff to ensure that living in a hospital on a full time basis was not the only possibility for ongoing care.

The program has two components:

1. A **community component** that provides for an individual with a primary carer to return to their own home with 24 hour support
2. A **residential component** where people who do not have access to a primary carer live in a facility that provides 24 hour nursing support

The community component is contracted to Perth Home Care Services, a community based organisation located in the Perth metropolitan area. Personal Support Workers carry out the necessary care and support for people under the guidance and supervision of a Registered Nurse. The service accepted patients from as early as 2001 as they were individually funded by the Department of Health until the VDQ-CCP funding was formally established in 2007. Perth Care Home Care Services has delivered services to over 12 people on the ventilator dependent program at various locations throughout the state.

The residential component of the program is delivered by the Quadriplegic Centre to people who do not have a primary carer and therefore must opt for residential services. Nursing care is provided by Assistants in Nursing, Enrolled Nurses and overseen by a Registered Nurse. The centre is funded for 24 hour support for this group of people. In addition, the Quadriplegic Centre also delivers similar services to those who are compensable. In the past, some people in the SRW requiring permanent ventilation (who have completed their rehabilitation) have been discharged to the Quadriplegic Centre to await transition to the community component of the VDQ-CCP. At the time of the External Review Project Team's visit there were three residents at the Quadriplegic Centre requiring mechanical ventilatory support.

Information provided to the project team indicated that the current referral pathway to access VDQ-CCP services provides automatic access to the program for those undergoing primary rehabilitation in the SRW. However, people being treated at a hospital other than the FSH have no guaranteed access to funding through the program.

A clinical nurse located at the Spinal Rehabilitation Ward oversees the clinical care of ventilator dependent individuals both in the community and at the Quadriplegic Centre. This role forms a vital connection between people managed in the community and the clinical supervision of the ward.

### ***Paediatric Spinal Cord Injury Services***

Rehabilitation services for children with a spinal cord injury in WA are provided by the Princess Margaret Hospital (PMH). Whilst paediatric services were not formally within the scope of this External Review, the interface between paediatric and adult services for people with spinal cord injury is clearly relevant. At the request of PMH two members of the External Review Project Team met with senior clinicians of PMH during the first site visit.

The Paediatric Rehabilitation Unit and the SRW are the only primary rehabilitation services for people with a SCI in WA and for many years have had a close association including an informal spinal transition program where shared clinics are held to assist the transition process. There has recently been some disruption to the clinics with the move of adult services from the Shenton Park Campus to FSH, however it is believed that this should only be temporary.

The PMH runs a program for children requiring assistive technology which is similar to the VDQ-CCP. This program is known as the CATCH Program – Children who Are dependent on Technology and are Cared for at Home. Children with SCI or other diagnoses who require mechanical ventilation or those with a tracheostomy plus or minus non-invasive ventilation are assisted by funding through this program. Children who are ventilator dependent and cannot live at home reside at Lady Lawley Cottage, a respite facility located on Cottesloe Beach run by the Red Cross. Currently there are three children age 3, 12 and 17 years living at this facility. During the consultation process it became apparent that there is not necessarily a smooth transition for children onto the VDQ-CCP when they become adults as they do not always meet the current referral criteria. At the time of the site visit, planning was under way for the eldest of the three children to transition to adult services and this would have potentially resulted in a referral to the Quadriplegic Centre as the child does not have a primary carer and therefore does not meet the eligibility for community VDQ-CCP component. It was agreed by all the decision makers in this child's life that this would not have been an appropriate outcome (moving from one institution to another) and at the end of November 2015, the child will move into a Community Home (Nulsen Haven) and be funded jointly by VDQ-CCP and DSC.

The External Review Project Team did not feel that a full review of paediatric spinal cord injury services was within the team's expertise and any review of children's SCI services should involve a specialist paediatric SCI review team, dedicated time and appropriate resources to ensure the best possible outcome for future children's services.

## ***The Quadriplegic Centre***

### **Brief History**

The Quadriplegic Centre was built in the mid 1960's and opened in 1969. An increasing need for services offered by the Centre resulted in the development of additional wings with an ultimate 100 bed capacity. The Paraplegic and Quadriplegic Association of Western Australia, now known as the Spine and Limb Foundation Incorporated (SLFI) was involved in the planning and development of the Centre. The facility became the first formal post-acute care option for people with SCI and was contemporary and innovative at that time.

In 1969 the Centre also established the Community Nursing Service for people with spinal cord injury requiring information and support in the community. This service still operates today in its original form and remains a highly respected service.

The Centre is co-located with the SLFI, incorporating the Paraplegic and Quadriplegic Association of Western Australia and the Civilian Maimed and Limbless Association. Until recently the state's Spinal Unit was located opposite the Centre (Royal Perth Hospital, Shenton Park Campus) which offered the Centre excellent clinical support. The SLFI owns

the land title and buildings on which the Quadriplegic Centre and Para Quad Industries are currently located.

The centre has reduced its bed capacity to 74 over recent years due to some areas being deemed un-inhabitable. At the time of the second site visit by the External Review Project Team there were 51 residents occupying the Centre.

## **Categories of Service Provision**

Traditionally the Centre has predominantly offered long term residential services but over the past 15 years, it has also focused on providing transitional care for people moving from the acute sector and re-establishing themselves in the community.

The Quadriplegic Centre identifies its primary role as the provision of health care and outreach services to people with permanent high levels of SCI. The Centre's services are delivered by a skilled team of staff including nursing, occupational therapy, physiotherapy, social work, psychology and recreation staff. Community clients receive support and clinical liaison services provided by the Centre's Community Nursing Service. The team is led by the Director of Nursing; medical services are provided by a local general practitioner (GP) or other GP's of the individual resident's choice. Other executive, administration and grounds services are either funded by or contracted to the SLFI.

Nursing services are provided to the Centre's residents 24 hours per day with 77.25 FTE (21.68% of nursing FTE is allocated exclusively to those requiring permanent ventilation) delivering services across all shifts. The nursing team consists of Registered Nurses, Endorsed Enrolled Nurses and Assistants in Nursing.

Physiotherapy services (1.5 FTE) are offered to all residents, particularly in relation to maintaining and improving their capacity for independence and their respiratory function. The physiotherapy gym whilst old is described as adequate by staff; bedside programs are delivered to people confined to bed. Programs offered are often conducted in conjunction with the Occupational Therapy Department. In addition, physiotherapists provide induction and manual handling training for all staff.

The Occupational Therapy Department has 1.5 FTE staff. A goal based framework is used to deliver services with a focus on maximising independence in activities of daily living. A large part of the Occupational Therapist's role is to assist people in the acquisition of equipment through the Community Aids and Equipment Program (CAEP) and other various trusts and grants. All allied health staff have a strong focus on getting people in the transitional care category out of the Centre with appropriate skills and equipment. Therapists report a considerable volume of calls from people with SCI in the community in relation to advice and support on equipment and other occupational therapy needs.

Psychology and social work services are relatively new but welcome additions to the services offered by the Centre. The services focus is on assisting people with adjustment to their injury and in dealing with, what some described as "the sense of hopelessness that comes from continual rejection of funding applications for appropriate housing and support within the community".

The Centre employs a part time Resident Service Officer (RSO) to support patient's individual needs. This role assists patients with day-to-day domestic needs such as banking and shopping and liaises with families. Other staff of the Centre include administrative, domestic and maintenance staff.

The Centre describes itself as delivering several different models of care:

1. **Extended Rehabilitation** (long term care) – describes people receiving extended care, because for various reasons they have been unable to transition to the community. This category includes people with high level cervical SCI who often present with multiple comorbidities in addition to their SCI. Some people have been in residence at the Centre for over 10 years and up to 20 years. Of the 51 current residents, 69 percent of people fall into this category and have a mean length of stay of 8.7 years.
2. **Transitional Care** (up to 12 months) – describes residents undergoing rehabilitation at the Centre whilst in transition to community living. This service was introduced in 2007 and people in this category often use the Centre as an interim measure while they await suitable housing, care packages and/or compensation pay-out. At the time of this report there are 13 people in transition, some of whom have been in transition for more than 3 years.
3. **Ventilator Dependent Quadriplegic Program** – provides constant clinical support for residents requiring ongoing mechanical ventilation to maintain their respiratory function. The program commenced in 2007 and there are currently 3 people requiring this type of support at the Centre. Funding for this purpose is provided under the Ventilator Quadriplegic Community Care Program (VDQ-CCP) through SMHS. Where possible, these people will return to live in the community with ongoing support, however the funding guidelines state they must have a primary carer/family member willing to live with them and take responsibility for backup and other support needs.
4. **Respite Care** (up to 28 days per person per year) - the Centre has some capacity to admit people with quadriplegia from the community to enable respite for families and their carers or if regional clients require further medical review and support as an outpatient of the Spinal Rehabilitation Ward. It is understood that since the bed closures of 2010 this service has been much more limited. There were no admissions for respite at the time of the External Review however data provided indicates there were 745 bed days for respite care during the 2013/2014 financial year.

The Centre had expanded its capacity to cater for a fifth category i.e. the ongoing management of people with previous SCI and with major pressure injury (both prior to surgery and post operatively), with subsequent discharge back to the community. However, this program known as the Sub-Acute Spinal Injury Program (SASIP) is no longer in operation. Differing views were expressed as to why referrals for the program had ceased but the project team was advised that ongoing funding for the program was not provided by the State Rehabilitation Service and SMHS as of November 2013, as it was felt that the Centre was already receiving sufficient “funding from Health” to deliver this service. Also, since the relocation of the Spinal Unit to Fiona Stanley Hospital it had become more difficult

to provide the required appropriate medical supervision for post-operative patients. The Centre did express a desire to re-commence the program in the future.

At the time of the review there were a total of 51 residents in the Quadriplegic Centre - 35 in extended care, 13 in transition care, 3 in the ventilator dependent program and none in respite care.

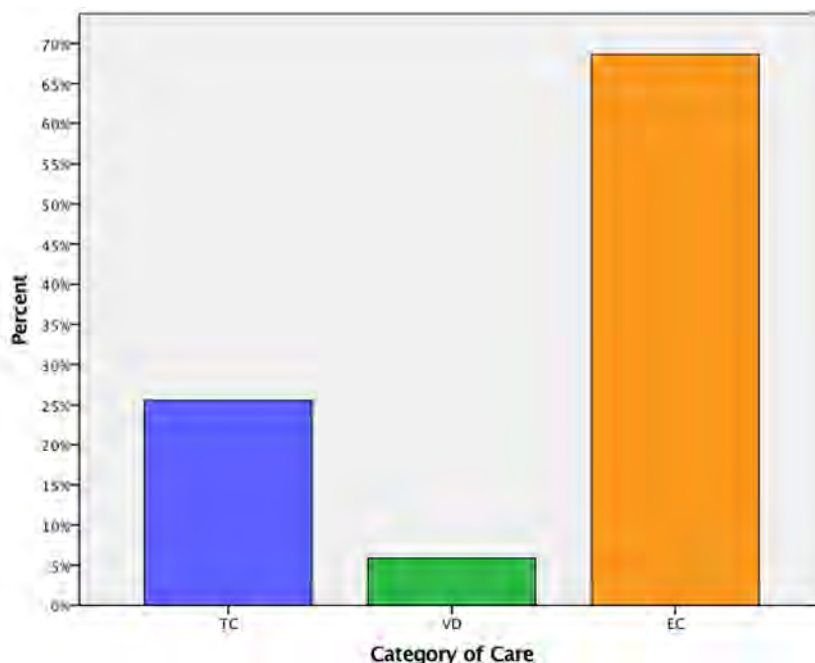


Diagram 2: Categories of Care

## Model of Care

The Quadriplegic Centre describes their current model of care as a medical model. A medical model of care can be defined as one whereby illness or disability is seen as the result of a physical condition which is intrinsic to the individual and causes clear problems and disadvantages for the individual. The Centre recognises that disability advocacy groups often view the medical model of disability as sub-optimal in contemporary terms and even as a civil rights issue. These groups are often critical of the medical model as they see it as promoting a negative, disempowering image of people with disability as it focuses on the individual's problems and their impairment.

The Centre's stated admission criteria include services provided to adults over the age of 18 years with high level SCI resulting from trauma or approved disease processes leading to high-level care needs. These admission criteria are considered narrow by some and stakeholders suggested that the services be extended to include people with paraplegia who require long term support due to aging or other health issues.

There has been a decline in the admission rate from the SRW to the Quadriplegic Centre in the last 12 months, with the most recent admission to the Centre being November 2014. The Centre staff stated they were not aware of the reason for the decline however, the SRW staff described a number of variables contributing to the reduced rate of admission to the Centre including a recent reduction in the incidence of people with tetraplegia as well as a number of people refusing to be admitted to the Centre. Instead these people preferred to be

discharged to their own home, even if personal care services were inadequate and needed to be topped-up by family support and other limited services.

## **Governance**

The Quadriplegic Centre is a publicly funded hospital governed by an Independent Board of Management appointed by the Minister for Health. This unique management structure was established under section 15 of the Hospitals and Health Services Act 1927 (WA). The Board of Management provides an annual report to the Minister but no specific performance reporting requirements were identified.

The executive staff (CEO of the SLFI and Director of Nursing, Quadriplegic Centre) provide the governance and day to day operational management of the Centre. They work collectively with the Board to resolve issues and implement the strategic intent of the Board.

The operational management of the Centre and the responsibility for the facility itself is supported by a Contract Manager within the Department of Health. Whilst the Centre functions independently of the Area Health Services, it is administratively aligned under the umbrella of the North Metropolitan Health Service (NMHS). In contrast, clinical oversight and the referral source of new patients to the Centre are predominantly from SRW which is under the governance of SMHS.

## **Funding**

The SLFI own the facility; and the land on which the Centre is located is in trust to the Foundation from the WA Government. The Quadriplegic Centre Board of Management is responsible for the provision of services at the Centre; however there does not appear to be a formal contract or a funding agreement in place between the Department of Health and the Centre. The review team were informed that this is because the Centre is considered to be a Hospital and part of existing WA Health services. The External Review Project Team was also not able to identify any formal agreement that describes key performance indicators or activity targets.

