Canadian Paraplegic Association (Alberta)

Client Services Program Design

2014

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1.0 Introduction

The Canadian Paraplegic Association (Alberta)'s mission is to assist persons with spinal cord injuries and other physical disabilities to achieve *Independence*, *Self-Reliance* and full *Community Participation.* CPA (Alberta) strives to achieve its mission and provide the best service possible through a focus on six core service areas which include: Rehabilitation Support and Service Coordination; Community Development and Systemic Change; Aboriginal Services; Peer Program; Information Services; and Active Living.

CPA (Alberta) supports its clients through many challenging transitions, including relationships, sexuality, parenting, aging, recreation, education, employment, etc. Through committee participation, CPA (Alberta) also assists communities to become more inclusive by creating awareness of critical issues such as accessible transportation, housing, healthcare and other supports.

This program design is focused on the area of Rehabilitation Support and Service Coordination.

2.0 The Need

Although it is difficult to get exact numbers around the number of people with spinal cord injury (SCI) across Canada and within Alberta, there are a number of studies that have estimated the numbers of both traumatic and non-traumatic SCI rates.

2.1 Prevalence rates of SCI in Canada

The World Health Organization estimates that Canada has a nationwide prevalence of SCI (as of 2010) of 85,000.[1] Similarly, the Rick Hansen Institute has estimated that the overall prevalence of spinal cord injury in Canada is 85,556 people.[2]

According to the Rick Hansen Institute, 51% of Canadians living with a SCI, experienced the injury as a result of a traumatic injury, such as a motor vehicle accident, fall, or violence. The rest are a result of non-traumatic injuries, resulting from chronic health conditions such as, infectious or inflammatory disease, a tumor, or a health disease that may be congenital, metabolic, vascular or developmental. However, it is important to

[1] World Health Organization (2013)
[2] Rick Hansen Institute (2010)

keep in mind that estimates for non-traumatic injuries are intentionally conservative as exact data for these numbers is not available.[3]

2.2 New cases of SCI in Canada

There are approximately 4,259 new cases of spinal cord injury in Canada every year.[4] Of these, 42% are estimated to be a result of traumatic injury and 58% as a result of non-traumatic causes.[5] After sustaining the spinal cord injury, approximately 3,675 of these individuals are discharged from the hospital.[6] The remaining individuals die at the time of their injury or before they are discharged from the hospital. Of the 3,675 discharged, 1,389 suffered from their SCI as a result of traumatic injury and 2,286 because of non-traumatic injury.[7]

2.3 Prevalence and new cases of SCI in Alberta

Based on data collected from the Alberta Ministry of Health and Wellness, records from the Alberta Trauma Registry, and death certificates from the Office of the Medical Examiner collected between April 1997 and April 2000, the annual incidence rate in Alberta is estimated to be 52.5/per million, and the number with spinal cord injury that are discharged from hospital is 44.3/per million/year[8]. In a more recent study, the authors found that 146 patients with a SCI were admitted to hospitals across Alberta each year.[9] Motor vehicle accidents account for 56.4% of the injuries, followed by falls, which account for 19.1%.[10]

2.4 Demographics related to SCI

Generally, the occurrence of spinal cord injuries peaks at two points over the life course. The first peak is during young adulthood, when traumatic SCI resulting from motor vehicle or sporting accidents are the most common. The second peak occurs during old age (around 70 years old) when non-traumatic SCI resulting from chronic disease is common.[11]

On average, injuries among males are higher than among females.[12] A study looking at the hospitalization rate for SCI between 2006-2008 found that on average, males with SCI outnumbered females 4 to 1.[13]

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[3] Rick Hansen Institute (2010)
[4] Rick Hansen Institute (2010)
[5] Rick Hansen Institute (2010)
[6] Rick Hansen Institute (2010)
[7] Rick Hansen Institute (2010)
[8] Dryden et al (2003)
[9] ACICR (2010)
[10] Dryden et al (2003)
[11] ACICR (2010)
[12] Dryden et al (2003)
[13] ACICR (2010)

Moreover, SCI will vary according to geography. In particular, individuals living in rural areas are more likely to suffer from SCI compared to those living in urban areas. In fact, rural residents in Alberta are 2.5 times more likely to have an SCI compared to urban residents.[14] However, because of the number of people living in urban compared to rural areas the absolute number of individuals with an SCI in urban areas is still larger those in rural areas.

Injuries may also be associated with a particular industry in a region, such as combat services.

2.5 Needs of newly injured persons transitioning to community

A number of needs related to individuals' transition back to their community after a spinal cord injury have been identified, including:

- Mental health services
- Access to assistive technology
- Economic support
- Services related to employment
- Services related to education
- Services related to housing
- Peer mentoring
- Support for families and caregivers of those who are injured

Supports and services can help to reduce the dependency that can result as a consequence of spinal cord injury and support individuals' re-integration back into their community.[15]

However, it is important to keep in mind that the needs of the individual who is living with a SCI will vary greatly, especially according to:

- The age at which the injury occurred
- The severity of the injury
- The availability of resources and services
- The environment in which the person lives (i.e. urban versus rural, physical, social, economic, attitudinal).[16]

2.6 Mental Health and Wellbeing

According to the World Health Organization 20-30% of individuals with a SCI display significant symptoms of depression worldwide. Similarly, another study found that

[14] Dryden et al (2003)
[15] World Health Organization (2013)
[16] World Health Organization (2013)

depressive symptoms were present for 31% of their sample.[17] In addition to depression, people with SCI have been found to suffer from higher rates of post-traumatic stress, alcoholism and anxiety after their injury.[18]

In a survey of 1,137 Canadians who suffered from a traumatic injury, 42% suffered from a mood disorder (occasionally or frequently) in the first year to 7.5 years after their injury. Although the number goes down over the years, even after 30 years of living with a SCI, 23% of individuals still reported suffering from a mood disorder.[19] Moreover, of the 412 individuals who suffer from non-traumatic injuries, 48% suffered from mood disorders in the first year up to 7.5 years after their injury. Moreover, only 52% of people surveyed were 'satisfied' or 'very satisfied' with their psychological health.[20]

Attitudes toward people with disabilities, social supports, and socioeconomic status can all affect an individual's psychological wellbeing.

2.7 Assistive Technology/Equipment

Having access to assistive technology/equipment, such as wheelchairs, is also an important consideration in an individual's successful transition back into the community. Wheelchairs, environmental control systems and computer technology are the most important assistive technologies to consider when thinking about transition to independent living for an individual with a SCI.[21] Additional devices may include communication devices (such as communication boards, speech amplifiers, speaking valves etc), self-care devices (bathing and showering, grooming, toileting, dressing, eating and drinking), devices to assist with domestic life (including modified kitchen utensils) and environmental control units (remote controls that can be activated by head position etc).

In a survey of 1,137 Canadians who suffered from a traumatic injury 93% of people surveyed reported needing adapted equipment.[22] Of the 412 Canadians surveyed after a non-traumatic injury, 82% expressed a need for adapted equipment.

2.8 Poverty

Not only can SCI impair an individual's ability to work but the ongoing access to medical care, rehabilitation programs and assistive technologies means that the costs associated

[17] Kennedy et al. (2006)
[18] World Health Organization (2013).
[19] Rick Hansen Institute (2013)
[20] Rick Hansen Institute (2013)
[21] World Health Organization (2013)
[22] Rick Hansen Institute (2013)

with SCI can be significant.[23] Generally, people who have experienced SCI are more likely to experience poverty than those who have not.[24]

In a survey of 1,137 Canadians who suffered from a traumatic injury 57% of people surveyed experienced the need for financial support and only 34% were satisfied with their financial situation.[25] Of the 412 individuals who experienced a non-traumatic injury 44% needed financial support.

2.9 Social attitudes

Positive personal relationships with family, friends, neighbors, colleagues and service providers all have the capacity to help people with spinal cord injuries make the adjustment back into the community.[26] Making sure that individuals who have a SCI can interact with mainstream society through their integration into mainstream schools, public transport, neighborhoods and the workplace, has the capacity to help increase understanding and inclusion of this segment of the population.[27]

In fact, in one study of 482 people with SCI, the characteristics of their social environment were most likely to be identified as being crucial to improving a person's life satisfaction.[28] For example, the attitude and support of immediate family and relatives can have an important influence on an individual's social participation and independence.[29]

2.10 Supports for family and friends

Family and friends who become informal caregivers of individuals with a SCI can become overwhelmed and feel untrained for the job, increasing stress and depression among this group.[30] Therefore, during inpatient care, family members should be involved in any educational activities around the medical, psychosocial, community/integration, employment or financial issues that need to be considered.