An historical arrangement has been in place for several years whereby the Department of Health estimates the annual budget based on historical budget provision. The Centre's current allocation is approximately \$13 million per annum and this is the primary source of funds for the Centre's operations. The Centre draws revenue from three other sources:

1. SLFI provides administration and executive services to the Quadriplegic Centre on a cost recovery basis.
2. SMHS funds the Ventilator Dependant Quadriplegic Community Care Program (VDQ-CCP) at approximately \$42,000 per month per person.
3. The Centre charges gazetted nursing home type fees to each of the residents or charges insurance companies for those people who are compensable under compulsory third party processes.

The current VDQ-CCP is out of contract and the procurement and contract management processes are unclear. The VDQ-CCP services have been extended for 2014/15 by way of a



grant to the Centre for the residential component, to enable the future procurement plan for the VDQ-CCP program to be developed.

The Centre's Community Nursing Service receives partial funding from the Home and Community Care Program (HACC) to assist in providing support to clients living in the community. The remainder of this program is funded by sources of revenue from the Quadriplegic Centre.

Feedback from residents and health professionals through interviews and focus groups conducted during the review revealed concerns regarding the issue of fees paid by residents. Some residents, especially those who had additional external financial commitments often found the cost of the nursing home type fees very difficult.

## **Physical Environment and Facilities**

Almost all stakeholders agreed that the physical environment of the Centre is in a poor state of repair. Permanent bed reductions have occurred over time since 2010 and have been necessary due to the some sections of the Centre being deemed unsafe or uninhabitable. Individual rooms allocated to patients are small with little space for personal possessions. Equipment storage areas where wheelchairs and other equipment are housed are generally inadequate.

The physiotherapy gym is open to patients Monday to Friday and while there has been some upgrade to the facilities in recent years they are still not as good as they should be for the extensive services offered to a large number of residents.

Residents also report little opportunity for privacy. Concerns were also expressed regarding security in the Centre and there was an incident involving theft of a resident's valuables on the day prior to the review team's second visit.

Some residents also reported a lack of satisfactory heating and cooling within the Centre which can be particularly important for people with high level SCI who may not have the ability to satisfactorily regulate their body temperature.

While there is a recreation area in the Centre where painting and other activities can be undertaken, it is outdated and is also accessed by a number of external groups with residents from the local community encouraged to attend.

On the positive side, the Centre is well located in Perth, with good community infrastructure which has developed over many years. Residents and staff alike identify the benefits of good access to local transport and shopping precincts. The Centre was offered the opportunity to relocate at the time the Spinal Unit transferred to the Fiona Stanley Hospital however this was declined as it was considered that the area around Fiona Stanley Hospital did not have as good community access and infrastructure.

## ***Spine and Limb Foundation Inc***

The Paraplegic and Quadriplegic Association of WA, founded in 1955 was instrumental in the development and delivery of services to people with SCI in WA, in particular the Quadriplegic Centre. In 2012 the Association amalgamated with the Civilian Maimed and

Limbless Association Incorporated and is now known as the Spine and Limb Foundation Incorporated. The SLFI has combined the strength of these two organisations and now runs a diverse range of services, both for people with disabilities and for those who are aged.

The SLFI is a not for profit organisation governed by a Board of Management. A number of SLFI board members also sit on the Quadriplegic Centre Board. The foundation offers a range of services including ParaQuad Industries, an Australian Disability Enterprise that offers a diverse range of goods and services to the private and commercial sectors; supported and residential accommodation (4 facilities in total) to those who are aged; and extended rehabilitation and transition services (the Quadriplegic Centre) to people moving back to the community following discharge from the SRW. The Foundation also provides support, information, advice and advocacy services that enable people with disabilities to participate in their community.

Some feedback received through the consultation process was critical of the diversification of services that has occurred at SFLI over the years, feeling that the change in the direction of the organisation to include, for example aged care and services for people with amputation has not always been in the best interest of the original core membership (people with SCI). Overall there was much praise for the work of the staff of the Quadriplegic Centre however others were critical of the model of care employed.

## **Current Service Models and Literature Review**

As part of the review, the External Review Project Team was asked to undertake “research on national and international contemporary best practice service models for whole of life clinical care, rehabilitation and support from acute care to rehabilitation to supported community living, for people with quadriplegia and their families and carers”.

An extensive review of current models of SCI service provision in Australia and a search of peer-reviewed and other literature on national and international, best practice service across the SCI continuum of care was performed. Unfortunately, there was relative paucity of high quality evidence related to SCI models of care and community rehabilitation services but what was found is summarised below.

### ***Current SCI Community Rehabilitation Services in Australia***

A national and international web review was carried out to identify the range of contemporary practices within Australia and in other parts of the world.

Firstly, a review was conducted looking at Spinal Injuries Units, other SCI services and consumer peak body organisations in Australia to draw comparisons regarding service types across the continuum for people with SCI. Information was collated based primarily on material available on the organisation’s websites and other publically available documentation rather than organisations being contacted directly and asked to provide the information. Therefore, the following information is presented not as an exhaustive or absolute list but as an example of the range of services currently available in various parts of Australia.

### **Outreach Services**

In most states dedicated specialist multi-disciplinary SCI outreach services, in some form are now offered.

In **New South Wales**, the NSW Spinal Outreach Service <http://www.royalrehab.com.au/rehab-services/spinal-injury-rehabilitation/spinal-outreach-service/> consists of the Metropolitan Spinal Outreach Service and the Rural Spinal Cord Injury Service. The metropolitan and rural spinal outreach services support people with a SCI, their carers and local clinicians across New South Wales. Supporting professionals on the team include doctors, nurses, physiotherapists, occupational therapists and social workers. The service is based at Royal Rehab and works closely with the spinal units at Royal Rehab, Royal North Shore Hospital and the Prince of Wales Hospital. The Metropolitan Spinal Outreach Service serves people with recent SCI who are being discharged from NSW spinal units and who live within the area bounded by the Southern Highlands, Wyong and Lithgow. The Rural Spinal Cord Injury Service provides specialist medical and multidisciplinary clinics to regional centres and rural areas for rural people with recent and persisting SCI (regional centres include but are not limited to Coffs Harbour, Ballina, Tamworth, Dubbo, Wagga Wagga. Centres are determined on a needs basis through an annual review).

ParaQuad NSW <http://www.paraquad.org.au/community-programs/> offers spinal nursing, occupational therapy, peer support and social work services through their Clinical Programs Team.

In **Queensland**, the Queensland Spinal Cord Injuries Service (QSCIS), <https://www.health.qld.gov.au/qscis/> offers outreach services through the Brisbane based Spinal Outreach Team (SPOT) <https://www.health.qld.gov.au/qscis/html/spot.asp> and outreach services are also provided from Townsville Hospital based North Queensland Spinal Service (NQSS) <https://www.health.qld.gov.au/qscis/documents/nqss.pdf> The Spinal Outreach Team (SPOT) supports people affected by SCI throughout Queensland by providing quality, timely and client focussed consultancy, early intervention and education services in the areas of social work, physiotherapy, occupational therapy and nursing and more recently a rehabilitation medicine registrar. The North Queensland Spinal Service (NQSS) has a multi-disciplinary team including rehabilitation medicine consultant, clinical nurse consultant, social worker, occupational therapist and physiotherapist.

In addition, Spinal Injuries Australia <http://www.spinal.com.au/> provide the Spinal Allied Health Service (SAHS) (incorporating nursing services). The Spinal Allied Health Service is a state wide team who work in collaboration with people with SCI and Post Polio Syndrome, to enhance their independence and lifestyle and operates out of offices in Brisbane, Townsville and Cairns.

The QSCIS and SIA services work together cooperatively to provide state-wide specialist services to people all over Queensland.

In **South Australia**, the South Australia Spinal Cord Injury Service (SASCIS) <http://www.rah.sa.gov.au/hampstead/hrcspin12.php> is developing the Spinal Outreach and Transition Team (SORT) which is a multi-disciplinary (Rehabilitation Medicine specialist, OT, PT, SW and Nursing) team providing a combination of both transition and outreach services to people all over SA. Outreach clinics are also held in Mt Gambier, Whyalla and the southern metropolitan area.

South Australia also provides outreach services to the **Northern Territory** with the Orthopaedic, Amputee and Spinal Injury Service (OASIRS) offering face-to-face clinics in Darwin, Alice Springs and outlying areas such as East Arnhem and Katherine.

Paraquad SA <http://www.pgsa.asn.au/> offers Community Lifestyle Advisors who are Registered Nurses whose role is to provide education, guidance, support and advice to people with a SCI and their families. They can provide assistance with skin, continence and other medical issues. A Home-Based Counselling Service provides a qualified social worker who can do home visits.

In **Victoria**, the Victorian Spinal Cord Service (VSCS) <http://www.austin.org.au/page/539> runs an outreach service known as The Spinal Outreach Risk Reduction Team (SpORRT) that consists of a nurse, occupational therapist and a physiotherapist which aims to reduce the risks of developing complications associated with SCI, prevent an admission to Austin Health as a result of complications and prevent emergency presentations to Austin Health as a result of complications. The

Community Spinal Nurses (CSNs) provide an outreach service to clients of the VSCS. They work with people living with SCI to assist with needs such as continence, equipment, attendant care, sexuality and fertility, skin care and wound assessment. CSNs also liaise with local health care providers and with the VSCS rehabilitation team. Consultation is available for up to 2 years after discharge

In **Western Australia**, the Quadriplegic Centre Community Nursing Service provides a community nursing and support service. Clinical nurses who specialise in the management of SCI and disease provide this service to over 500 people in WA. Two and a half full-time equivalent registered nurses manage the service from the Quadriplegic Centre, which covers all metropolitan areas and they also visit country patients during the year extending as far north as Geraldton and south to Albany.

## **Transitional Rehabilitation / Living Services**

A national web based search also looked at transitional rehabilitation or transitional living models for people with SCI.

In **New South Wales**, the Sargood Centre <http://www.sargood.org.au/> at Collaroy Beach offers 24 apartments for residential respite and transitional rehabilitation in a less medical environment. The capital construction was met by Spinal Cord Injuries Australia and recurrent costs are met by the Department of Ageing, Disability, and Home Care (DADHC).

Also in NSW, ParaQuad has the Berala Complex <http://www.paraquad.org.au/community-programs/accommodation/berala-sydney/> which offers transitional accommodation for people to improve their living skills in single motel style units or 2/3 bedroom homes. ParaQuad also offers accommodation at Ferguson Lodge <http://www.paraquad.org.au/community-programs/accommodation/ferguson-lodge-sydney/>. Ferguson Lodge was established in 1979 but underwent a rebuild in 2008, ultimately opening in 2011. It offers permanent residential and respite services through independent living in a modern community setting. There are 10 two bedroom units and 24 full time care beds set out in a village green concept.

In **Queensland**, the QSCIS has the Transitional Rehabilitation Program (TRP). <https://www.health.qld.gov.au/gscis/html/trp.asp> Queensland's model of transitional rehabilitation takes place in people's own homes (if they live in Brisbane and surrounds) or in private rental accommodation within the Brisbane metropolitan area for people who normally reside in rural or remote locations. This innovative model has been operational for the past 18 years.

In **South Australia**, ParaQuad's Transitional Housing <http://www.pgsa.asn.au/services/accommodation> is an innovative housing project of three wheelchair accessible homes, which have been planned using the principles of universal housing design. This transitional housing is for people who have experienced SCI, when they are ready for discharge from the Hampstead Rehabilitation Centre and to address the problem of discharges sometimes being delayed while modifications were made to their existing home, or while waiting for a wheelchair accessible home to become available.

In **Victoria**, the VSCS offers the Spinal Community Integration Service (SCIS) which is designed to meet the transition and community integration needs of people with SCI. It provides a coordinated approach to trans-disciplinary support and education and commences in the inpatient unit and continues for 12 months post discharge into the community. It aims to increase independence, self- management and integration in the community after a SCI.

In **WA**, the Quadriplegic Centre offers both transitional and long term residential models of care to people with quadriplegia from across the state.

Neither Queensland nor Victoria offer residential facilities.

## **Current SCI Peer Support Services in Australia**

Peer Support Services in Australia are generally provided by the relevant SCI consumer organisation in each state in close co-operation with the state health department SCI service.

In **New South Wales**, Spinal Cord Injuries Australia (SCIA) <http://scia.org.au/peer-support> have an established peer mentoring service for people who have sustained a SCI which is currently operational at Prince of Wales Hospital, Royal North Shore Hospital and Royal Rehab. A community based support service is also available to assist with the hospital to home transition. This service is available until the confidence and skills to live as meaningful and independent a life as possible have been achieved. Similarly, those with an established SCI can request the service at any time. Assistance is also available through SCIA's regional social networks (Central West, South Coast, Northern Rivers, Canberra and New England).

ParaQuad NSW <http://www.paraquad.org.au/community-programs/> offers spinal nursing, occupational therapy, peer support and social work services through their Clinical Programs Team.

In **Queensland**, Spinal Injuries Australia <http://www.spinal.com.au/services/peer-support/> provides a peer support service in close association with the Queensland Spinal Cord Injuries Service. Peer staff visit the Spinal Injuries Unit on a daily basis to connect with inpatients undergoing rehabilitation, as well as make post discharge follow up calls once a patient is discharged. People with SCI living in the community access the service on an as needs basis. The Peer Support Team run informal sessions called 'Check In' days on an adhoc basis in a variety of locations throughout the state.

In **Victoria**, the Australian Quadriplegic Association (AQA) has recently launched Spire <http://www.spire.org.au/> as a brand of peer-facilitated supports and resources for people with SCI to help them tackle issues of life. Spire emerged from what was previously the information and peer support department. The Peer Support Service also attends the Austin Hospital's Country Spinal Clinics in regional Victoria.

AQA also provide a peer support network for **Tasmania**. Contact is made with Tasmania patients at the Victorian Spinal Cord Service during their rehabilitation. This contact is continued when the person returns to Tasmania as needed. Independence Australia <https://www.independenceaustralia.com/services/support-groups/for-families-of-people-with->

[spinal-cord-injury](#), Royal Talbot Rehabilitation Hospital and AQA also facilitate a Family Peer Support Group at Royal Talbot.

In **South Australia**, Paraquad SA <http://www.pgsa.asn.au/services/peer-support> offers the Peer Support Advocates who provide support, advice, information and advocacy for clients and their family and friends. They work at the Hampstead Rehabilitation Centre's Spinal Injury Unit and also provide a home visiting service.

In **Western Australia**, the Paraplegic Benefit Fund (PBF) <http://www.pbf.asn.au/index.php?id=27> currently provides a Peer Support Officer who works with inpatients undergoing primary rehabilitation in the Spinal Rehabilitation Ward.

## ***Literature Review***

### **Beyond Primary Rehabilitation**

Successful community reintegration is the ultimate goal of any rehabilitation program however; many studies indicate that rehabilitation is often not complete upon discharge from a SCI rehabilitation centre. There is a clear need for appropriate healthcare and continued follow-up long after discharge from primary rehabilitation in order to prevent or at least decrease the common secondary complications and achieve a high quality of life.<sup>4-7</sup>

A coordinated, integrated and multidisciplinary approach that includes people with SCI and their family members helps to ensure a smooth transition between inpatient, outpatient and community-based care.<sup>8</sup> Follow up care has been found to be delivered via many different methods across the SCI community rehabilitation sector with some of the most important thought to be home visiting and telemedicine along with others such as outpatient clinic reviews and peer support.<sup>9-11</sup>

People with SCI report difficulty in adapting the knowledge and skills learnt in the tertiary setting to their own community environment on discharge as being one of the most challenging aspects of their journey as a person with a new disability. The loss of independence is difficult to cope with and often underestimated by an individual when in the inpatient setting.<sup>12-13</sup> There are benefits of putting into practice these new skills in a real world environment using integrative activities (e.g. working out in a local gym) and not just in the confines of a hospital based rehabilitation setting; using and developing problem solving skills enables a person to adapt in their home environment.

However, translating the basic skills acquired during primary inpatient rehabilitation into the 'real world' requires supervision and assistance from appropriate health professionals. Unfortunately, research into bridging the gaps between hospital and community by Kendall et al<sup>6</sup> found that the gap between the provision of hospital-based rehabilitation and that of community-based service provision is wide, resulting in a fragmented service continuum that allows many people to fall between the cracks. Another study confirmed that people with SCI and their families are often left to deal with the difficult transitional period alone due to a lack of professional and peer support follow up.<sup>12</sup>

There is also an increasing acknowledgement of the need for multi-disciplinary teams with Bloerman et al.<sup>9</sup> and many other authors suggesting that transition services that are staffed



by one or two disciplines only are not as effective as multi-disciplinary teams whose goal is to provide people with the ability to self-manage their health.<sup>5-6,9,13-14</sup> Kendall describes transitional rehabilitation as aiming to ensure continuity of care for people with SCI by providing a necessary link between traditional hospital-based rehabilitation and current community based rehabilitation services.<sup>6</sup> While, the concept of transitional rehabilitation is a relatively new service model, it is being adopted by many specialist areas, including acquired brain injury rehabilitation in order to enhance the rehabilitation experience and ensure successful community reintegration.<sup>15</sup>

Many studies have suggested that the management of SCI places an excessive burden on the healthcare system.<sup>5</sup> Even though this cohort is small in number they are one of the most expensive in terms of their ongoing support and health care needs. People with SCI often require long periods of hospitalisation during their primary admission, lifelong monitoring and large amounts of equipment is required for maintenance of full independence. They also frequently require health interventions and multiple readmissions to hospital secondary to complications.

A study by Cox et al<sup>16</sup> involving a needs assessment of 54 people with SCI living in the community found that the greatest perceived barrier to needs being met was limited local specialist knowledge about SCI. They confirmed the need for specialist, multidisciplinary SCI outreach services following primary hospital-based rehabilitation services. Participants in this study stated that they needed both home visiting services, and telephone advice and consultancy. Access to specialist SCI services is thought to assist in maintaining an individual's health across their lifetime by prevention, early detection and management of secondary complications that are common in people with SCI. Freedom from secondary complications allows individuals with SCI to pursue a life within the community that would be considered by many to be a good quality of life. Wolf et al<sup>27</sup> noted that enhancing quality of life is an inherent goal of rehabilitation and that there is a continual challenge to close the gap between treatment activities and functional competence in the individual's actual environment. Another study suggests that community participation equals quality of life and that successful community integration has three aspects to it – social, vocational and independent living.<sup>17</sup> Goal based approaches are also suggested to be integral to successful community integration.<sup>13</sup>

Some authors have also suggested that another problem is that primary rehabilitation in specialist SCI inpatient units often focuses more on physical recovery than on emotional needs and that even people with SCI understandably prioritise their physical recovery over a holistic approach to their rehabilitation journey. This has meant that there has had to be a shift in the focus of community SCI care from achieving good health outcomes to meeting the long term rehabilitation goals of community integration.<sup>12</sup>

Over the last decade there has been a paradigm shift towards community based rehabilitation service delivery within the health sector with the idea that specialist multidisciplinary services can act to build the capacity of generic community services through the provision of appropriate resources and education and empower individuals through tailoring services that meet an individual's goals and health needs, thus assisting people to achieve self-efficacy.



## Disability and Rehabilitation Models and Philosophy

The models used and the philosophies that underpin service delivery to people with SCI have changed dramatically over the past 50 years.

Until the 1980's, the medical model dominated the health service delivery sector. The emphasis in a medical model is on treating and curing a problem that exists with an individual<sup>6</sup>. There is a focus on a person's disability and not the person themselves. Up until the 1980's, the majority of people with disabilities lived in large congregate care facilities (like hospitals). These types of facilities, although smaller in number still exist today. However, over the last 30 years there has been a move away from institutions to independent community living with alternative care services being progressively developed.<sup>18</sup> The World Health Organisation (WHO) report also suggests that well planned and adequately resourced community services are much more cost effective than institutional care.

During the 1980's, the theory of social role valorisation (SRV) or normalisation became popular and it was considered to be the catalyst for the deinstitutionalisation process where most large institutions were devolved and people moved to more community based living options. SRV was based on the principle that people with disabilities were entitled to the same choices and services as other people within the community. The normalisation model continues to underpin disability practices but has been enhanced by other theories and frameworks of social inclusion and independent living.<sup>19</sup>

The social model that followed this period encouraged people to be players in their own lives, making decisions about their care that empowered them and it ensured they were not just passive recipients of services.<sup>20</sup>

Supports and services are necessary for people with disabilities if they are going to participate in their community. A discussion paper published by the Disability Services Commission WA in 2012<sup>21</sup> confirms the need for people with disabilities to have better choice and control over the services and supports they receive. This report suggests that key features of contemporary services include that they should be designed and directed by the service recipient, promote social inclusion and should be as close to community norms as possible.

Jenkinson in her discussion paper for People with Disabilities WA in 2008<sup>22</sup> states that person centred planning and individual funding in a variety of formats are common tools used in current approaches of service provision. She also discusses current theories of service provision as focusing on the individual and on community when developing services for people with disabilities.

The World Health Report on Disability<sup>18</sup> confirms that barriers to service delivery such as inadequate policy, lack of funding, physical access barriers, negative community attitudes and a lack of knowledge undermines quality of life for people requiring services and supports. The report provides evidence to support the notion that innovative policies and programs can improve the lives of people with disabilities. It also recommends that a diversity of models is required but that there should be common overarching principles, namely that services need to be provided in the community, be person centred, have

individuals being involved in the decisions that affect them and give them maximum control over their own lives.

Over the last four decades people with disabilities themselves have driven much of the change within the sector. Today there is call for services to people with disability to be person-centred with individualised funding and often self-managed. People want more streamlined and flexible service systems that allow them to achieve the goal of independent living and they want to be involved in the development of policy and services.

Only ‘whole of life’ models of service can provide services that assist people over the longer term.<sup>23</sup> Future models need to be goal based, build community infrastructure and utilize the principles of empowerment and community inclusion in order for people to gain control over their life<sup>24</sup>

With respect to rehabilitation models, current literature suggests that they should be underpinned by the principles of the International, Classification of Functioning (ICF) framework. Contemporary rehabilitation programs would be likely to follow the ICF based conceptualisation of rehabilitation that aims to enable people with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning in interaction with the environment.<sup>25</sup>

## **Future Approach to Services for People with Disabilities**

The most recent large community consultation process involving people with disabilities conducted in 2009 is the National Disability Strategy Consultation Report entitled “Shut Out: The Experience of People with Disabilities and their Families in Australia.”<sup>26</sup> The report states that many Australians with disabilities, along with their families, friends and carers are still experiencing systemic disadvantage in a system that is described as being broken. The report recommends a whole of government approach underpinned by a whole of life approach. The results of this consultation and the development of a national strategy is the introduction of the National Disability Insurance Strategy and the National Disability Insurance Scheme (NDIS). The NDIS is currently in a trial phase throughout many states of Australia and offers much hope for the future within the disability sector.

## **The Consultation Process**

The External Review Project Team felt it was imperative that people receiving and delivering services at the coalface in WA be the primary focus of the review process. To ensure the views of as many people as possible across key stakeholder groups were heard, the External Review Project Team undertook a number of surveys, held several focus groups and held face to face interviews. These consultation processes provided an invaluable source of data and information for the team.

### **Surveys**

The Survey was divided into three streams – current patients of the Quadriplegic Centre; staff of the Quadriplegic Centre and SRW; and people with SCI, their carers and service providers. Surveys were provided in an online format using the Survey Monkey tool, paper based surveys were provided to people who did not have access to email or the internet and a review team member was made available for a considerable period of time to assist residents or other people who did not have the physical capacity to complete a survey independently. To ensure the survey reached a broad range of people within the community, the links to Survey Monkey were posted on the Spinal Chatter Facebook page and the Spinal WA website, as well as emailed to a number of groups through key personnel contact lists.

Each of the surveys contained a number of common questions focussing on people's perceptions of the current model of care and services at the Centre, the common barriers to living in the community, best practice models, gaps in services and the continuity of care in WA. Participants were also asked to comment on the current state of the facilities and opportunities for improvement to services currently offered by the Quadriplegic Centre.

Response to the survey was varied with 48 people completing the staff survey, 15 completing the community response survey and only 6 completing the current resident survey. Graphs 1-6 on the following pages indicate the survey results for the key questions common to each of the survey streams (i.e. results from each survey combined into one graph) while other key results (Graphs 7-10) can be found in Appendix 1 of this report.

The External Review Project Team believe that while the number of survey responses from residents was not as high as would have been optimal; the resident focus group was well attended suggesting that this was a preferable method of providing feedback for many people.

### **Focus Groups**

In total there were four separate focus groups convened with stakeholders. The key target groups included staff of the Quadriplegic Centre (n=12), Quadriplegic Centre residents and their families (n=25), staff of the SRW (n = 20), and a community consultation including past residents, their carers and other interested people with SCI (n = 12). The staff groups were well represented across each discipline. Each of the focus groups was facilitated by several members of the review team and administrative support was provided by the NMHS.

The following key questions drove the focus groups discussions:

1. What are the barriers to people with SCI living successfully in the community?
2. What range of supports would someone with a SCI need to live comfortably in the community?
3. In an ideal world, what could the continuum (from hospital to life-long care) of services for people with a SCI look like in practice?
4. The current model of services offered at the Quadriplegic Centre is described as a medical model. If a design team were starting from scratch, how could the services the Centre delivers in the future have a more individualised and community feel to them?
5. How would you describe the positives and challenges of your stay at the Quadriplegic Centre?
6. What services do you think the Quadriplegic Centre could offer (or improve on) in the future?

The issues and key discussion points largely reflected the finding of the surveys. The focus groups helped to elaborate on the issues allowing people further opportunity to present their views and tell their personal stories, which only served to further highlight the issues raised in the survey.

## ***Interviews***

In order for the External Review Project Team to gather as many opinions as possible, across a broad range of stakeholders, we conducted simultaneous interviews at different sites. Two members of the review team were in attendance at the interviews and these were held during both the first and second site visits.

Interviews were conducted with senior staff of key organisations and government departments. The interviews whilst structured using pre-prepared questions, allowed for open conversation and good discussion on many issues faced by people with SCI. This allowed the External Review Project Team to develop a deeper understanding of how services are delivered to people with SCI and whether gaps existed in the current services offered; and enabled the team to gather views on potential future services, particularly in view of the impending introduction of the NDIS. Information gathered during interviews offered valuable insights into the current service system. The ideas and reflections provided by interviewees showed an overall commitment to improving outcomes for people with SCI.

## Key Findings and Themes

### 1. *'There are Gaps in Spinal Rehab Services'*

The majority of people participating in the consultation reported that services for people with SCI in WA are fragmented and that in any future service model, services and systems need to be much better co-ordinated and integrated.

On an individual basis most services were described as doing a good job and there was much praise for spinal rehabilitation services within WA. However, overall the consultation process showed that the continuum of care for people with SCI was incomplete with a resounding number of those consulted identifying multiple gaps in the continuum.

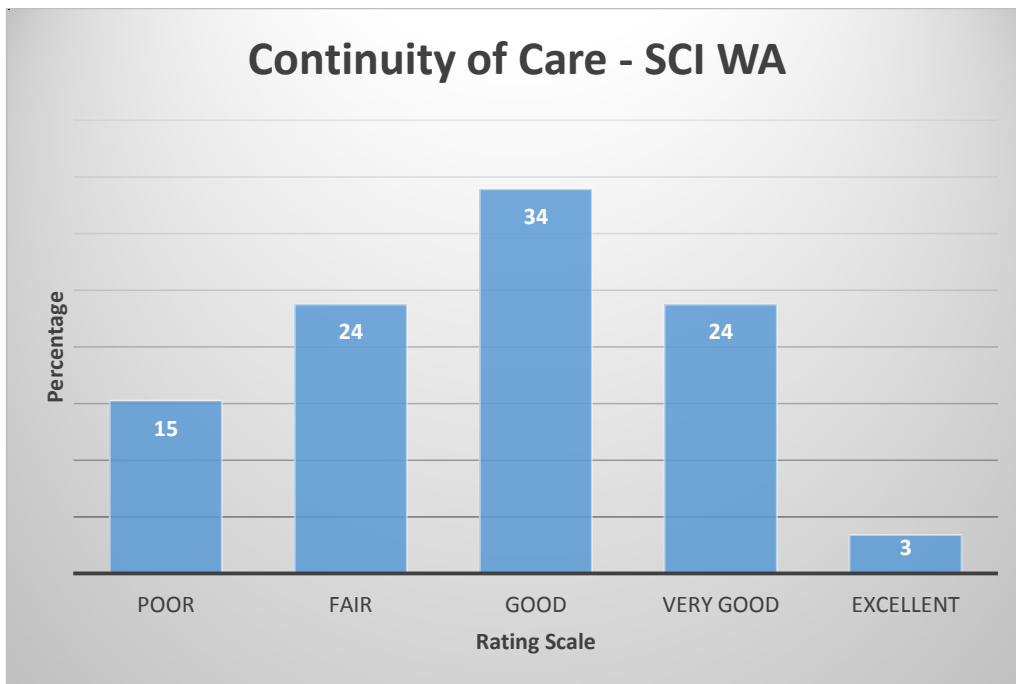
The quality of care provided at the SRW was described as excellent and it was felt that inpatient services provided a very good base for ongoing rehabilitation. However, all staff felt that they were limited by the lack of available SCI specialist community services. As a result most people with SCI are discharged for ongoing rehabilitation with the generalist community rehabilitation service Rehab in the Home (RITH). RITH is the only home-based rehabilitation service in WA and is available only in the metropolitan areas and for a maximum period of up to 6 weeks. From the consultation responses it appears that specialist SCI experience within RITH teams is generally fairly limited.