The availability of emotional and problem-solving support from families is also important for the life satisfaction of people with spinal cord injury. Family and friends can help promote feelings of dignity, pride, confidence, hope and joy that the person with SCI may be struggling with.[31] Intimate relationships can also help and improve the

[23] World Health Organization (2013)
[24] World Health Organization (2013)
[25] Rick Hansen Institute (2013)
[26] World Health Organization (2013)
[27] World Health Organization (2013)
[28] Noreau et al (2002)
[29] Noreau et al (2002)
[30] World Health Organization (2013)
[31] World Health Organization (2013)

quality of life for people with SCI. Rehabilitation teams have the responsibility to address issues related to sexuality with their patients.

Family members should also be educated and empowered around their loved ones needs with rehabilitation, access to assistive technologies, and follow up care, in order to ensure a smooth transition back into the community.[32]

2.11 Peer mentoring

People who have suffered from a SCI have to deal with coping with a new identity, which may bring about feelings of depression, anxiety, loneliness, anger, fear, and low self-esteem.[33] While support from family and friends is certainly an important aspect of a person's re-integration in their community, peer support, including situations where people with SCI can meet people who are experiencing similar challenges and circumstances may help people feel less socially isolated.[34] People who have been living with SCI for a number of years can provide insight into particular issues in the day-to-day reality of living with an SCI.[35] Boschen et al (2003) found that peer support groups were invaluable to individuals re-integrating into communities after their SCI.

While some mentoring programs are geared toward meeting people in a similar situation, they can also be used to provide information as well as emotional support from a volunteer with or without a similar disability. In an assessment of the "Back on Track" mentoring program, which matched young people who had sustained a SCI with a mentee, with or without a disability, the authors found that the program helped young adults with SCI access post-secondary education and employment.[36]

2.12 Environmental Barriers

Overcoming environmental barriers is also a key factor influencing a person with SCI's reintegration into the community. Environmental barriers can affect a person's access to: housing, transportation, employment, education etc. Aspects of the built environment such as stairs, having enough space for a wheelchair to pass, having lifts installed on buses, accessible parking and restrooms are all important aspects of the built environment that can impede the ability for someone with SCI to live independently. Accessible public transport, including having ramps, lifts and safety lock systems may not be widely available, impeding a person's ability to access services, their place of employment or educational institution independently.[37]

[32] World Health Organization (2013)
[33] Patterson et al (2004)
[34] World Health Organization (2013)
[35] Patterson et al (2004)
[36] Shem et al (2011)
[37] World Health Organization (2013)

The physical environment that a person with SCI lives in is deeply connected to their life satisfaction and ability to participate socially in their community.[38] Based on a study of 482 participants, physical environmental factors were specifically singled out as the main barriers to the life satisfaction of people with SCI.[39] For example, a factor particularly pertinent to the Albertan context, is the effect of winter conditions on the accessibility of the environment for people with SCI. In addition, the accessibility of a person's residence is especially important to the social participation of an individual with a SCI.[40]

2.13 Education

Education is important in terms of individuals' participation in the community, employment, independent living, and life satisfaction. Basic accommodations such as physical access to the schools (ramps, wide enough hallways), toilets, and classroom assistance (including assistive technology) that may be needed by the student need to be made for a smooth transition.[41] Informal mentoring systems have also been shown to be helpful for children returning to school.[42]

For younger children who have experienced a SCI, partnerships between the school, hospital professionals, parents and students may be important to ensure that the student's return to school goes smoothly and their needs are clearly communicated.[43]

Ensuring that individuals with SCI can continue their education is important in considering their opportunities later on in their lives. For example, individuals who have finished their post-secondary education are two times more likely to be employed compared to those who have only completed high school.[44]

2.14 Employment

Many individuals with SCI are excluded from the workforce and the opportunity to make money for themselves and their families. In fact, one of the main predictors of employment after SCI is pre-employment history, which is particularly troubling given that young adults, who may have no employment history, are the largest age group where traumatic SCI occurs.[45] Employment is not only an important source of income, but it is an important source of identity and sense of achievement and plays a big role in an individual's reintegration into the community.[46] In fact, in one study of 195

[38] Noreau et al (2002)
[39] Noreau et al (2002)
[40] Noreau et al (2002)
[41] Knight et al (2008)
[42] World Health Organization (2013)
[43] Knight et al (2008)
[44] Jongbloed et al. (2007)
[45] Shem et al (2011)
[46] Jongbloed et al. (2007)

Americans and Canadians who sustained a SCI before the age of 18, it was found that employment was significantly associated with community integration, independent driving, independent living, higher income, and life satisfaction more generally.[47] It is associated with higher quality of life and life satisfaction for people with spinal cord injuries.[48]

According to a systematic review of 50 studies looking at the employment rates of people with SCI, North America had the lowest average employment rate, at 30%.[49] Another study from 1997 found that only 38% of Canadians with a spinal cord injury were employed, compared to 70% in individuals without any disabilities.[50] In another study where 195 Canadians or Americans who sustained a spinal cord injury before they were 18 years old, the researchers found that 40% were unemployed.[51]

However, employment rates vary according to different characteristics of the individuals with SCI. The younger, more educated and less severely injured a person is, the more likely that they will be employed. Caucasian males are also more likely to be employed post-injury compared to other ethnic groups in Canada.[52] While discrimination plays a part in these low levels of employment, so does inaccessibility of the work place. One study found that up to 20% of the variability in terms of employment was as a result of access to transportation.[53] Vocational rehabilitation can be an effective way to address some of the issues related to the unemployment among people with SCI. [54] [55]

In a survey of 1,137 Canadians who suffered from a traumatic injury only 27% of people surveyed were engaged in a paid job as much as they wanted to be, and only 43% were satisfied or very satisfied with their professional situation.[56] Only 20% of the 412 individuals with non-traumatic injuries felt like they experienced a need for professional training.

[47] Anderson and Vogel (2002)
[48] Jongbloed et al. (2007)
[49] World Health Organization (2013)
[50] Jongbloed et al. (2007)
[51] Anderson and Vogel (2002)
[52] Jongbloed et al. (2007)
[53] Noreau et al (1999) in Jongbloed et al. (2007)
[54] World Health Organization (2013)
[55] Jongbloed et al. (2007)
[56] Rick Hansen Institute (2013)

3.0 Models for Community Rehabilitation

3.1 Bio-Psychosocial Model

The **Bio-Psychosocial Model** (Steins et al, 2002) is a model for understanding and supporting the unique processes of adaptation following SCI

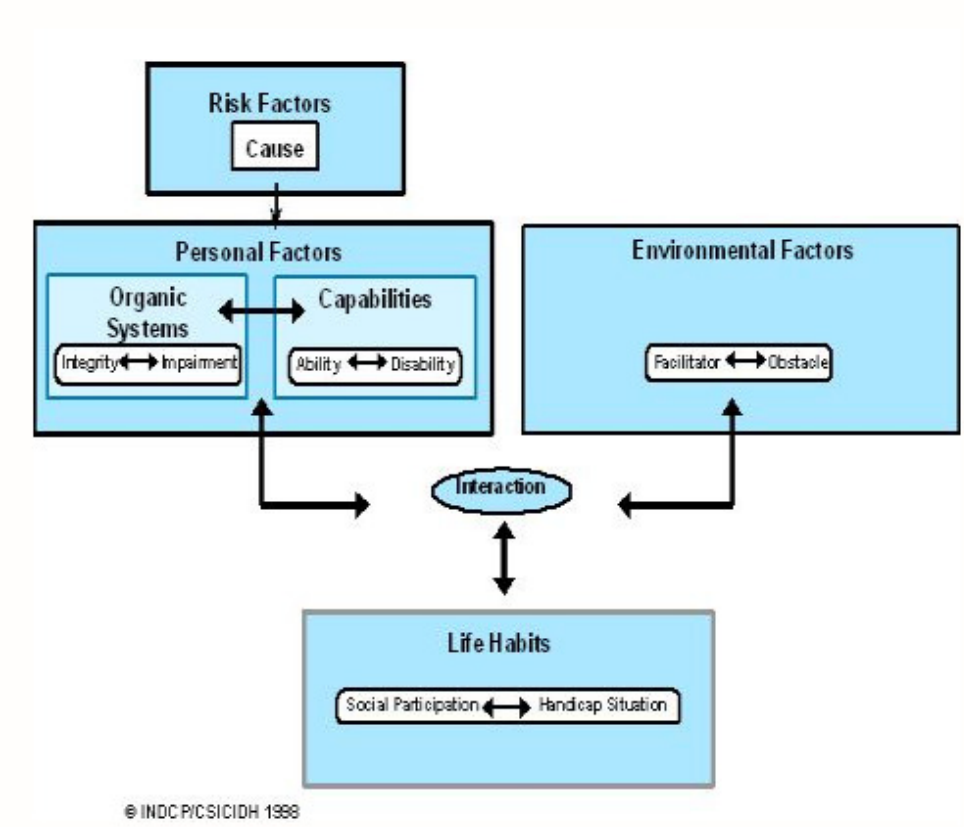
- This model draws from contextualized 'sector divisions of the environment' which consider needs and experiences of living with SCI at the more immediate personal level, the intermediate or home environment level, the community level, and the level of the wider natural environment.