Following RITH many people continue for a short time in outpatient therapy but specialist spinal outpatient therapy services (at SRS, Fiona Stanley Hospital) are also time-limited and do not have the capacity to perform the type of in-home or community based functional training activities that most inpatient therapists saw as vital to allow a successful community transition. In addition, attendance at outpatient therapy appointments may be very difficult for people with SCI, particularly for those with high care needs and limitations with transport.

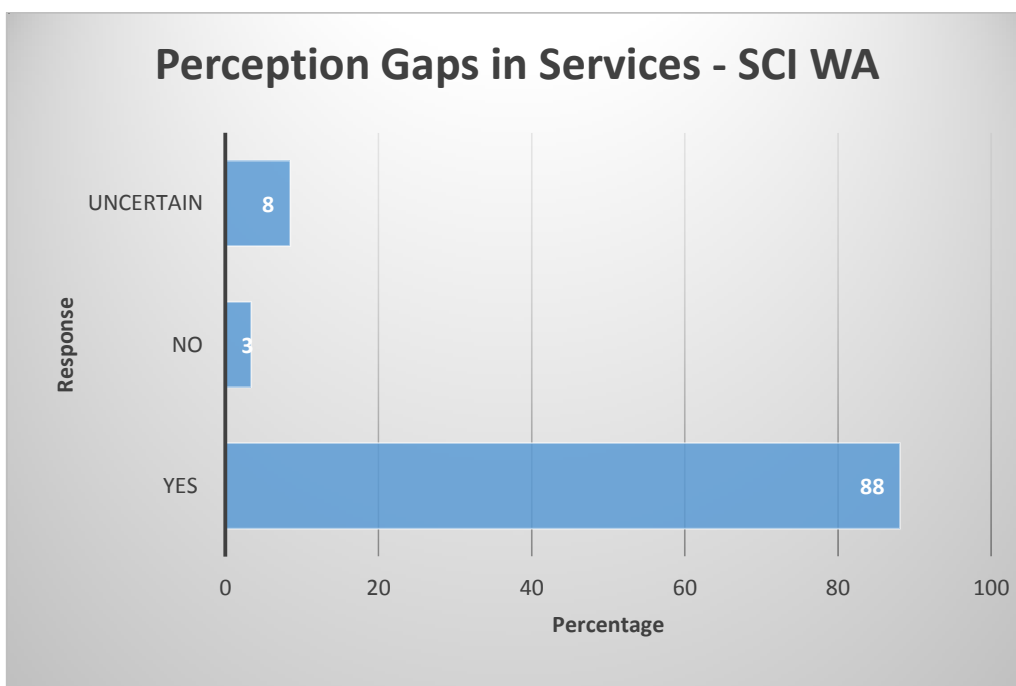
Access to other rehabilitation and therapy services with any degree of SCI knowledge and skills following discharge from hospital was generally thought to be very challenging. This included social work, occupational therapy, psychology, general medical and adequate nursing support.

Although the Quadriplegic Centre provides outreach services through its community nurses and this is seen as a valuable asset and the only specialist provision of services for these complex patients, it was also felt the community service was not closely enough linked to the tertiary facility of SRW. Although the services of the 2.5 full-time equivalent community nurses at the Quadriplegic Centre are available to people outside of the Perth metropolitan area, home visits were not possible in all areas of the state.

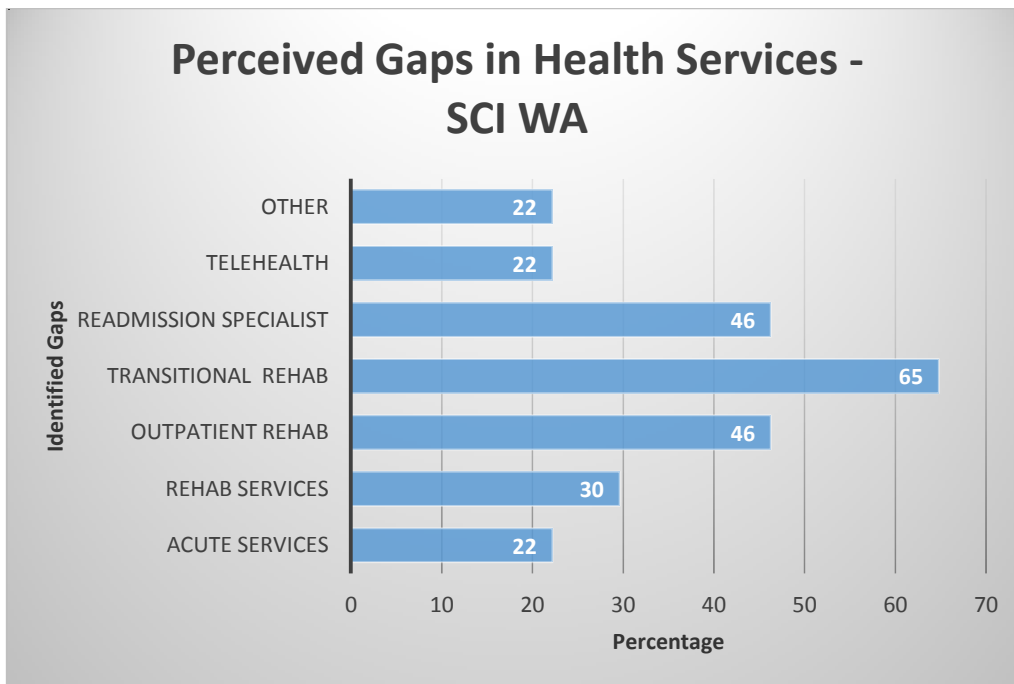
Overall, it was felt the absence of a multidisciplinary SCI outreach or community transition team in WA significantly impacts on the continuity of care following discharge. The review team was advised that a business case for outreach services had previously been submitted but had never received approval or funding. There was general consensus that the addition of specialist SCI transition and outreach teams to the SCI continuum of care would be highly beneficial and be a major step towards closing the existing gaps in the service model.



*Graph 1: Views on Continuity of Care for people with SCI in WA (n=59)*

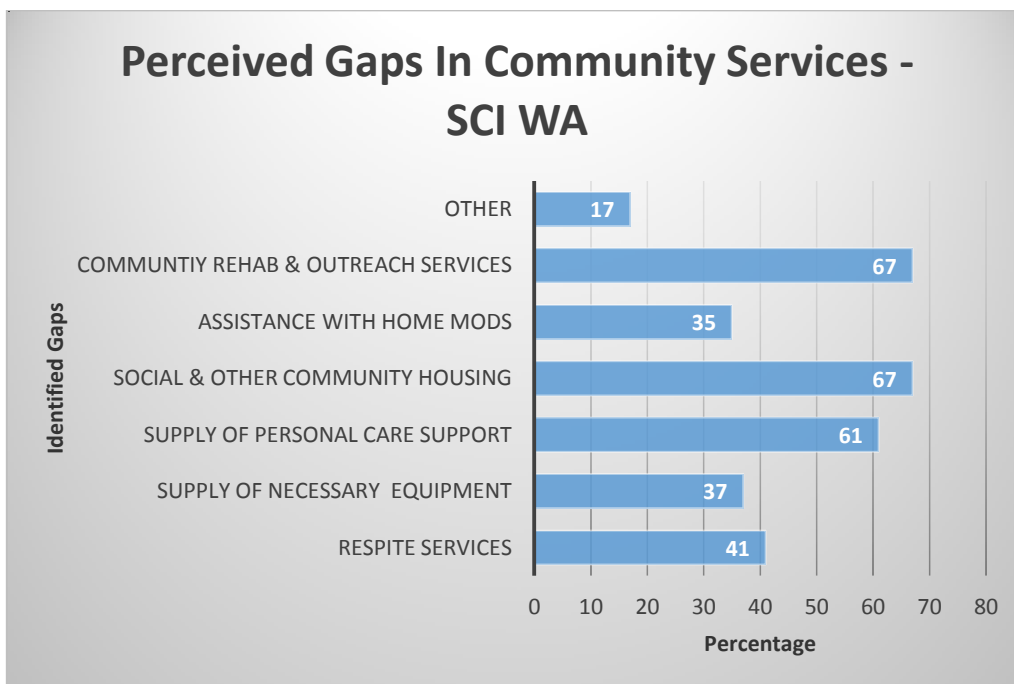


*Graph 2: Are there Gaps in Services in WA for People with SCI ? (n=59)*



**Graph 3: Where are the Gaps in Services for people with SCI in WA ? (n=59)**

(N.B. “Other” included: rehabilitation services outside of the metropolitan area, outreach services, transition between paediatric and adult services)



**Graph 4: Where are the Gaps in Community Services for people with SCI in WA ? (n=59)**

(N.B. “Other” included: staffing for ‘difficult patients’, services for those who have a diagnosis other than tetraplegia, return to work and recreation programs)

## **2. Barriers to Timely Discharge Home**

Consultations revealed that there were a range of issues that acted as barriers to timely discharge from the SRW.

As would be expected there are significant differences between the services offered following discharge for people with SCI who are compensable through compulsory third party (CTP) processes and those who are not.

Those who were non-compensable, were described as being left in limbo, having to wait long periods for the outcome of Disability Service Commission (DSC) applications in funding rounds that occur only once or twice per year. DSC funding was described by some respondents as “a lottery” and some individuals with SCI confirmed waiting up to 9 years for funding approval. People who were compensable usually had the opportunity to discharge home with a well-funded plan in place giving them access to appropriate levels of care, all of the necessary equipment and an accessible affordable housing option. However, while generally people with access to compensation seemed to be in a better position, there were occasions when, even for this group, admission to the Quadriplegic Centre was necessary because there was a delay in settlement of the claim or when CTP insurers did not provide advance payment for the costs of rehabilitation and personal care needs and so discharge from the SRW would be delayed.

When no personal care funding is available prior to discharge from the SRW, there are few other options available in the community available for people under 65 years of age. There are even fewer options for people over 65, for whom a Commonwealth funded care package is the only likely option offering a maximum of 12 -15 hours care / week. Recipients of these packages are unable to access the necessary equipment programs such as the Community Aids and Equipment Program (CAEP), as according to guidelines the equipment items are to be funded under their allocated Commonwealth package, which then in turn decreases the number of care hours available to a person. Many people feel as though they are in a ‘catch 22’ situation because of the requirement for a large variety of highly specialised and often expensive equipment to maintain their independence. Even when applications are successful, these Commonwealth funded services still fall far short of the hours needed to perform basic care requirements for someone with a SCI.

Throughout the consultation process, many nurses described their concerns regarding the inability of most personal care agencies to perform basic bowel cares for people with SCI thus causing extra strain on the community nursing services that were the only services able to provide these cares. This, in turn is seen as causing significant issues for people with SCI returning to the community as it adds a further layer of complexity to the co-ordination of care required between the care agency, community nurse and other care givers. This reduces the person’s ability to resume normal daily activities such as community access and employment.

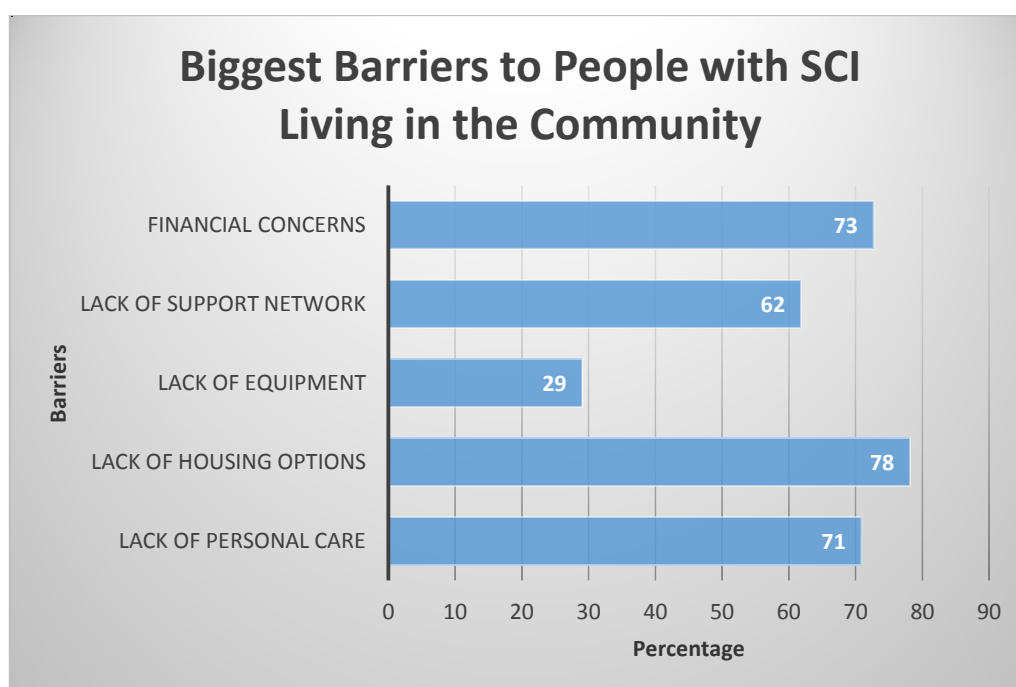
Another significant barrier exists when individuals are not able to return to their previous accommodation or require major home modifications to allow them to do so. For those people who do have suitable previous accommodation, there are some funds (but only up to \$10,000) available for minor home modifications. This amount will only cover fairly basic modifications resulting in people having to live in poorly accessible accommodation. For



people from rural and regional areas, home modifications are the responsibility of the local regional hospital and the timelines for completion of modifications are often much slower, which in turn delays discharge.