Fig 1. The person is related to the sectors of the environment. The environment is that which is outside the person. The *immediate environment* is directly in contact with the person and moves with the person (eg, clothes, adaptive equipment). The *intermediate environment* is the personal living space (ie, home) and workspace (eg, office). The *community environment* is the space modified for public use. The *natural environment* is the space that has been minimally changed or left unaltered. Reprinted with permission.[60]

3.2 The Disability Creation Process Model

The "**Disability Creation Process**" model understands the interaction between personal factors (i.e. age, sex, sociocultural identity) and environmental factors (both physical and social) as having an important impact on the level that a particular situation is 'disabling' or not.[57] Disabling environments are understood to occur at three different levels: personal environment, community environment and societal environment. These environments can either facilitate an individual's accomplishment of their life goals and social participation or be an obstacle to it. Tools such as "Measure of the Quality of Environment" can be used to understand how different environmental factors are influencing an individual's ability to participate in their community. By understanding environmental factors as being integral to understanding the life chances of an individual with a disability, the practitioner or individual gains a deeper understanding on the disabling or enabling factors influencing that individual's life experience.[58]

INITIAL REPRESENTATION OF THE DCP COMPONENT IN THE HDM-DCP (1998)



[57] International Network on the Disability Creation Process, accessed 2014
[58] International Network on the Disability Creation Process, accessed 2014

3.3 Biographical Disruption and Reconstruction Model

One theoretical framework that has contributed to understanding direct qualitative experience with SCI is ***biographical disruption and reconstruction*** theory. Biographical disruption theory was developed by medical sociologists and characterized in terms of three dimensions: "the body, conceptions of self, and time – suggesting that an injury that leads to an inability to perform valued activities of every-daylife may lead to a loss of certain aspects of the self, such as perceptions of competence and self-worth."[59] Hammell (2007) found this theory to 'encapsulate' recurrent conceptualizations of the relationship of the body to the self in SCI literature. Hammell (2007) makes reference to studies that drew a connection between 'restoration of a sense of self-worth' and perceived quality of life. Hammell also found that sense of self-worth and personal competence was connected with opportunity to "use time in personally meaningful ways."[60]

4.0 Best Practice Considerations

4.1 Physical Health: Considerations

- Acute and post-discharge ongoing rehabilitation programming should be tailored with respect to the cause of the spinal cord injury to realize the most effective programming.[61]

Problems identified by individuals living with SCI living in the community include:[62]

- Difficulties asking for assistance and expressing assertiveness, managing pain and adapting to changes in ability and body regulation, in particular bladder and bowel regulation; dependence on personal care assistance (page 26)
- "Reported problems [for integration following discharge from hospital] include physical problems like pain, spasm, pressure sores, bladder and bowel problems… transportation and financial problems, difficulties in care management, feelings of sadness and lack of adequate housing."[63]
- Pain is the greatest barrier to for both daily and social activities; bladder and bowel regulation is a greater barrier for social activities than it is for daily activities[64]

[59] Hammell (2007:134) citing Bury (1982) and Corbin & Strauss (1987).
[60] Hammell (2007:134)
[61] Kennedy, Cox & Mariani (2012).
[62] Bloemen (2006)
[63] Bloemen (2006:19)
[64] Bloemen (2006:42)

Physical Health: Best Practice

Research has identified areas where improvements in programming for the ongoing rehabilitation and community living for individuals who have sustained SCI:

- Increased continuity of care and better coordinated follow up care including improved coordination between rehabilitation care centres and the primary health care system. "…primary health care professionals only sporadically see patients with SCI in their practice [and] therefore, these professionals might not have much opportunity to expand their knowledge about the specific care these patients need."[65]
- Need for improved knowledge about SCI for primary health care workers such as general practitioners and primary health care nursing staff
- Improved training about secondary health conditions that can be prevented or delayed, or for which living adjustments can be made. Reducing secondary health problems improves the opportunity for increased participation and community integration. The authors note the importance of providing health related information at multiple points pre- and post- discharge because the individual's readiness to receive the information and perceived relevance of the information will be influenced by experience gained through returning to daily living in the community context.[66]
- Increased access to follow up care through multiple modalities, e.g. home visits, telephone consultation, peer meetings
- Access to rehabilitation, specialized care, and mainstream care must be available as early as possible to avoid secondary complications, increase potential for maximum functionality, and help with social integration.[67]
- Family members and individuals who have sustained a SCI should be included in the processes related to their physical health, educated and empowered to understand and look after their health as much as possible.[68]
- Assistive technology that will maximize the independence of the person with SCI should be provided as soon as possible.[69]

Ideas suggested by individuals living with SCI for addressing problems experienced in the community include:[70]

- More preparation for discharge from hospital rehabilitation setting, including more supported practice living with changed bladder and bowel regulation and pain management with day-to-day activities for healthy living, for example fitness activities and swimming (page 25)

[65] Bloemen (2006:33), citing Dryden et al (2004))
[66] Bloemen (2006:60)
[67] World Health Organization (2013)
[68] World Health Organization (2013)
[69] World Health Organization (2013)
[70] Bloemen (2006)

- In preparation for discharge, staff in the rehabilitation hospital should encourage individuals with SCI to problem solve before offering help to solve problems, and to practice moving around in unadapted environments (page 25)
- Peer group mentoring in the community "to discuss the period after discharge from rehabilitation, and to attune care more closely to their needs and the situation after discharge"
  (Page 25)
- Additional consulting hours for follow up care through the rehabilitation centre as well as extended access to day treatment in the rehabilitation centre following discharge from clinical rehabilitation (page 25)

4.2 Health Maintenance Throughout the Life Course: Considerations

- There are a number of health issues that are specifically associated with spinal cord injuries; therefore, individuals may require specialized medical interventions throughout the life course. [71]
- On top of the specialized needs environmental barriers to mainstream medical care are also important to consider. [72]
- Bloemen completed a study which compared the outcomes of an enhanced follow-up care program with the usual follow-up care available for SCI in the Netherlands and found no significant difference in perceived satisfaction with the follow-up support or secondary health difficulties at one year after discharge. (page 117). The enhancement of the programming was achieved by assigning nurses in a case management format.
- Individuals who have experienced SCI access the emergency department for concerns that would be more appropriately channeled through the primary care system in about 50% of cases. Examples of concerns that would be more appropriately addressed in the primary health care system include ambulatory care concerns. This can result in challenges for coordination of care with the primary care system, such as duplication of or inconsistent treatment because emergency medical professionals are not in a position to follow clients. Emergency department use is also less cost-effective.[73]

Follow-up care programs tend to fall into the following service delivery formats: [74]

- telemedicine, that is, health and medical support accessible using telecommunications technologies. This may also be particularly important for rural or remote areas. [75]
- outpatient consulting hours providing physicals, reviews of daily functioning and support in case of health problems

[71] World Health Organization (2013)
[72] World Health Organization (2013)
[73] Guilcher et al. (2012)
[74] Bloemen, 2006
[75] World Health Organization (2013)