Where there is no long term accommodation at all in place, people are forced to wait for suitable and affordable housing through the private rental market or through social housing programs. Despite applications being completed in the early part of a patient's admission, priority listing for social housing can often mean a twelve month to two year wait. When this situation arises, people with SCI often have no choice but to transfer to the Quadriplegic Centre for ongoing care. However, this may not even be an option for people with paraplegia who may not meet the Centre's admission criteria.

During the consultation process many people noted that extended hospital stays often adversely affect the individual's mental health and wellbeing and that in many ways an individual's satisfactory discharge trajectory may depend on their own personal resources and finances.



Graph 5: What are the biggest barriers to people with SCI Living in the Community? (N=55)

### 3. Quality of Services at the Quadriplegic Centre

Historically there has always been a strong relationship between the Quadriplegic Centre and the Spinal Rehabilitation Ward, particularly so when the SRW was located at Shenton Park, opposite the Centre. The convenience of the location was a good selling point for people to transfer to the Centre. Residents would often return to the ward for outpatient therapy services which enhanced the services provided by therapists at the Centre. It was a collaborative approach and the liaison between the therapists was quite straightforward. As previously discussed the Centre's model was described by most as a medical model which provided comprehensive care to people with SCI. Some respondents however indicated that they felt that in recent years, the Centre had attempted to re-brand itself as an agency that utilises a more contemporary rehabilitative approach.

The majority of survey responses from residents described the services provided by the Centre as being good to very good but believed they were not adequately staffed to provide ongoing rehabilitation and therapy. The Centre's inpatient therapy was described as modest in nature but those consulted felt that the therapists worked extremely well with the people under their care. The supportive and social environment provided in the Centre was viewed as very beneficial. The views of Centre staff, in many ways mirrored that of residents and many positive features of this type of group living arrangement were described especially in terms of the peer and other supports available. However, it was acknowledged by some that there may come a point where disadvantages outweigh advantages and it becomes difficult for a person to envisage a life of outside this highly supportive environment.

While many people had many positive things to say about the Centre, there were also a considerable number who described the Centre as a large residential institution where there is a culture of isolation from the rest of the disability community. Also these people often felt strongly that the Centre was a completely inappropriate setting for young people and that people accept admission there reluctantly because it is viewed as the only service that can provide expert SCI management.

Unfortunately, there seemed to be a general feeling of hopelessness expressed by residents i.e. "you just can't do it on your own in the community". It was reported that people living at the Centre often give up applying for DSC support funding due to years of unsuccessful applications and now consider the Quadriplegic Centre as their permanent home. The following opinion was expressed by a respondent (past resident of the Centre) in the community consultation survey:

*"WA is failing miserably when compared to other states. There is no routine access to mental health and other allied health services for those living at the Quad Centre. You are not encouraged to live in the community and the only way you can get out is to get funded, which you are lucky to be able to do. There is no encouragement to live in the community, no peer support and no assistance outside of a clinical model. People with SCI are disconnected from the rest of the disability sector."*

Those consulted described the primary reasons for admission to the Centre as being a lack of availability of personal care options and/or a lack of availability of permanent accommodation. Feedback received revealed that few respondents routinely viewed the Centre as an option for ongoing transitional rehabilitation services. There have been no referrals from the Spinal Rehabilitation Ward at SRS to the Centre since November 2014 and staff at SRS discussed the increasing difficulty in convincing inpatients to accept transfer to the Centre. They reported that SRW inpatients who visited the Centre to have a look at it, described it as being dark and dingy and additionally, were frightened their application for DSC funding would no longer be seen as a priority because the Centre is considered a long term accommodation option. Whilst DSC confirmed to the review team that this would not be the case, anecdotal reports by staff and residents were at odds with this view. The other reported disincentive for transfer to the Centre is the financial one with the accommodation charges being around 85% of an individual's disability support pension.

The consultation process also revealed that a number a respondents felt that a centre such as the Quadriplegic Centre was required because, as people with SCI aged and could no

longer support themselves in the community (due to a lack of care), they would need somewhere else to live with support, on a permanent basis.

In summary, the majority of those consulted believed that following discharge from primary rehabilitation, some form of transitional rehabilitation services and accommodation should be offered but that this should not be presented as a one size fits all model. People felt there needed to be a range of options on offer to cater for people's varying needs and abilities.

#### **4. Better Peer Support Services**

Participants in the consultation process including people with SCI, their relatives and clinicians all expressed a clear view that "peer support" is very highly regarded and essential to those undergoing primary rehabilitation. Haas et al. defined peer support as "the giving of assistance and encouragement by an individual considered as an equal". Learning from peers has been described as vital in the context of rehabilitation and peer support along with social support in general, has been shown to be a key factor in accomplishing the adjustments necessary for living with a SCI."<sup>21</sup>

Currently there is one Peer Support Officer who works with inpatients undergoing primary rehabilitation in the Spinal Rehabilitation Ward. This service is funded by the Paraplegic Benefit Fund (PBF). There is no formal peer support program offered to residents of the Quadriplegic Centre however they definitely draw on each other's experiences for support. A Facebook page has recently been set up with the assistance of People With Disabilities, WA to assist with peer support and information sharing.

It was universally agreed that the development of enhanced peer support services would assist greatly in increasing the support for people with SCI in assisting them to reintegrate into the community.

#### **5. Advocacy and Information for People with Spinal Cord Injury**

It became evident in the early stages of the External Review that there was not one united strong advocacy voice in WA for people with SCI with a number of organisations variably involved. Respondents did not appear to see the Spine and Limb Foundation as a source of strong systematic advocacy for people with SCI. People with Disabilities WA is another disability advocacy group who mainly provide advocacy for individuals and some systemic advocacy. More recently this group has been assisting individuals who reside in the Quadriplegic Centre with advocacy issues.

Those who participated in the consultation frequently expressed the need for a "one stop shop" providing information for people with SCI. More recently the formation of the Spinal WA group is attempting to provide these services through their website. The site is being funded by Spinal Cord Injuries Australia NSW and operated by people with disabilities themselves and other volunteers.

#### **6. What the Current Residents of the Quadriplegic Centre Say**

Those who responded to surveys and attended focus groups (totalling over 50% of residents) consisted of people who were in a transition program, people awaiting housing

and support packages to enable a move into the community and people who were long term residents and have come to call the Centre home.

Of the survey respondents, 100% of people stated they did not expect to be at the Centre for as long as they had been. In short, although most originally saw it only as a stepping stone to community living, many had never made that transition. Half of respondents reported that they enjoyed living at the Quadriplegic Centre and indicated that the things they liked most were the security of care and accommodation and the quality of care provided at the Centre. The least liked aspect was the food provided.

Most respondents indicated that they often used the gym and allied health services and when asked about the quality of therapy services, they stated it to be in the very good to excellent range. The quality of care provided by the nursing staff was reported to be in the good to very good range. Some respondents suggested that higher staffing numbers were required during peak times of the day e.g. between 6am and 10am to accommodate the numbers of residents requiring care at that time and that the quality, experience, communication and training of staff in general, needs to improve.

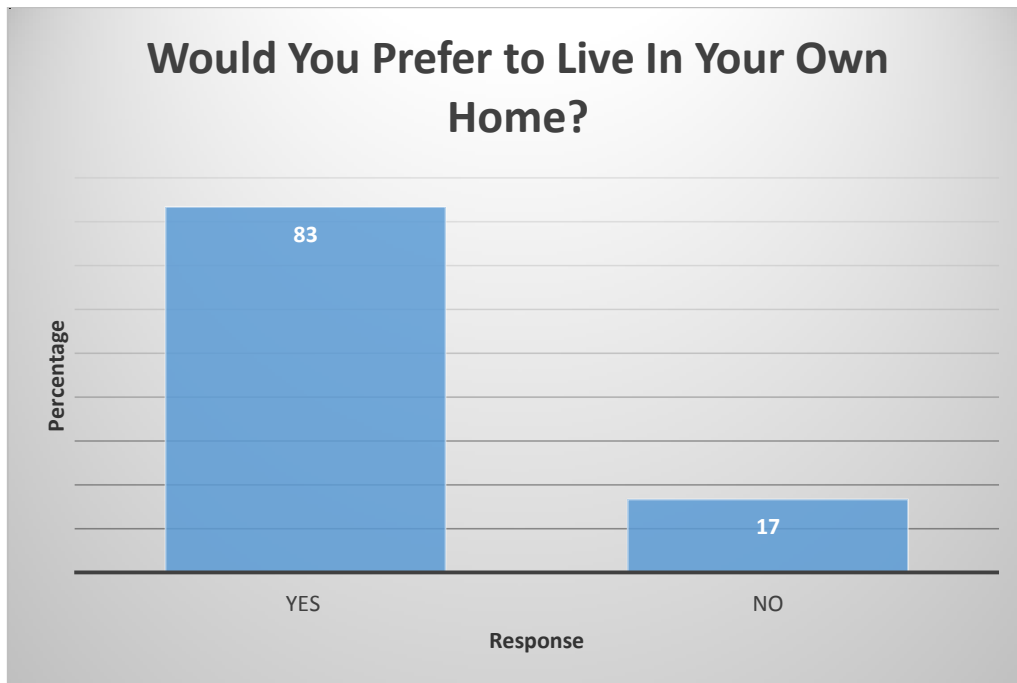
When asked about the quality of the facility, most people indicated it was in the poor to fair category. Other concerns raised included the lack of privacy and 50% of residents indicated that they felt they had very little choice and control over their own lives.

Residents described multiple barriers to living in their own home including lack of personal care funding and inflexibility of care options, no suitable and affordable accommodation and absence of any peer support. When asked what supports and services they thought they would need in addition to suitable accommodation and adequate support to live comfortably in the community, many people described the need for transitional accommodation and support between discharge from hospital and community living. They also indicated the need for specialised care and advice in the community regarding secondary health issues that arise as a result of their SCI, peer support and opportunities for social interaction.

Discussions during the resident and family focus group asked participants to comment on what services the Quadriplegic Centre could offer or improve in the future. Residents indicated they wanted better access to medical and dental services as these had been previously offered on the Shenton Park Campus prior to the move to the Fiona Stanley Hospital. They also described the need for more training for support staff, an improved understanding of resident's individual care needs and an overall improvement in the standard of care as they felt that the level and quality of their care fluctuated depending on the experience of the staff member providing the care.

If a rebuild of the current facility was imminent, residents indicated they would like a range of living options inclusive of individual units and shared and group accommodation. Generally, they liked the idea of staying on the Shenton Park site and described it as a good location, a safe suburb, with good access and close proximity to shops and transport. Residents related a number of personal stories which indicated a need for residential accommodation, particularly for people who came from remote towns with limited or no access to appropriate housing or care agencies.

The review team had extensive discussions with many residents and it was apparent that many had great difficulty imagining a life outside the Centre and also expressed a strong need for 24 hour care. Throughout the consultation process, many stakeholders expressed the view that some residents of the Centre were likely to be very “institutionalised” and felt that a move to community living would be difficult if not impossible after spending most of their adult life at the Centre.



**Graph 6: Living Preference of Current Residents (N=6)**

## Recommendations

In examining the information and data obtained through the consultation process, three key themes have emerged from the Quadriplegic Centre External Review Project:

1. The need for further enhancement of the model of care for management of SCI in WA and specifically to develop community transition and outreach services and create a contemporary, best practice continuum of care.
2. The model of care under which the Quadriplegic Centre operates is no longer contemporary and the facility itself beyond its useful life. Therefore the Centre should not be rebuilt but rather be devolved through offering the current residents a number of options to transition to more community based living arrangements.
3. The need for a coordinated whole of government approach to provide personal care, housing and home modifications, and health related services and equipment to all people with spinal cord injury in WA is essential.

The following recommendations are made based on the known evidence and established principles of SCI management as well as consideration of extensive stakeholder consultation, literature review of current research, contemporary practice and models of care and likely impact of emerging system developments including the introduction of the NDIS.

### Recommendation 1

***The External Review Project Team recommends an enhanced three-stage SCI Continuum of Care for the management of people with SCI in Western Australia (See Diagram 3).***

This new entity (with suggested name Western Australian Spinal Cord Injury Service - WASCIS) should be considered as one continuum with three distinct areas of service delivery under its umbrella. These three stages encompass hospital based primary rehabilitation incorporating outpatient services, community based transitional rehabilitation and a community based outreach service. The service will incorporate the Spinal Rehabilitation Ward (SRW), State Rehabilitation Service, the Transitional Rehabilitation Service (TRS) and the Spinal Outreach Service (SOS). (*NB: TRS and SOS are suggested names only*). The additional new services forming one SCI continuum of care would come under the governance of the State Rehabilitation Service, Fiona Stanley Hospital, SMHS. While the clinical components of the transitional and outreach services should be kept somewhat separate they could have a shared a management structure (e.g. Team Leader, Business Manager, Administration Officer's and Research and Development Officer).

***The Spinal Rehabilitation Ward, State Rehabilitation Service*** would have strong links to the new Transitional Rehabilitation Service; where patients and staff view the TRS as a natural progression in the rehabilitation process. The development of a community based transitional rehabilitation service has the potential to reduce length of stay in the SRW through earlier discharge. TRS staff would continue to work with the goals identified by the individual during their inpatient stay and in addition would develop new community goals. Members of the TRS team would be heavily involved in discharge planning and final goal

planning meetings to assist with a smooth transition from hospital to community. It is the responsibility of the inpatient SIU team to ensure that patients moving into the TRS are at the appropriate level of functioning and otherwise ready for transition e.g. necessary equipment prescribed and ordered etc. Rotation of some staff from inpatient services to the new community teams and vice-versa, to gain skills and experience in community SCI issues, would be highly desirable.

***The Transitional Rehabilitation Service (TRS)*** will provide community based rehabilitation to reduce length of hospital stay in the SRW and provide an efficient and effective program to assist individuals with SCI to return to independent and satisfying lives within their communities. TRS services involve clients undertaking transitional rehabilitation programs in their own homes. For clients living outside a reasonable TRS travel range, temporary accommodation (not likely to be more than 2 or 3 houses or apartments) will need to be offered in the metropolitan area. This accommodation is a core component of the TRS program and as such is the responsibility of the Department of Health (WA Health). However, if arrangements can be made with Department of Housing (DoH) to assist then this may be workable although the location of the properties involved must be stable. This accommodation could be purpose-built near the Fiona Stanley Hospital or acquired through the private rental market in the local area and modified for purpose.

TRS requires a full interdisciplinary team inclusive of nursing, physiotherapy, occupational therapy, social work, psychology and an appropriate level of rehabilitation medicine FTE to deliver time limited goal based rehabilitation. The TRS team is responsible for assisting people to achieve successful community reintegration and would also assist individuals discharged to residential aged care facilities by providing support to the individual and the facility staff. It would be worth considering travel by this team to remote and rural locations at the end stages of an individual's program to ensure successful transition to the individual's own community. It is important that the new community-based services of TRS (and SOS) offices are located in the community (rather than on the hospital grounds) but close to the SRW at Fiona Stanley Hospital.

***The Spinal Outreach Service (SOS)*** will provide a community based service, which supports people with spinal cord injury, their families and service providers throughout WA through consultancy and early intervention. SOS will provide direct clinical services, education and research. Education and training of local services providers managing people with SCI will be a key role. Outreach services are an efficient and cost effective method to reduce the human and financial costs of preventable complications after SCI. This interdisciplinary team is represented by each of the disciplines including nursing, physiotherapy, occupational therapy, social work, psychology, and shared positions with TRS that include an appropriate level of rehabilitation medicine FTE, administration, research officer and management structure. The research and development officer, particularly in the early stages of these new services will provide valuable feedback and advice on future development of processes and service delivery used within these teams. SOS is co-located with TRS which is both cost effective and allows an effective use of human and physical resources. This team will conduct regional visits throughout the year to rural and remote areas of WA. The potential for multi-disciplinary outreach clinics to the larger population satellite areas in WA should be considered.

The External Review Project Team also recommends that an appropriately staffed (e.g. Project Manager, Service Manager, Business Manager and Administrative Officer support) Project Implementation Team is established to ensure efficient and effective planning and implementation phases for the new community SCI services.

## **Recommendation 2**

***The External Review Project Team recommends the use of and development of an enhanced peer support program to deliver services across the SCI continuum (See Diagram 3).***

It was the clear and almost universal opinion of participants in the consultation process that peer support services in WA require further development and expansion to better meet the needs of the SCI community. Enhancement of existing or creation of new services is highly recommended and these services need to be available in all the components of the new WASCIS and work closely and collaboratively with WASCIS staff. An ideal model would include peer support in an inpatient setting and transitional rehabilitation and on an as needs basis as required throughout an individual's life.

Peer support in other states is highly valued as part of the multidisciplinary team approach. Whilst in most states of Australia peer services are operated in the non-government sector by peak bodies for people with SCI, a new peer support program would initially require seed funding from DoH to establish the necessary services in a timely way. A tender process for peer services in WA for non-government organisations such as Spinal WA or SLFI could be offered. Recurrent funding may be a consideration in a future NDIS model.

The External Project Review Team view peer support as an essential service component in any new model of service implemented in the future and in the devolution of the Quadriplegic Centre.

## **Recommendation 3**

***The External Review Project Team recommends the use of and collaboration with Rehabilitation in the Home services (RITH) for appropriate patients discharging from the SIU.***

WA Health has an extensive network of excellent RITH services and access to the intensive allied health services currently offered by the RITH teams would be highly beneficial for a range of people with SCI discharging from the SIU and participating in TRS. For example, ambulant patients who require higher intensity rehabilitation to achieve mobility related goals but no longer require in-patient management would benefit from this collaborative approach. For some people requiring intensive hands-on therapy, RITH will assist in improving rehabilitation outcomes following discharge and the new specialist SCI services would play a key role in providing expert advice, support and education to assist the RITH teams in the more specialised aspects of SCI rehabilitation. However, in addition to therapy services, people with SCI require access to specialist medical, nursing and other allied health services for support and education with other key needs including medical complications, psychological adjustment, sexual function and skin, bladder and bowel management. There is sometimes variability in composition of some RITH teams and there are no nursing services provided through this program. A collaborative approach between the new SCI



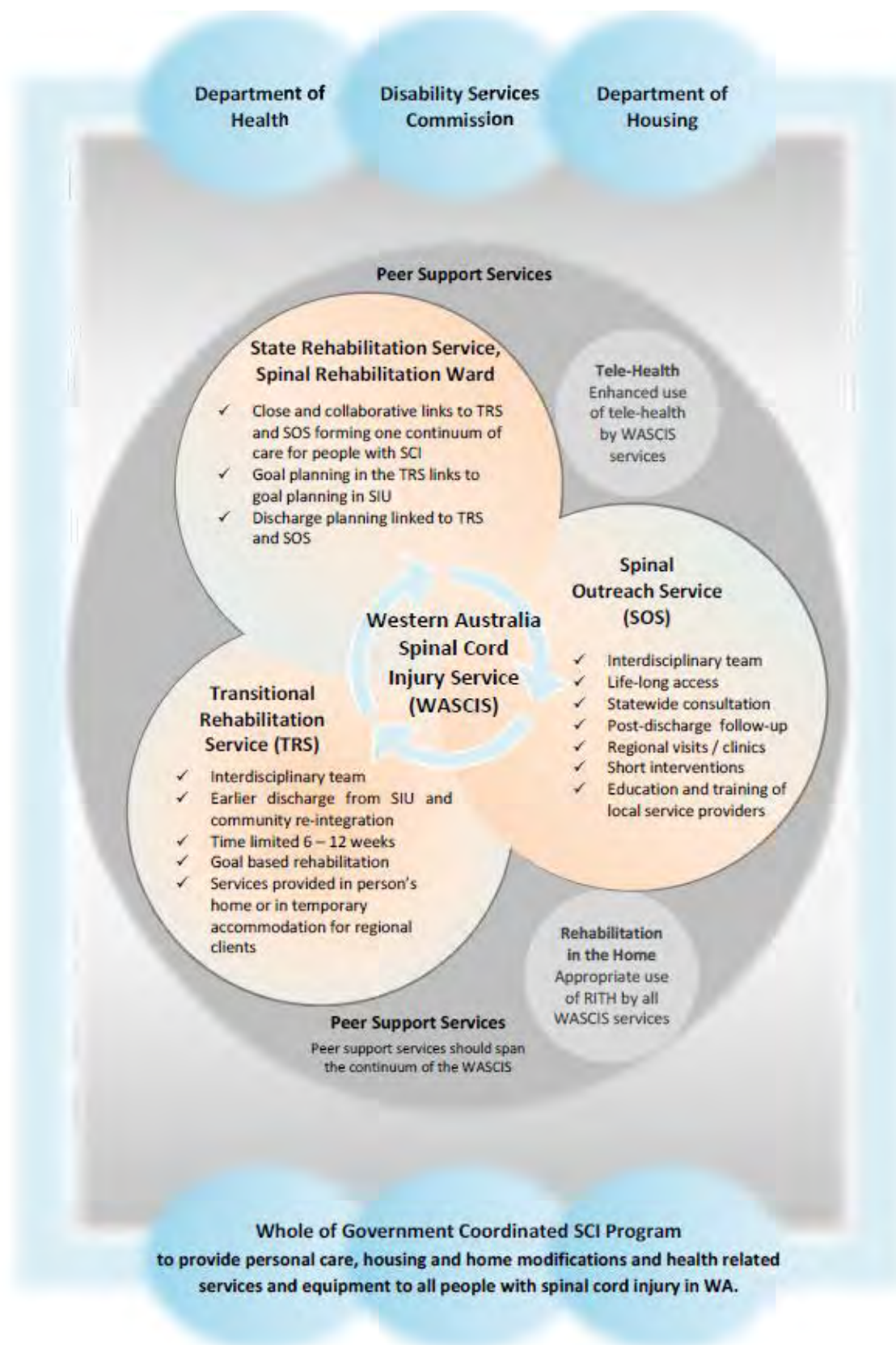
community services and the existing RITH team may enable earlier discharge from the inpatient setting.

The project team recommends close and co-operative consultation and liaison between the specialist SCI community rehabilitation teams and the RITH teams to ensure that appropriate therapy and rehabilitation is provided to people with SCI as necessary.

#### **Recommendation 4**

***The External Review Project Team recommends the use of the existing tele-health services by all components of the new SCI model as an adjunctive method of delivering services in more rural or remote regions.***

WA Health has a significant existing network of tele-health services in place throughout the state. All services within the new WASCIS continuum will investigate and maximise their use of tele-health (particularly video-conferencing) services as a method of ensuring the best possible outcome for their clients living in and transitioning back to more rural and remote areas of WA.



*Diagram 3: Proposed Model of Western Australia Spinal Cord Injury Services (WASCIS)*

## **Recommendation 5**

***The External Review Project Team recommends that the Quadriplegic Centre be devolved through offering the current residents a range of choices in accommodation options; wherever possible this needs to be a community based living arrangement (See Diagram 4).***

The Quadriplegic Centre describes their model of care as a medical model. The medical model dominated the disability sector until the 1980's and the emphasis in this model is on treating a problem that exists within an individual highlighting the impairment and not the person. Movement within the sector by people with disabilities has produced significant changes since the 1980's with a move towards approaches based on human rights and citizenship. These concepts imply an entitlement to services that empower people with disabilities to have equal access to the services that meet their needs.

Unfortunately, the model of care under which the Quadriplegic Centre operates is no longer contemporary and the facility itself is acknowledged by almost everyone to be in need of major upgrading. In view of this, the Project Team cannot in good faith, recommend a rebuild of the Quadriplegic Centre in its current form. Contemporary models suggest people with SCI require more flexible community living options based on the principle of choice.

The following choices should be offered to the current 51 residents:

### ***Choice 1: Independent community living in their own home***

- ✓ Independent community living in their own home or like residence with adequate personal support hours and the necessary equipment to fully participate in community life.
- ✓ Residents with existing families and/or other support networks should be able to return to their own home with appropriate modifications or if there is no current residence re-locate choosing the area in which they would like to live to enable them to utilise their existing networks.

### ***Choice 2: Shared Community living with Option A or B***

- ✓ Option A: Independent living in an apartment block (individual dwellings for each person) where the care could be shared across the individual tenants (e.g. a block of 6-8 townhouses). This style of accommodation allows individuals to be independent but still benefit from the support of their peers. This option is suitable for residents who do not require 24 hour care but require care at several intervals throughout the day.
- ✓ Option B: Shared Community living with a shared care option for those who do not wish to live alone. These should be small numbers of people (3 -4) living together in a home with individual private bedroom and bathroom facilities (similar to the residence Nulsen Haven currently located in Perth) and shared general living areas within a home in the community. The shared care in this arrangement could allow for 24 hour support within the home, allowing for overnight care for residents who require this type of support or need the assurance of a safety net of this kind.

Residents who opt for this option should have the right to choose with whom they live (e.g. their house mates).

- ✓ Personal care provision for both option A or B should be done through an open tender process with potential service providers assessed against predetermined standards. In this way, a number of different providers could be accessible through a Standing Offer Arrangement (SOA) or similar. Ideally, people living together in each home sharing care should be involved in selection of the care provider for that home. This could be facilitated through the SOA arrangement outlined above.
- ✓ Another possibility is that care could be sourced through existing Disability Services (DSC) processes. It is envisaged approximately four to five homes would be required to accommodate the current residents of the centre who do not opt for Choice 1 or 3. Ideally, these homes should be spread throughout the Perth metropolitan community but may be within close proximity to accommodate a co-operative care arrangement. Feedback from the focus group held with residents of the Quadriplegic Centre highlighted the strong desire of residents to remain within the Shenton Park area. Consideration should be given to locating a number of these shared living arrangements in the suburb of Shenton Park.
- ✓ People who require mechanical ventilation and are funded under the VDQ-CCP program could also access this option.
- ✓ The intention would be that, when no longer required these properties would be sold or could be re-purposed e.g. used by people with other disabilities for whom group living may be appropriate such as people with intellectual / developmental disability or acquired brain injury.
- ✓ Prior to commencement of any new building works, residents of the Quadriplegic Centre should be consulted regarding their choice in new living arrangements to ensure the configuration of any new build required meets the residents future accommodation needs.

### ***Choice 3: Transfer to a Residential Aged Care Facility***

- ✓ Transfer to a Residential Aged Care Facility should be considered for those who are age appropriate and do not wish to consider a community living option. This transition will require support for both the resident and aged care facility staff to ensure success.