- home visits
- case management, "involving the coordination of care within, between, and beyond the acute and rehabilitation programs, extending care and coordination to the community and managing the reemerging needs of the population over time"
- Combinations – combining elements of the above with additional supports such as "peer teaching and support, outings, ongoing support, therapy from several care disciplines, SCI education, providing SCI expertise and support to community health care providers, coordination of care with community nursing agencies"
- Approaches that promote self-management are important for the long-term maintenance of individuals' with SCI's health. [76]
- The coordination of services that a person with SCI receives is important for the smooth transition between different stages of reintegration. [77]

Health Care Maintenance Throughout the Life Course: Best Practice

- Follow up care should be provided within the first 12 months, on a regular basis to ensure that medical complications are dealt with promptly. Ongoing medical care thereafter is also important given the specialized and mainstream issues that people with an SCI may face. Including family members in this discussion is important and will ensure that they are also educated and empowered with regards to the health of the person with SCI. [78]
- There needs to be a system to coordinate between all aspects of a patients care both over time (acute care, rehabilitation and health maintenance) as well as across aspects of health (physical, mental, social).[79]
- Family members can be essential resources in directly providing medical care, helping the individual access rehabilitation programs and providing assistance for daily living activities. Formal training should be considered a best practice in regards to family members. [80]
- The needs of an individual will change over time. Needs related to, for example, assistive technology as an individual with SCI ages, need to be considered.[81]
- Hammell (1994:776) found that spouses of injured persons need to be included throughout the rehabilitation process including prior to discharge since they are likely to become responsible for ongoing rehabilitation and support. Hammell (1994) highlights the value of including spouses and friends and other support people where possible early in rehabilitation, even during initial acute rehabilitation in the spinal cord unit. Hammell suggests ongoing follow up

[76] World Health Organization (2013)
[77] World Health Organization (2013)
[78] World Health Organization (2013)
[79] World Health Organization (2013)
[80] World Health Organization (2013)
[81] World Health Organization (2013)

should include assessment of psychosocial needs and access to counseling services on a long term bases for injured persons and their spouses/carers (776).

4.3 Mental Health and Well-being: Considerations

- The period following discharge from hospital is identified in the SCI literature as the most critical period for the individual's psychosocial adjustment[82]
- There is clearly a higher prevalence of depression, anxiety and PTSD among people with a SCI. As well, overall life satisfaction is substantially lower than the general population.[83]
- "Perceived control, resilience, sense of coherence, self-worth, hope and purpose of life" are all associated with quality of life after an individual sustains a SCI.[84]
- Low levels of social contact have been associated with decreased and deteriorating levels of social and emotional functioning for people who sustained a severe physical injury[85].
- SCI is associated with unusually high levels of substance abuse, risk of suicide and psychological morbidity.[86]
- There are large differences among individuals in terms of their mental health and satisfaction with life. An individual's life satisfaction and mental health can also change over time. It is often much lower in the period directly after the individual sustains the SCI; however, there are mixed findings related to this as well. This may also be a limitation to studies that can't differentiate between a depressed mood and a disorder[87]
- Current studies looking at the effects of interventions on the mental health for people with an SCI are lacking. They often deal with a small sample size, lack of randomization and an inability to identify the mechanisms through which interventions may or may not improve the mental health of participants.[88]

Hammell (1994) found the lowest levels of social integration among participants with SCI and this was not related to length of time since discharge (i.e. it does not significantly improve over time).

While the findings in the literature may be mixed,[89] a number of studies have found that depression, and other mental health issues is an important issue to consider after a

[82] Bloemen (2006:19)
[83] Post and van Leeuwen (2012)
[84] Post and van Leeuwen (2012)
[85] Hammell (1994:771) citing Patrick, Morgan and Charlton (1986), Morgan (1989), Judd et al. (1991), and Elliott et al (1992)
[86] Post and van Leeuwen (2012)
[87] Post and van Leeuwen (2012)
[88] Post and van Leeuwen (2012)
[89] Hammell (1994) found no relationship between incidence of depression and SCI, however the study notes this is not consistent with other studies that have shown

person sustains their injury. For example, in a review the authors found that 20-30% of people who have a spinal cord injury deal with significant symptoms of depression. Some studies have found that depression onset during initial hospital stay can in some cases last over 1-2 years after SCI.[90] Hoffman et al (2011) also highlight that onset of major depression can take place months or even years after SCI.

Depressive symptoms are linked in SCI literature to negative outcomes for physical health such as pressure ulcers, UTI's, and reduced social integration including pursuing less leisure and social activities and less community mobility. [91] In fact, depressive symptoms appear to be associated with mortality rates after controlling for other factors.[92] Not only is this important in terms of the individual who sustained the injury, but for the family members close to the individual as well. Personal factors, such as previous mental health history, age and gender, may affect a person's experience as well an environmental factors such as cultural beliefs, values and attitudes toward individuals with spinal cord injuries. [93]

Having an SCI challenges a person's independence and self-identity. Self-esteem and issues around controlling one's own body may be important to consider when thinking about life satisfaction. [94]

Mental Health and Wellbeing: Best Practice

Social supports, access to assistive technology, and one's socioeconomic status have been found to influence an individuals adjustment. Best practices may include:

- Attention to risk factors such as increasing pain, decreasing health status, and changes (increase or decrease) in alcohol/substance use[95]
- Early screening and assessment of pre-injury history of depression
- Provision of information regarding support services available
- Long-term, systematic monitoring
- Peer mentoring has also shown to be significant in improving the adjustment of individuals with a spinal cord injury. [96]
- Attention to the possible depressive effects of medications prescribed for the treatment of conditions associated with SCI such as anti-spasm and anti-seizure medications and opioids[97]

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correlation between onset of depression and experience of SCI. See e.g. Decker & Shultz (1985)

[90] Hoffman et al (2011:412) citing Craig et al., and Hancock et al., in the 1990s.

[91] Hoffman et al (2011:412) citing Craig et al., and Hancock et al., in the 1990s.

[92] Hoffman et al (2011:411)

[93] World Health Organization (2013)

[94] World Health Organization (2013); see also, e.g., Decker & Shultz (1985); Hoffman et al. (2011).

[95] Hoffman et al (2011:415)

[96] World Health Organization (2013)

- Inclusion of "depression treatment and coping skills training as elements of any plan to treat alcohol abuse in the aftermath of SCI"[98]

Research has found that assessments at the time of hospitalization are not reliably predictive of who will most benefit from psychosocial support after discharge.[99] It is therefore important to have ongoing contact with individuals after hospital discharge which includes attentiveness to, and assessment of, psychosocial well-being.

A number of studies have found that while depressive symptoms may have showed a significant reduction during the given intervention, this is not always maintained after the end of the intervention, making follow-up and life-long care important. Moreover, it's unclear what the mechanisms for this change is (i.e. coping techniques v. change in perception of SCI).[100]

Participation in sports and recreation has been found to increase the physical and psychological health and quality of life more generally of people with SCI. Sport and recreation is a way to participate in social interaction, adjust to one's disability, self-esteem, and have fun.[101] However, it is important to note that most studies looking at this connection have small sample sizes, are retrospective and cannot establish causality.[102]

Peer-mentoring or self-help groups can be helpful in improving individuals' feelings of isolation and lack of confidence. [103]

4.4 Sexual Health: Considerations

- Many individuals with SCI are unsatisfied with the quality of information they receive about their sexual health and unsatisfied with their sex life.[104]

Sexual Health: Best Practice

- Couples should be provided marital counseling, including information about intimate relationships, sexual and reproductive health.[105]

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[97] Hoffman et al (2011)
[98] Hoffman et al (2011:415)
[99] Hammell (1994: 776) drawing from research about head injury, citing Livingstone et al (1985) and Peters et al (1990)
[100] Post and van Leeuwen (2012)
[101] Slater and Meade (2004)
[102] Slater and Meade (2004)
[103] World Health Organization (2013)
[104] Kennedy et al. (2010)
[105] World Health Organization (2013).

- Individuals may not feel comfortable approaching clinicians for information about sexual health. Booklets, internet resources and encouraging the topic with a peer-mentor are alternative routes to discussing the topic.[106]

4.5 Social Reintegration: Considerations

Müller et al (2011) reviewed the literature about the role of social support and social skills for people who have sustained SCI. They made the following observations:

- The relationship that was found the most consistently in the literature is that social support is associated with better mental health.
- Social support is associated with lower depression, helplessness, pessimism, negative thoughts about the world and about oneself, suicidal ideation, feelings of hopelessness, lower stress related anxiety, less severe post-traumatic stress, less substance use, and less psychosocial disability.
- Social support, in particular reciprocal relationships and support from peers, is associated with greater participation and interest in leisure activities
- Social support was positively related to beliefs about self-efficacy, hopefulness, sense of perseverance and humour
- Internal coping styles were associated with higher degree of support compared to external (more visible) coping styles
- Supportive friends was associated with greater acceptance of disability and better adjustment
- Emotional support was associated with personal growth
- Social support is associated with better physical health, including less frequent health problems and difficulties with secondary conditions such as pressure ulcers and UTIs
- Social support was related to higher ratings of life satisfaction and quality
- Life satisfaction was related in particular to social support of peers (p. 98)

Social Reintegration: Best Practices

- Individuals should be provided information about accessible sporting, religious, cultural political and leisure opportunities in their community.[107]
- Hammell (1994:775-6) suggests that "the rehabilitation team has a role in assisting… individuals to acquire additional social skills and techniques to enhance comfortable social interaction."
- A key focus in the literature about enhancing social reintegration is through peer support, both in the hospital where initial connections in the community can be established, and through ongoing mentorship in group or paired mentorship relationships.
- Positive benefits have been found for social support intervention as group therapy as well as training for effective coping, however these studies and many

[106] Kennedy et al. (2010)
[107] World Health Organization (2013)

of the peer mentorship studies in the SCI literature are focused on the acute rehabilitation period.[108]

4.6 Peer Mentoring: Considerations

Individuals living with SCI identified participation in peer support groups as "a welcome opportunity to share experience with others in the same situation" and researchers emphasize that this format of social contact are beneficial for the rehabilitation process.[109]

Peer Mentoring: Best Practice

Peer mentors have also been found to provide support and decrease medical complications. By sharing skills with fellow patients, increasing their confidence, addressing psychosocial adjustment, providing advice about self-care and health maintenance, including the prevention of secondary complications, peer mentors can be an effective means of sharing information and being a source of support.[110] Peer support has also been associated with positive outcomes for returning to work and school.[111]

When looking at peer mentoring programs, it is important to consider whether the program is meant to provide:

- Informational support (education)
- Emotional support
- Instrumental support (pointing individuals toward resources)

This can impact the efficacy and impact of the program.[112]

Based on a study of 25 patients who took part in a peer-mentoring program for one year post-injury, Ljungberg et al. found that the program helped patients better understand the challenges that they had to deal with in relation to their newly acquired spinal cord injury.[113] In this case, peer mentors not only helped with the emotional well-being of the individual with SCI, but also monitored any medical complications, risky behaviors and health status. All mentors also had an SCI. While this support can be provided by other health professionals, some studies have found that in fact, the relationship between peers cannot be replicated by other professionals.[114]

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[108] Müller et al (2011)
[109] Hammell (1994:776-7).
[110] World Health Organization (2013)
[111] Haas et al (2013:296) citing Shem et al (2011) and Veith et al (2006).
[112] Shem et al (2011)
[113] Ljungberg et al (2011)
[114] See e.g. Haas , Price & Freeman (2013).

Veith et al. found that mentees experienced practical, emotional and identity-related benefits from the peer mentoring program.[115]

Similarly, in a two year study of 100 individuals with SCI, a "dominant finding" was that the peer mentoring programs (as well as social support from family and friends) were invaluable to patient's quality of life.[116]

Haas, Price, and Freeman (2013) explored the experience of a UK peer mentorship program that focused on providing peer mentorship in the acute rehabilitation hospital setting. The program is operated through the Spinal Injuries Association and consists of a Community Peer Support Officer (CPSO) who lives with SCI who visits people in general hospitals who have recently sustained SCI. They found that the benefits reported for participation in the peer support program could be grouped under four headings:

1. psychological and emotional support by a person with an SCI
    a. the 'listening ear' of someone who had experienced SCI personally and could model that quality of life and independence is attainable
    b. comfort of receiving information from someone with direct personal experience
    c. for caregivers and relatives of the person living with SCI the peer mentor offered a perspective and attention beyond the focus of clinical imperatives
2. sharing information and experience on living with an SCI;
    a. information was perceived to be more meaningful and holistic, and the peer mentor was viewed to have a deeper level of understanding and credibility
    b. in some cases the peer mentor was able to provide informal education for medical staff for example by sharing what are the latest research findings for SCI
3. practical experience and information;
    a. Sharing experience/information about bowel, bladder, and skin care and management; sources of appropriate housing and financial support; relevant assistive technologies and ways to adapt environments
    b. Individuals, their relatives and caregivers also appreciated explanations as to what to expect in the longer term
    c. Sharing this kind of practical information has been associated with gains in self-efficacy and reductions in medical concerns/secondary conditions
4. on-going support and friendship.
    a. The CPSO offered ongoing psychological support through the processes of experiencing, accepting, and redefining the self post-SCI

[115] Veith et al. (2006)
[116] Boschen, Tonack and Gargaro

b. Health professionals indicated that the peer mentorship relationship sparked motivation for rehabilitation and engendered hope in a unique way

Haas et al. (2013:296) note that while mentor training is generally accepted to enhance, and be more likely to produce optimal outcomes, "no particular training" was needed for peer mentors to be effective as credible sources of information about the realities of living with SCI. The qualitative interviews revealed key peer mentor personality characteristics are friendliness, compassion and trustworthiness. In reviewing the literature about peer mentorship programs following traumatic injury/illness, Haas et al (2013) found the qualities of effective peer mentors: empathic, reflective listening, non-judgmental, aware of and maintain appropriate boundaries. The literature also suggests that mentor-mentee matches benefit from "flexible availability, similar age, interests and level of injury; same a mentor of the same gender, who is also sociable, has a good sense of humour and is able to address the mentees personal learning style."[117]

Haas et al (2013) found that the hierarchies that can exist between health care professionals and peer mentors in the hospital setting can cause problems if there is not sufficient clarity of roles. They encourage clearly defined peer mentor roles to enable the best delivery of peer support and collaborative engagement in the rehabilitation process.

4.7 Environment: Considerations

Physical Environment
Hammell (1994:777) points to the disabling environment as the source of disability and social disadvantage and the role rehabilitation professionals and society more broadly can play in removing environmental and social barriers, stating this may be the avenue for producing the most positive outcomes. All participants with SCI indicated that lack of access (environmental barriers) was the key barrier to participation in the community.

Social Environment
The accessibility of environments can impact the attitudes that the wider society has towards people with an SCI. If homes, neighborhoods, workplaces, and schools are not accessible to people with an SCI, it is difficult for people in the general population to interact and know how to act around someone with an SCI. Attitudes among professionals such as doctors should also be considered important. [118]

Environment: Best Practice
Physical Environment

[117] Haas et al (2013:297)
[118] World Health Organization (2013)

Barriers such as stairs, narrow hallways, and inaccessible kitchens and washrooms are the beginning of the considerations that would have to be taken into account in the home of an individual with SCI. The same aspects must be considered in terms of public buildings as well. Moreover, the accessibility of public transportation is important for an individual to be able to reach their place of work, school, or to engage in social activities outside of the home. [119]

- Information about cost-effective ways and the feasibility of adapting ones home.
- Keep a register of accessible housing

While assistive technology is an integral component to the adjustment and integration of a person with spinal cord injury back into their community, it is important to consider the environments, which they are re-entering, which may impact the necessary assistive technology. While the physical environment can impact what is needed in terms of assistive technology, personal factors such as a person's age, fitness and lifestyle need to be considered as well. These personal factors can also change over time, as a person transitions to the workforce or ages. making it difficult to make sweeping statements about needs surrounding assistive technologies. Regardless, wheelchairs, environmental control systems and computer technology are the most widely used. Not only do assistive technologies help to improve the independence of people with a spinal cord injury, it also improves the social and civil life of individuals and also individuals' self-esteem and satisfaction with life more broadly. [120]

Social Environment

- Public awareness around SCI is important to ensure that negative attitudes toward people with SCI don't impact an individual's opportunities for employment, education, and social participation.[121]

4.8 Education: Considerations

- Higher levels of education are associated with higher levels of life satisfaction, employment prospects, independence and community participation. [122] Individuals who have completed a post-secondary degree are two times more likely to have a job compared to those with a high school education.[123]
- Both physical and attitudinal barriers can impeded a child's or adult returning to school full participation in mainstream education after a SCI.[124]