## **Recommendation 6**

***The External Review Project Team recommends that a Reference Group / Steering Committee inclusive of a consumer representative is formed to drive the implementation of the recommendations in this report***

Forming a steering committee with representatives from the key agencies within the sector will ensure that the recommendations within this report are implemented in a planned way, considering the views of people with SCI and ensuring appropriate resourcing of an implementation plan. Membership should consist of senior representatives from each

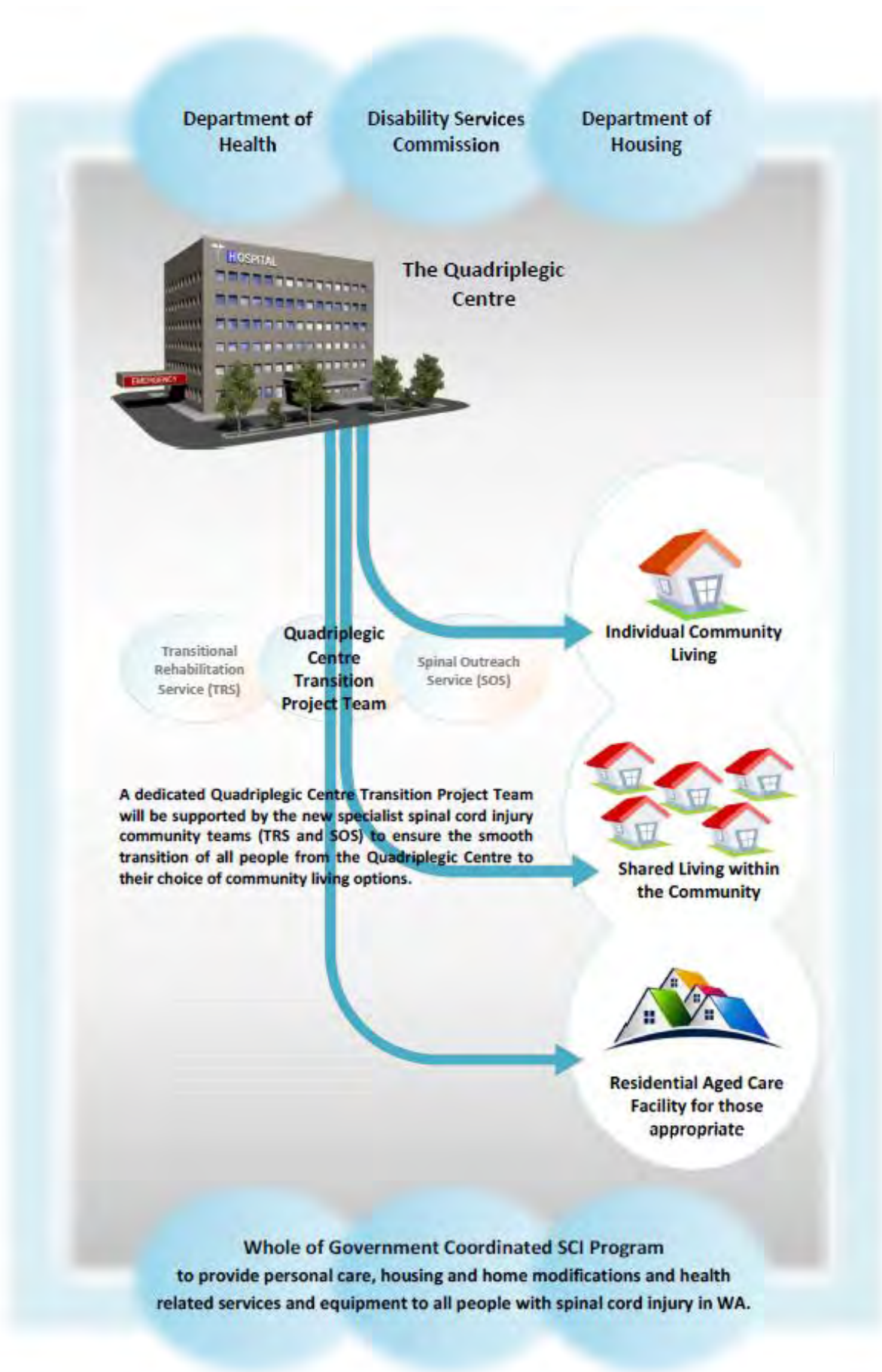
agency who have the capacity to make decisions at a strategic planning level and have the power to commit the appropriate resources. A consumer representative on this Committee is essential.

## **Recommendation 7**

***The External Review Project Team recommends the formation of a dedicated suitably resourced Project Team to establish and implement the Quadriplegic Centre Devolution and Transition Project.***

The External Review Project Team emphasizes the importance of adequately resourcing a Project Team to undertake the devolution and transition process. This will clearly be a significant and major change for these individuals, which will cause anxiety and distress for many and requires extensive change management expertise to ensure people have a smooth transition and positive experience and outcome.

The devolution process will require a comprehensive implementation plan to be effected by a multi-skilled team which should include people with skills in project and change management, health professionals preferably with knowledge of SCI, peer support officers and other support staff. Consideration could be given to recruiting suitable staff from the Quadriplegic Centre into some of these roles because the residents would be familiar with and have an existing rapport with these staff. This team will need to work closely, collaboratively and sensitively with residents through the planning and transition phases to ensure successful community integration.



**Diagram 4: Devolution and Transition of Residents of the Quadriplegic Centre**

## **Recommendation 8**

***The External Review Project Team recommends a co-ordinated whole of government approach to providing personal care, housing and home modifications, health related services and equipment to all people with a new SCI discharging from the SRW.***

The current barriers to discharge from the SRW have been clearly highlighted through the consultation process and include a lack of personal support and appropriate housing upon discharge from primary hospital based rehabilitation. Successful transition to the community requires an integrated and timely approach to meet the needs of people with SCI. Suitable housing and an adequate level of personal care funding will need to be in place prior to discharge from inpatient services to enable SCI community services to assist people to transition back into their local community.

A whole of government approach and coordinated program to provide personal care, housing and home modifications and health related services and equipment to all people with spinal cord injury in WA is essential and will require the collaboration of multiple government agencies to ensure the development of equitable and collaborative program guidelines.

Personal care programs should be tailored to an individual's needs inclusive of personal care support, domestic duties, meal preparation, rehabilitation and health maintenance, parenting responsibilities, community access and vocational and educational support hours. A suitable social housing property or funding for reasonable and necessary major structural changes and minor modifications to a person's long term accommodation should be allocated and completed prior to discharge. Whilst the current Community Aids and Equipment Program (CAEP) offered within WA appears to meet the needs of individuals it should be expanded to include electric beds and other technology items that promote an individual's independence and safety such as environmental control units and emergency call systems. Consideration should be given to the requirements of personal care agencies, whose health and safety policies may mandate height adjustable beds to accommodate safe manual handling practices.

Whilst the project team envisage the ultimate rollout of the NDIS will, in many ways meet many of these needs, the outcome of current NDIS trials is still unknown. An interim solution to meeting the needs of people discharging from the SRW is warranted.

## **Recommendation 9**

***The External Review Project Team recommends that a Clinical Nurse Consultant or other Senior Nursing position be created within the new spinal outreach service to provide services to people on the VDQ –CCP across all components of the WASCIS continuum.***

In addition to the usual specialist SCI services, people who are ventilator dependent require additional support in relation to respiratory management. The Spinal Rehabilitation Ward has recognised this need and currently has a dedicated nurse based in the Ward who assists with discharge planning, transition and management of ongoing community interventions for this group. It was unclear to the review team as to whether this role is currently a permanently funded established position. The project team recommends this position be

included within the multidisciplinary teams of transition and outreach services which will enhance collaboration with other disciplines in meeting the ongoing needs of ventilator dependent people in the community. This position will work across all aspects of the WASCIS continuum, providing support, education and advice during the discharge planning, transition and ongoing community management phases.

## **Recommendation 10**

***The External Review Project Team recommends consideration is given to providing early intervention vocational rehabilitation services across the SCI continuum of care.***

Currently in Australia return to work rates for people who have sustained a SCI are low compared to the general population. Given that SCI occurs frequently in young adults, return to work and study is highly important in achieving a successful return to community life. The level of disability and the previous work history often necessitates a change in vocation after a SCI. The benefits of employment are well documented with employment being related to better overall health, mental health, standards of living, and quality of life as well as increased social interactions, community participation and enhanced sense of purpose in life. A dedicated vocational rehabilitation service or program within the large SCI continuum providing advice and specialist support around employment issues, including being a pivotal contact point for employers of newly injured people with SCI would be an innovative and much needed addition to the proposed core services.

## **Recommendation 11**

***The External Review Project Team recommends that the VDQ-CCP program be reviewed particularly in relation to current funding eligibility and the need for a primary carer to reside with individuals requiring mechanical ventilation.***

Current guidelines for VDQ-CCP program limit individual choices with respect to community living options. People with high levels of SCI have the right to make the choice and should be supported to live within the community with adequate levels of personal care despite the lack of a primary carer. It is recommended that the guidelines be reviewed with respect to the need for an individual to have a primary carer in order to live in the community.

## **Recommendation 12**

***The External Review Project Team recommends that consideration should be given to undertaking discussions with NDIS / My Way to include the devolution of appropriate residents from the Quadriplegic Centre as a “pilot program” for NDIS implementation in WA.***

The Quadriplegic Centre Devolution and Transition Project has many elements that are core features of NDIS implementation and consideration should be given to whether this Project could be adopted as a “pilot program” in NDIS implementation.

## **Recommendation 13**

***The External Review Project Team recommends a comprehensive review of rehabilitation services for children with SCI in WA.***



Whilst the review of children's services was not within the formal scope of this project it is evident there needs to be a more clearly defined pathway for transition from paediatric to adult SCI services. There is particular disparity between the paediatric CATCH program and the adult VDQ-CCP and a strong argument can be made for the need for outreach services that have expertise in paediatric SCI. The staff of the Paediatric Rehabilitation Services at PMH are passionate about ensuring the voices of children and their families are heard and positive change occurs in the future for children with SCI. The project team recommends and supports a comprehensive review of rehabilitation services for children with SCI in WA.

## **Recommendation 14**

***The External Review Project Team recommends consideration is given to assisting community based personal care agencies to develop the necessary competencies to be able to perform invasive procedures such as bowel therapy.***

An important issue raised by nurses during the consultation process highlighted the fact most personal care agencies do not have staff who are competent in the task of administering bowel therapy. Often this procedure has to be performed by (HACC funded) community nursing agencies and this may complicate the timing of people's morning personal care routines e.g. people have to wait long periods of time for a nurse to be able to attend and provide assistance with administration of bowel therapy. This situation may be exacerbated in the future and put a strain on community nursing services especially as the Quadriplegic Centre Devolution and Transition Project commences and there are a large number of people moving to community living.

It is recommended that this issue be further explored and discussions undertaken with key personal care agencies in relation to developing competencies for invasive procedures such as bowel care involving administration of enemas, suppositories and the manual evacuation and digital stimulation procedures.

## **Recommendation 15**

***The External Review Project Team recommends that further consideration is given to the interim accommodation needs of people with SCI and that, in addition the WA Patient Assisted Travel Scheme (PATS) is reviewed to ensure that funding allowances under that scheme are sufficient to support the requirements of people with SCI.***

The Quadriplegic Centre has played a role over the years in providing short term interim accommodation for people discharging from the SRW and for those individuals from regional and remote areas returning to Perth for outpatient review.

In the future, Individuals who have completed their primary inpatient rehabilitation but are unable to discharge home because their community accommodation and/or personal care is delayed may still require an interim accommodation and care option, although it is difficult to predict how much of a problem this is likely to be in future. If required, the proposed shared care community living apartments (Choice 2: Option A) could be used for this purpose when a vacancy exists.

People with SCI returning for outpatient services should be encouraged to maximise the funding available through the Patient Assisted Travel Scheme (PATS) and the scheme

needs to be sufficiently resourced to support their needs. However, this group may also require access to this interim accommodation option should a vacancy exist.

The project team would hope that, in the future the combination of a well-functioning Whole of Government Co-ordinated SCI Program / NDIS model, which provides accommodation and care packages available at the time of discharge from hospital and a well-functioning PATS to adequately support non-metropolitan clients, would mean that interim accommodation options should rarely be required.

## **Recommendation 16**

***The External Review Project Team recommends that further consideration is given to an appropriate future model for the provision of respite services for people with SCI in WA.***

The Quadriplegic Centre currently provides respite services on an as needs basis for people with SCI in WA although the usage of this service has not been great in recent times.

The review team envisage a reduction in the need for “physical” respite beds in the future as people with SCI receive appropriately funded personal care packages which include in-home respite services, either through the Whole of Government Co-ordinated SCI Program or NDIS models.

For the small percentage requiring respite (outside of an in-home respite option) consideration should be given for the use of the shared care apartments (Choice 2: Option A) where there is unused capacity.

## **Recommendation 17**

***The External Review Project Team recommend that the initial work being undertaken by the Spinal WA group, to ensure that specialised information and education is available to individuals with SCI, their families and service providers be encouraged and supported and that other key SCI services providers review their own methods of communication and websites to ensure that they are providing the information that people with SCI are requiring.***

Another common theme in feedback from the consultation process was the difficulty in accessing a broad range of current, specialist SCI information and education material in relation to their particular needs. Individuals with SCI and service providers all stressed the importance of ready access to this kind of information but indicated that it was often not easy to find in WA.

The review team acknowledge the work already being undertaken by the Spinal WA group. Spinal WA <http://spinalwa.org/> is a new initiative providing a central information point and bringing together agencies and stakeholders in WA with an interest SCI to work collaboratively and enhance communication between organisations and the spinal injured community.

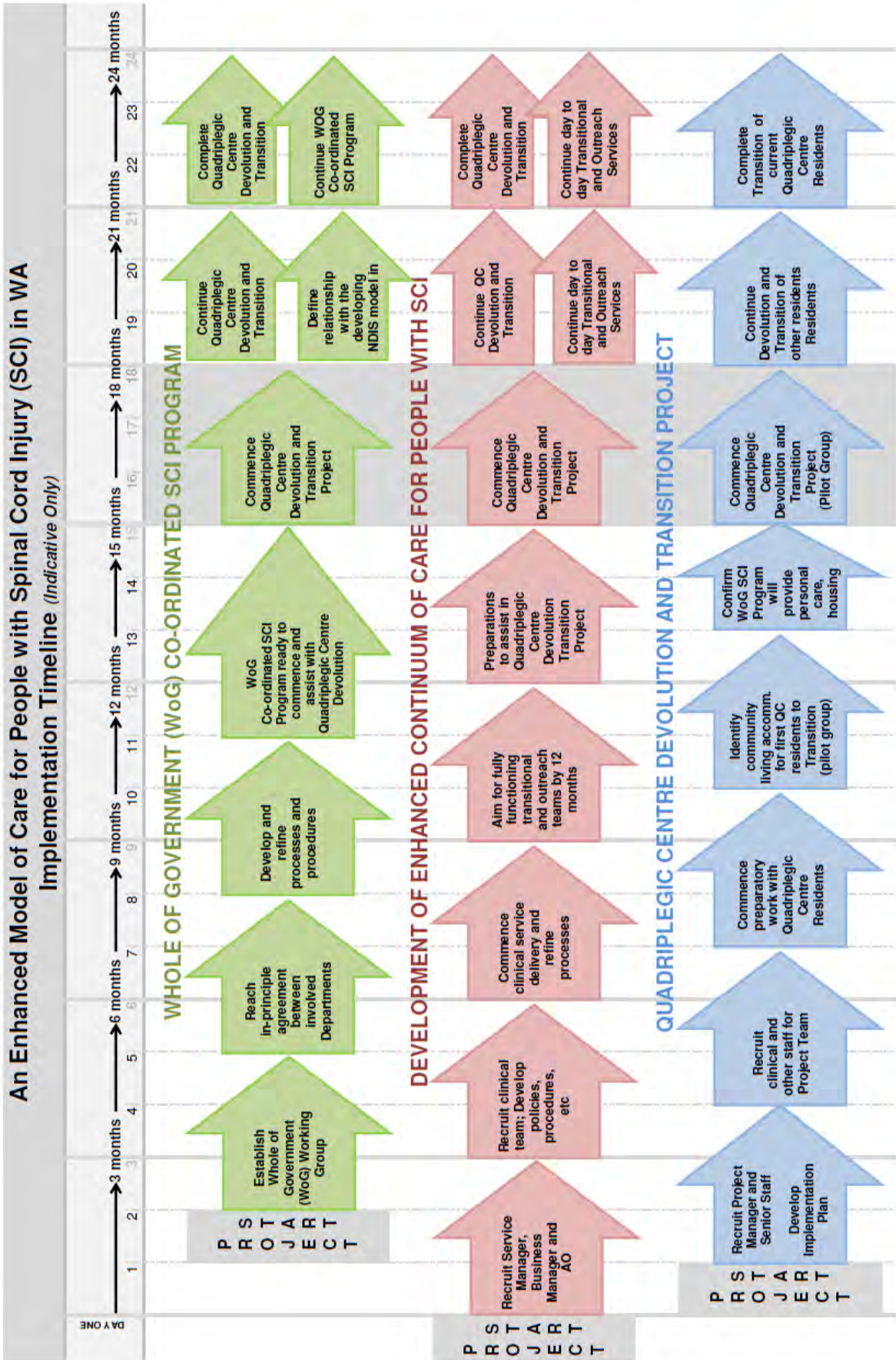
## Implementation

While providing detailed advice regarding implementation of any of the recommendations in this report is outside the scope of the report, the External Review Project Team provides the following information to emphasize the intersection and interdependence of various sub-components of the proposed Project (See Diagram 5).