[119] World Health Organization (2013)
[120] World Health Organization (2013)
[121] World Health Organization (2013)
[122] World Health Organization (2013)
[123] Jongbloed et al (2007)
[124] World Health Organization (2013)

Education: Best Practice

- Mainstream schooling is the best option for children; home schooling or individual instruction is second best. [125]
- The child, parent, school and health support workers should work together to ensure a smooth and informed transition back to school. Education for staff members may also be included. [126]
- Adaptation to the school's physical environment should be planned and executed in a non-stigmatizing way. Including the ability for the student to participate in the entire curriculum, including physical education. [127]
- Mentoring systems for children who are returning to school and their social worlds have been shown to help their integration and life satisfaction.[128]

4.9 Employment: Considerations

- Ability to return to work is associated with higher rating of quality of life, better health, and more social integration than for people who are unemployed with SCI[129]
- Ability to return to work can be affected by a lack of access to pertinent educational training, lack of access to vocational rehabilitation or job placement services, financial resources for self-employment, financial disincentives related to benefits, lack of transportation options, and a lack of workplace accommodations and appropriate assistive technology.[130] [131]
- Average time between injury and first post-injury job is 4.8 years; it takes an average of 6.3 years for full-time job.[132]

Anderson et al (2007) reviewed the literature about vocational outcomes and SCI and found 11 key factors associated with employability:

1. education, the strongest predictor, and professional interests
    a. less than 12 years of education (high school completion) is associated with disadvantage in re-employment post injury
    b. 16 years of education or more (bachelors degree or higher) has been found in one study to be associated with 95% re-employment rate. This may be explained in part by the fact that less change in occupation may be required than for someone who had less formal education but had been employed in a job requiring manual labour pre-injury. Other factors may be that higher education is associated

[125] World Health Organization (2013)
[126] World Health Organization (2013)
[127] World Health Organization (2013)
[128] World Health Organization (2013)
[129] van Velzen et al (2012:73)
[130] World Health Organization (2013)
[131] McKinley et al (2004)
[132] van Velzen et al (2012:73)

with greater autonomy and motivation and/or more positive personal expectations. (citing

c. further education and/or retraining improved employment outcomes

2. type of employment -
3. disability severity - Ottomanelli and Lind note, however, that although identified as a relevant factor by Anderson, the literature has not been consistent about severity of injury and employment. It did appear to be consistent that individuals with paraplegia were significantly more likely to be employed than individuals with tetraplegia.
4. age – younger age at time of injury is associated with greater employment outcomes
5. time since injury – employment outcomes are found to increase over time since injury, as does level of satisfaction with employment[133]
6. sex – men were found more likely to return to paid employment where as women were more likely to do unpaid work – it was not indicated clearly whether this was a change from pre-injury employment situations or not, however.
7. marital status and social support
8. vocational counselling
9. medical problems related to SCI
10. employer role
11. environment

However, demographic and variables associated with the extent of ones injury can only explain 30% of the variation in people's employment; therefore, it is important to consider broader environmental, social and political factors.[134]

The literature review by Ottomanelli and Lind (2009) found that ethnicity was also a factor associated with employment outcomes, with individuals from minority backgrounds disadvantaged in patterns reflecting the disparity found in the general population even when controlling for education level. For example, access to transportation can account for an additional 20% of the variability.[135]

Employment: Best Practice

- In order to transition into employment, students should be provided career development skills along with the general curriculum. [136]
- Access to vocational rehabilitation.[137]

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[133] Citing A 25-year longitudinal study of the natural course of aging after spinal cord injury by Krause JS, Broderick L Spinal Cord. 2005 Jun; 43(6):349-56.
[134] Jongbloed et al (2007)
[135] Jongbloed et al (2007)
[136] World Health Organization (2013)
[137] World Health Organization (2013)

- Provide information about access to micro-financing to pursue self-employment opportunities.[138]
- Supported employment model: support throughout job search; on-site support of advocacy and training, arranging accomodations, assisting with training; on-going, long term support. This is different from vocational training in that it is working with an individual's existing skills.[139]
- Technology, such as computer training, can increase the employment possibilities for an individual with SCI.[140]

4.10 Role of Family: Considerations

- SCI presents "great adaptation demands both on injured persons and on significant others living with them" and can result in social isolation for the carer as well as for the injured person[141]
- Limited research has explored the experience of "spouses' [and carers'] long term adjustment to living with a partner who has SCI"[142]

Role of Family: Best Practice

- Marriage has been found to be an important source of social support; however, divorse rates are higher compared to the general population.[143]
- Family members (including parents, caregivers, partners or siblings) should be provided counseling information that they can access as well as be provided informal or formal opportunities to meet other families in similar situations. Access to support services can help prevent stress and burnout among family members. [144]
- Couples should be provided marital counseling, including information about intimate relationships, sexual and reproductive health.[145]
- Family members and individuals who have sustained a SCI should be included in the processes related to their physical health, educated and empowered to understand and look after their health as much as possible.[146]
- Family members can be essential resources in directly providing medical care, helping the individual access rehabilitation programs and providing assistance for daily living activities. Formal training should be considered a best practice in regards to family members. [147]

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[138] World Health Organization (2013)
[139] Targett et al. (2004)
[140] McKinley et al. (2004)
[141] Hammell (1994: 772) citing Decker et al (1989)
[142] Hammell (1994: 772) Kester et al (1988)
[143] Post and van Leeuwen (2012)
[144] World Health Organization (2013).
[145] World Health Organization (2013).
[146] World Health Organization (2013)
[147] World Health Organization (2013)

4.11 Limits of literature review:

Research about follow-up care for SCI in the community is limited. Bloemen (2006) undertook a systematic review of 16 published follow-up care program studies in the Netherlands including telemedicine, outpatient consulting hours, home visitation, case management, peer support, facilitation of outings and access to therapeutic supports, care coordination and SCI education. However, Bloeman found that evaluative criteria for these programs were not adequately rigourous to be able to draw reliable conclusions about quality of follow up care or about the relationship between follow-up care and significant improvement in well-being, reduction in secondary health concerns, or reduction in costs of care etc. (page 66).

SCI research has successfully been filling the gaps identified by Hammell (1994) and others about the impact of the environment for social integration. This shift has led to the more standard recognition that the extent to which the environment is inclusive, accessible, and adapted determines the extent to which the person will be 'disabled'/experience disability. In a subsequent study, Hammell (2007:137) built on this theme and concluded that "By highlighting the impact of social, cultural, physical, legal, political and economic environments the findings of this review support the premise that the experience of SCI is inseparable from the context in which it occurs."

Hammell (1994) also highlighted the need for research about effective outcome measures of psychosocial and emotional well being for rehabilitation interventions. While considerable work has been undertaken to develop and test various outcomes measurement tools, the data available in SCI research about psychosocial and emotional outcomes suffers from difficulties making comparisons across studies. This is in part because researchers do not use the same outcomes measures across studies, and as Hammell (2007) notes, because there is a lack of participants' own perspectives and narratives in the research. More meta analysis would be possible if there was greater agreement across SCI researchers about which outcomes measures are the most effective and if more data sets using these measures could be captured. Similarly, meta synthesis of qualitative research findings would be bolstered if more studies documented participants' perspectives, thereby giving evidence that researchers' interpretations of qualitative data are plausible and conclusions well justified.[148] Hammell (207:135) further notes that a major limitation to meta synthesis of qualitative studies is failure to incorporate a peer-review by people with SCI.

Ottomanelli and Lind (2009) found that research about vocational outcomes and SCI has used varying definitions of employment and has been inconsistent in tracking factors such as time since injury, term of or length of employment, match of employment with skills and abilities, etc., and therefore results are often difficult to compare or

[148] See Hammell (2007:135)

generalize. The authors call for greater consistency of classification of vocational outcomes and for researchers to be detailed in defining employment for the purpose of their studies. They further urge an "Examining [of] current employment rates and employment history in conjunction with each other may be more beneficial than looking at either alone" page 504. Another variable often not considered is whether individuals who sustained SCI also experienced a traumatic brain injury, and how this may be relevant for vocational outcomes.

5.0 Client Service Coordination Program

5.1 Client Population

Primary Target Group: Individuals with a spinal cord injury, and their families.

Secondary Target Group: Individuals with other physical disabilities.

5.2 Program Assumptions

- Individuals with SCI can live full productive lives in the community.
- Each client situation is unique with unique needs, life experience, life skills, coping skills and therefore requires an individualized approach to service.
- The impact of SCI affects all areas of an individual's life and needs a holistic approach.
- Early engagement, as soon as possible after the injury, is critical.
- Limitations to independence often reside in the environment where accessibility varies and can create challenges for individuals with SCI.
- Over their lifespan, the individual with SCI will encounter changing needs and circumstances or new emerging challenges, which may require additional information or support.
- Individuals with SCI want to restore power and control over their own lives. Individuals with SCI should be empowered to live as independently as possible, with responsibility for making their own decisions, setting their own goals and directing their own life path.
- Individuals with SCI benefit from peer support and peer mentorship, especially those who are newly injured.
- CPA (Alberta) is recognized by health services as a full partner in contributing to the long term rehabilitation success of people with SCI.
- CPA (Alberta) is known for its expertise in working with SCI and shares this expertise with other community service providers.

Based on these assumptions, the following Theory of Change has been developed.

5.3 Theory of Change

If individuals with spinal cord injuries and their families have practical, emotional and service coordination support in their transition from hospital rehabilitation to community, in their adaptation to community living and access to intermittent support as needed over their lifespan, they can maximize their independence, optimize their physical, spiritual and emotional (overall) health and well-being and be a full participant in community life.

5.4 Goal

The goal of Rehabilitation Support and Service Coordination is to ensure that individuals with spinal cord injury or other physical disabilities and their families receive the support they need after injury to transition effectively from hospital back to their community, and supports as needed across their lifespan, such that they are able to achieve their optimal level of independence and integration in the community.

5.5 Client Service Coordination Role

Client Services Coordinators (CSCs) work directly with individual with SCI and their families, beginning at the time of injury (i.e. hospital liaison), to identify unmet needs, help access services, and set goals for the future. Their work is critical to ensuring that consumers avoid confusion, frustration, and hopelessness as they undertake the daunting task of adjusting to life with an SCI. They continue to be available to clients as they age with a disability, helping them to adjust and access necessary services as required.

In their role as “hospital liaison” the Client Service Coordinators who are assigned this role take responsibility for development and nurturing of strong collaborative working relationships with hospital/rehabilitation service provides and staff, in the interest of ensuring that clients have access to seamless and holistic supports that follow them into the community.

The CSC also acts as system navigator by providing individuals with SCI and their families with information on community resources, support as needed to access those resources, and advocacy in cases where resources where may be difficult to access. In rural areas in particular where community resources and services may be limited, the CSC role may include a community development aspect as they advocate for service development and improvements.

The CSC provides expertise, information and consultation to other service providers, including through in services and training. Maintaining strong relationships with other

service providers is particularly important in rural areas where local clients may have been discharged to the region so quickly from Calgary or Edmonton that they man not have connected with their regional CSC. In rural areas, the CSC relies on the awareness of other local service providers to refer these clients to CSC for support.

Aboriginal clients and Aboriginal communities are served through the Aboriginal CSC program whose workers forms part of the CSC team but are funded through separate channels. CSC workers from the Aboriginal program are better positioned to engage Aboriginal clients based on an Aboriginal worldview, common cultural experience and understanding, spirituality, as well as knowledge of systems, services, entitlements and issues specific to Aboriginal communities and First Nations status.

Client Service Coordinator Responsibilities Summary

- Provide assessment of client needs which may include physical, emotional and sexual health, housing, transportation, equipment, recreation, education and employment.
- Develop rehabilitation plans by assisting clients in identifying and setting goals and monitoring progress.
- Enhance public knowledge of available services by developing and maintaining effective working relationships with clients and their support networks, hospital staff, community agencies and government departments.
- Provide information for clients and their support networks to make informed decisions, access appropriate service and to advocate on their behalf.

The intensity and duration of the service depends very much on the individual, including the severity of the injury, how long they are an in-patient, whether they can go home or have to find other housing, what kind of insurance or other financial supports they might have access to, etc. Service can last from a few weeks to a couple of years, but the average duration is 6 months of weekly contact. In some, smaller communities, it may be as much as 2 to 3 times per week for the first year, and once a week after that. In-hospital contacts may be just a few minutes of checking in, but home visits can last a couple of hours.

All CPA (Alberta) services are voluntary and provided free of charge. A typical full time CSC caseload is approximately 20 to 30 active cases, but this may vary by region.

5.6 Service Phases

There are three distinct phases of service within the realm of Client Service Coordination:

- **Transition Phase** – from rehabilitation hospital to community

- **Adjustment Phase** – adjustment to community living during first five years post injury
- **Service on Request Phase** – covers those individuals who are no longer active but who may require future intermittent and ad hoc support to deal with issues or challenges as they emerge over the lifespan. These requests for service are client initiated. Only those situations requiring more than 3 hours of CSC service are reopened as an active file. Other requests are dealt with quickly and the client remains a "service on request" file.
- **Closed** – a client file is considered closed only if the client dies, moves out of province or the client requests "no contact". All other non-active files are classified as "service on request" in recognition of the potential future service needs that may arise across the lifespan.

5.7 Transition Phase

The initial contact with clients (individuals with SCI) and/or their family members typically occurs while the injured person is still in hospital/rehabilitation and ideally commences as soon as possible after the injury. In some cases the CSC may even connect with an individual while they are still in acute care, and sometimes the first point of contact is with a family member. Initial contact is made by the CSC assigned ***"Hospital Liaison",*** who may also connect the client with a Regional CSC, peer support or another CPA (Alberta) staff member with whom they might better engage, depending on their age, gender, Aboriginal background, etc. Another useful method for engagement has been use of CPA (Alberta) videos showing the real life experiences of others with a SCI. In addition, CPA (Alberta) provides a six week, twelve unit Spinal Cord Education series on a continuous basis at the hospital/rehabilitation centre.

Purpose of Transition Phase

- To make client aware of supports available to them through CPA (Alberta)
- To engage the client in a relationship built on trust in order to reduce anxiety and increase hope for a positive future
- To offer emotional support, practical advice and information to the clients and/or family members, provide a listening ear and understanding
- To demonstrate what adjustment to their injury and new life might look like - act as a role model or connect to potential peer role model
- To prepare the client for transition to the community mentally and emotionally and through assessment of needs, goal setting, and connection with appropriate community services.

In addition to the Hospital Liaison CSC visits, the Peer Support Program Coordinator may offer peer events/activities at the hospital/rehabilitation centre. In Calgary, peer events/activities are offered at the hospital/rehabilitation centre on a regular basis approximately twice a month.

5.8 Adjustment Phase

Once the client has been discharged from hospital/rehabilitation to the community, it is the Client Service Coordinator who provides follow up support services. The CSC may be assisted by other team members, under the direction of the CSC to help meet demand, or to ensure a more comprehensive service where another team member can offer a particular expertise (e.g. accessibility assessment). With clients who will be living in Calgary and Edmonton, they may stay on the caseload of the CSC who is the hospital liaison, or be assigned to another CSC. Those who move back to their home communities outside Calgary and Edmonton join the caseload of the CSC in that area. Aboriginal clients are served through the CSC Aboriginal program staff, who also liaises with organizations in the client's home community.

Purpose of Adjustment Phase

- To support client's adjustment to living at home and in the community with a SCI
- To assess client's needs in the community, e.g. determine functionality of home environment and how this might best be adapted or what additional equipment might be helpful
- To provide information, referrals and support for clients to access the community programs and services they need (e.g. financial supports, housing, transportation, equipment, etc.)
- To provide emotional support and encouragement during the early stages of adjustment to life with a SCI
- To provide practical information and act as a role model or connect to potential peer role model
- Connect client with peer support services for emotional support, role modelling, social support and leisure activities
- Provide family members with practical advice, information, referral and emotional support
- To empower clients to be as independent as possible and encourage clients to plan their future.

It is desirable to have the first visit after hospital/rehabilitation discharge in the home or place of residence, in order to assess the client's needs and determine any potential barriers in the home or local environment. After the initial visit, service location may

vary, with service provided in the home, in the community or at the local CPA (Alberta) office. Service contacts may also be made by telephone, email, etc.

At the first home visit, an initial assessment is conducted, and an individualized rehabilitation plan (IRP) is developed that includes goal setting. Four or five goals are usually set and then, as they are achieved, new ones are formulated. Once all goals are met, the client's status changes from "active" to "service on request" meaning that the client may self-initiate contact with CPA (Alberta) at any point in the future for information or support to address a specific need or issue.