The key features with respect to implementation include that:

1. The new WASCIS community based SCI clinical teams need to be established first, have time to develop processes and skills and will then form an essential element of the Quadriplegic Centre Devolution and Transition Project when transition of residents to other living arrangements actually commences.
2. The Quadriplegic Centre Devolution and Transition Project will also need to commence relatively early as development of a detailed Project Implementation Plan, recruitment of staff and preparation for transition of current residents will be required. Actual devolution of residents will not occur until the SCI community teams are established.
3. Negotiations between departments to establish the Whole of Government Co-ordinated SCI Program and the relationship to current and future NDIS services are likely to be complex and also need to commence early as a functioning collaborative model will need to be in place to enable residents to move as part of the Quadriplegic Centre Devolution and Transition Project.

Diagram 5: Implementation Timeline (Indicative Only)



## Conclusion

Since Sir George Bedbrook opened the first SIU in Perth in 1954 and revolutionised the management of people with SCI in Australia, WA has been at the forefront of the provision of high quality SCI services in Australia.

However, while there have been many advances in the acute medical and inpatient rehabilitation management of SCI over the past five decades in Australia, unfortunately the development and appropriate funding of services and support for people with SCI when they return to community living has often lagged behind other advances. In many areas, there is still a situation where adequate and necessary equipment and support services for people living with SCI are insufficient and not available when and where they are needed. Too often, people with a disability are without the services and equipment that are necessary to enable full participation in social, work and family life. These gaps in services for people with SCI were clearly identified by participants of the consultation process for the External Review.

It also became clear early in the External Review process that, while pockets of advocacy do exist, particularly at an individual level, there is no one strong voice advocating for the needs of people with SCI in WA. Perhaps for this reason as well as others, change within the disability sector (and particularly in relation to SCI) seems to have been slow and the traditional approaches to service delivery have not developed into contemporary service models. The Quadriplegic Centre, although valued by many, is an example of where changes in service delivery approaches have not realised their full potential.

The overall aim of the External Review Project Team has been to review the existing service model including the Quadriplegic Centre and to make recommendations to ensure that WA continues to provide best practice, contemporary and evidence based services for people with SCI for the foreseeable future.

The recommendations have been made based on extensive consultation with key stakeholders, review of the research literature and evidence base and current knowledge of best practice and review of existing SCI service model in Australia and New Zealand.

Three key themes have become evident during the course of the review project and recommendations have been made related to each theme.

1. A Whole of Government Approach and Coordinated SCI Program to provide personal care, housing and home modifications and health related services and equipment to all people with spinal cord injury in WA is essential and must be established as soon as possible.
2. An Enhanced Continuum of Care for the clinical management of people with SCI in WA - the Western Australia Spinal Cord Injury Service (WASCIS) is required and specifically the development of transitional rehabilitation and community outreach services. The new continuum requires improved collaboration with, use of and enhancement of other key services including a peer support service, telehealth and telerehabilitation services and vocational rehabilitation services.

3. The Devolution of the Quadriplegic Centre and Transition of Current Residents to Other Community Living Arrangements is recommended.

The review team acknowledges that the introduction of the NDIS will bring positive outcomes for all people with disabilities, changing the landscape of service delivery options in the future. Implementation of the scheme is planned for 2019 however the trial sites are still in their infancy. At this time, there is only one person with a SCI in the current trial sites. Many of the recommendations provided in this report will assist in preparing the health sector for transition to an NDIS model.

The External Review Project Team hope that this report and the implementation of its recommendations will, not only provide a blue print for the development of future services that will enhance health and lifestyle outcomes for people with SCI living in WA but also position the state as a future leader in the provision of services to people with SCI, not only in Australia but internationally.



## Similar beginnings...different journeys (continued)

“ *D's Story (continued)*

*Instead of a review being undertaken to assess why this was happening I received a phone call from the local OT stating that the supplier had told her that I was over inflating the cushion, so I proceeded to let air out of the cushion, little did I know what was to unfold next.....*

*Within 3 months I had developed a bursa (pressure sore) underneath my skin and as I had since split with my girlfriend, I was forced to go to the Quad Centre for 3 months.*

*The care I received was good and the OT there discovered that I had been sitting on the canvas of my wheelchair bottoming out because I had been given poor advice regarding the inflation of the cushion. The OT at the Quad Centre completed a review for which I am eternally grateful but the damage was done, and my skin continued to breakdown.*

*Eventually I was admitted to the Spinal Unit for a surgical procedure to help heal my pressure sore, it took 6 lots of surgery and 6 months in hospital and a further 12 months at home in bed with my skin continuing to break down. It took a long time but I now have a seating system that works for me and allows me to be up in my chair for 8 hours or more and to function as a human being again.*

*I believe a red flag should have gone up at the first problem I was having with my cushion, prompting an extensive review of my seating. If I had received the correct information and treatment, all of the issues that followed would have been avoided and it would have saved the Health Department tens of thousands of dollars in unnecessary hospitalisation, not to mention I would still be working in a role that I loved and was employed in prior to my injury.*

*I would like to say that I think everyone did the best they could at the time with the resources they had but I don't for one second believe that more couldn't have been done to avoid this type of situation from eventuating in the first place. We need to support people in the community to prevent this type of issue happening and help maintain quality of life. An outreach service with spinal specialists could have given me my life back a lot sooner.*

“ *H's Story (continued)*

*After my rehab was finished I lived with Mum and Dad just outside of the city.*

*Heading home was somewhat of a scary thing to do but I had help from the transition team initially and then access to the outreach service when I needed it. They helped me to find ways to get in and out of my local pool, helped me to get my license, get back in the gym and to try out a hand cycle.*

*I fell in love with riding and did it every day. I started to race at a state level and the last round of the national titles. I was lucky enough to get selected as a development rider to head over to Europe with the Australian team to learn the ins and outs of hand cycling. Since then I have competed on the national circuit every year and I am in the top 3 for my classification.*

*Apart from my cycling I soon got a job in an office in the city working as a sales assistant. After that I started to personally coach a few of the professional motocross riders competing in the National circuit. I am now about to commence studying at university to become a civil engineer; it's a four-year course and can't wait to get into it.*

*Life is awesome!! I've moved out of home and live in an awesome place, I now have an awesome girlfriend, I have awesome friends and a great family. With the support of the community teams, my family and friends, my spinal cord injury has made me into the man I am today and I wouldn't change a thing!*

”

The above stories are of two young men who sustained a spinal cord injury in the same month, in the same year and had a very similar levels of injury but whose journey's after their spinal cord injury were very different.

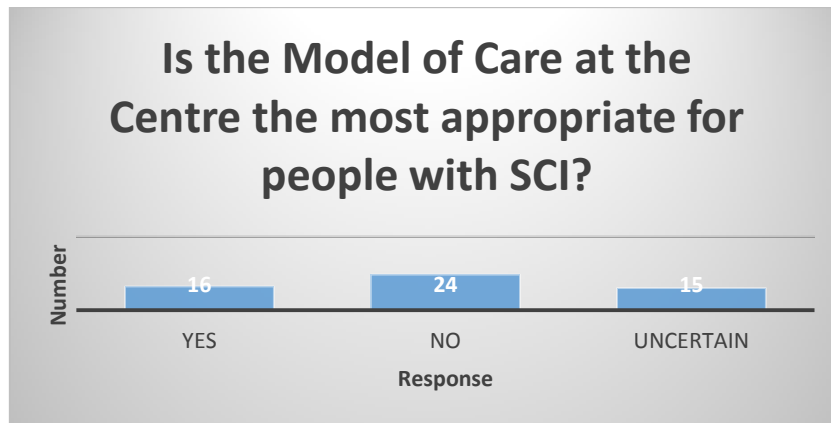
While there are clearly many and varied interacting factors that contribute to a path of a person's life following spinal cord injury, these stories are presented here to illustrate the possible roles and benefits that specialist multi-disciplinary community spinal cord injury services may play in that journey.

One man was injured where there was good access to these types of services and one was injured where these services do not yet exist.

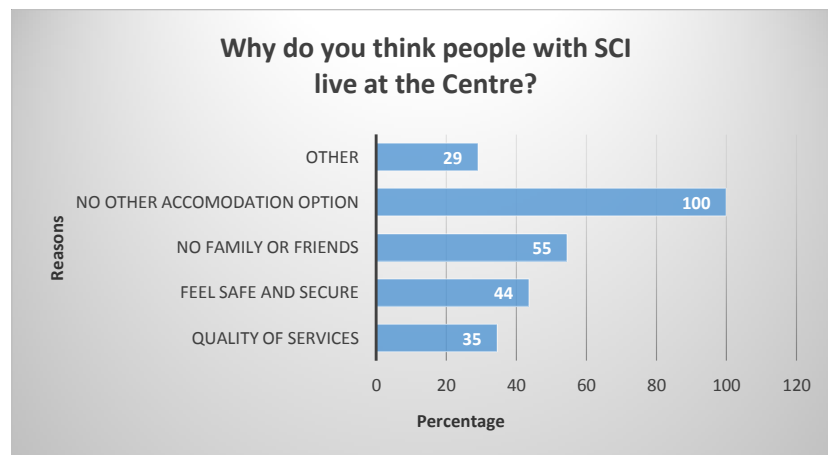
These are their own words and have not been altered or edited.



## Appendix 1 – Other Survey Results

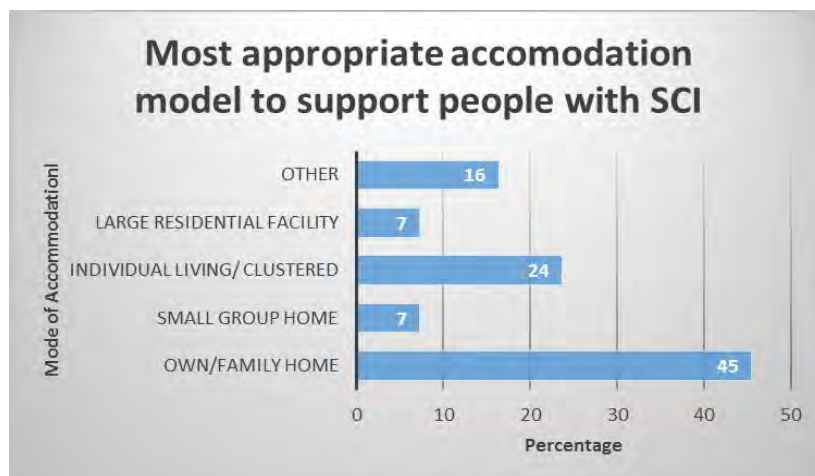


**Graph 7: Appropriateness of Quadriplegic Centre Model of Care (N=55)**



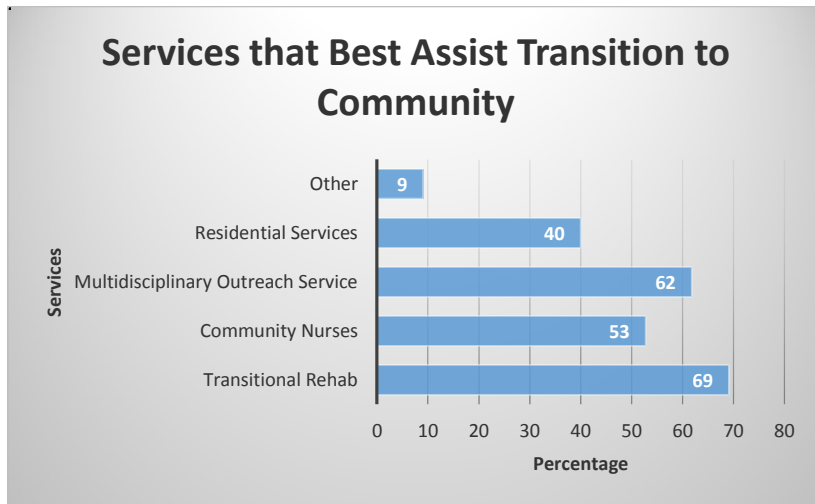
**Graph 8: Reason for Living at the Quadriplegic Centre (N=63)**

(NB: "Other" includes: all of the above responses, trained professional staff, awaiting DSC package, to develop relationships with other patients, insufficient care)



**Graph 9: Reason for Living at the Quadriplegic Centre**

(NB: "Other" includes: No one right category, all of the above)



**Graph 10: Services that Assist Transition to the Community (N=55)**

*(NB: "Other" includes: transitional houses, assistance to modify home and provide care, better peer support models)*

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