A Client Services Manual sets out procedures regarding what information should be provided when. For many needs, such as housing, employment, equipment, transportation, or funding, referrals are made to other service providers. The Client Services Coordinator acts as a 'systems navigator', helping clients to find funding and resources and providing assistance, in completing applications or preparing appeals. The CSC also provides information, advocacy, and social support, and helps to coordinate all the services needed. In addition, the CSC may help clients to explore interests in recreation/leisure or social activities and provide information on options. CPA (Alberta) has videos that illustrate adapted recreational activity options. The nature of the CSC's role depends somewhat on the geographic location.

5.9 Service on Request Phase

CPA (Alberta) services are always available to clients at any time throughout their lifespan. In order to facilitate this access, files are not closed after all goals are completed, but are reassigned to "service on request" status.

Over the course of an individual's life, circumstances or issues may arise in which the person seeks additional information or support through CPA (Alberta). Service needs vary greatly and may include practical issues such as housing, transportation, education, and finances, as well as personal/health issues such as sexuality, emotional health and caregiver issues. The approach is for CSC staff to serve as a resource to empower the client to do what he or she can on their own, providing information, referral, service connections, and advocacy as required.

For brief interventions of less than 3 hours, the service request is handled informally by the CSC. These requests often involve basic provision of information or guidance and the client manages the need/issue on their own. For more complex needs requiring more than 3 hours of service, the CSC will re-activate the client file, work with the client to set a goal and to complete that goal. Once the goal is completed, the file is returned to "service on request" status.

Purpose of Service on Request Phase

- To support clients to maintain their optimal independence and functioning over the lifespan.
- To provide information, referral and support to address issues that may arise at different stages of life or as a result of changing circumstances.
- To provide emotional support for clients and/or their family members.
- To ensure clients have access to the best and latest information available to address their interests and needs as they arise.

5.10 Complementary Services

CPA (Alberta) offers a number of complementary services that can be accessed by clients in order to enhance their progress and overall well-being.

Helping Way is an emergency fund of up to $1,000 annually available to clients to assist with a variety of special issues or circumstances (e.g. special equipment, rent/damage deposit shortfall, etc.). The fund is accessed through the CSC depending on client needs and circumstances.

Peer Support
Although Peer Support Services are considered a separate program offering at CPA (Alberta), they complement CSC, and help to engage and support clients in the realization of their personal goals. Individual Peer Support Services include peer matching and peer mentoring. Peer support services offer personal/social relationships, coaching and role modelling in a way that a professional CSC relationship cannot. Peer Support Services are offered to all CSC clients beginning when they are still in hospital or rehabilitation. Peer Support Services include one on one peer support visits as well as some peer group activities, special events and regular peer group outings. Peer Support offerings vary between regions depending on client interests, needs and availability of peer support volunteers.

Psycho-Education Groups – e.g. Discovering the Power Within Me.
Psycho-education groups are offered when resources allow. Some regions also offer spousal support groups.

Community Development
While the Client Service Coordinator prepares the client for return to the community, the Community Development Coordinator prepares the community for the client. The Community Development Coordinator worker performs accessibility audits on public spaces and building, and works to create positive relationships with community leaders and to raise awareness of the need of people with disabilities. The CSC may access the services of the Community Development Coordinator to help audit accessibility in the

client's living environment (e.g. neighbourhood, work space, etc.) and inform the client, community, school or employer on accessibility improvements or accommodations.

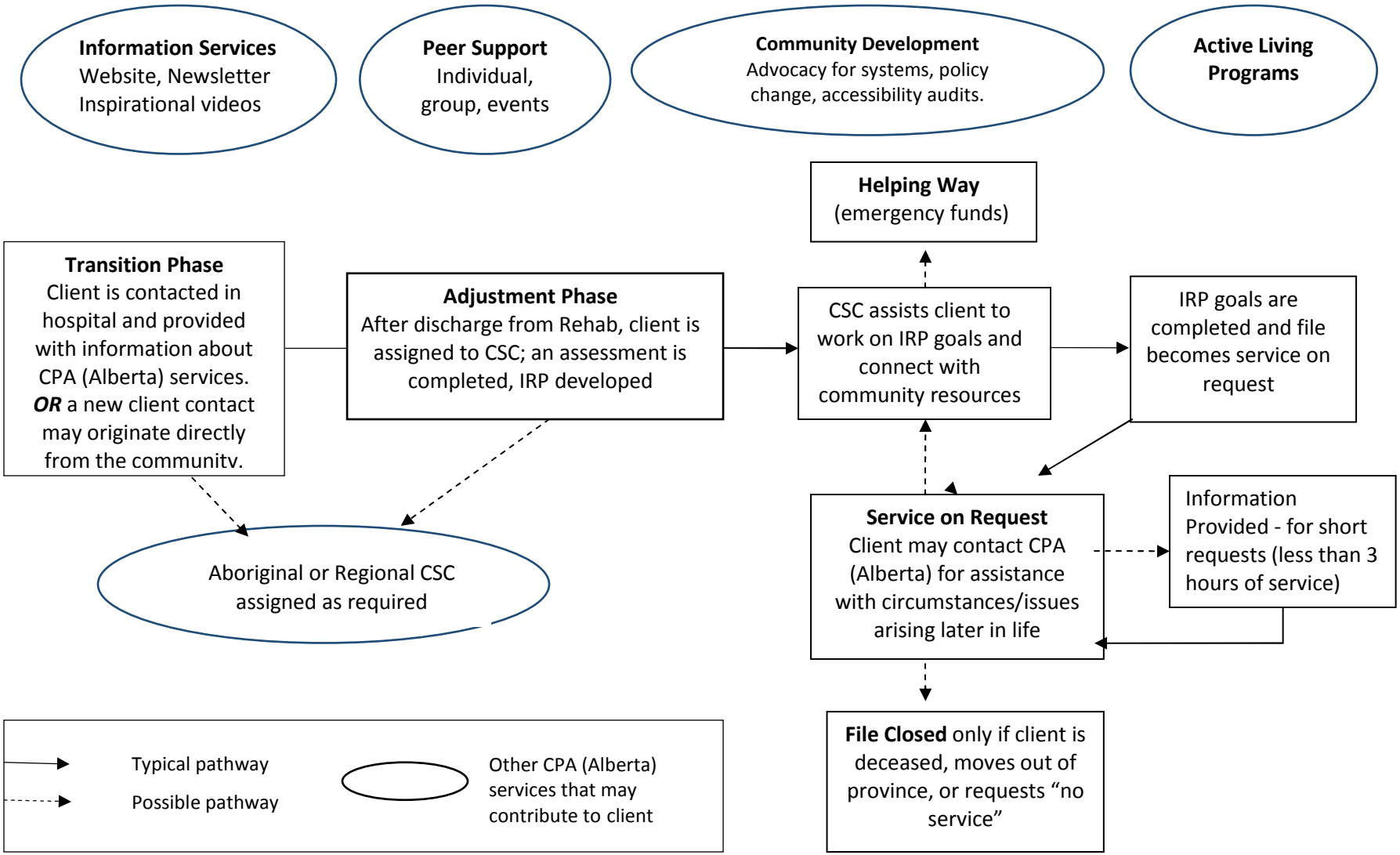
Information Services
CPA (Alberta) provides a broad range of information services that are directly accessible to clients, family and community through the website, newsletter or through the CSC or other CAP staff. Information services include on-line community resource guides and an on-line library of over 100 inspirational videos sharing the knowledge and experience of peers. Information services take an active role in addressing short term service needs (less than 3 hours service) of self-initiated "service on request" made by clients or others in the community.

Active Living
The focus on active living at CPA (Alberta) has been fairly recent but has grown tremendously over the past two years with the introduction of the Adapted Adventures program in Edmonton and the launch of the CPA (Alberta) Fitness and Wellness Centre in Calgary. Medicine Hat and Grande Prairie also have Active Living programs. The Active Living program supports repetitive training in order to increase functional capacity. Research is showing that early involvement in adapted physical activity optimizes recovery and leads to better overall health. Information and referral to Active Living programs may be made through the CSC to address individual client's IRP goals.

5.11 Closing Files

Files are closed only when a client dies, moves out of province or requests "no contact". Otherwise, those files where a client is not actively working on a goal are set to "service on request" status.

6.0 CLIENT SERVICE PATHWAY



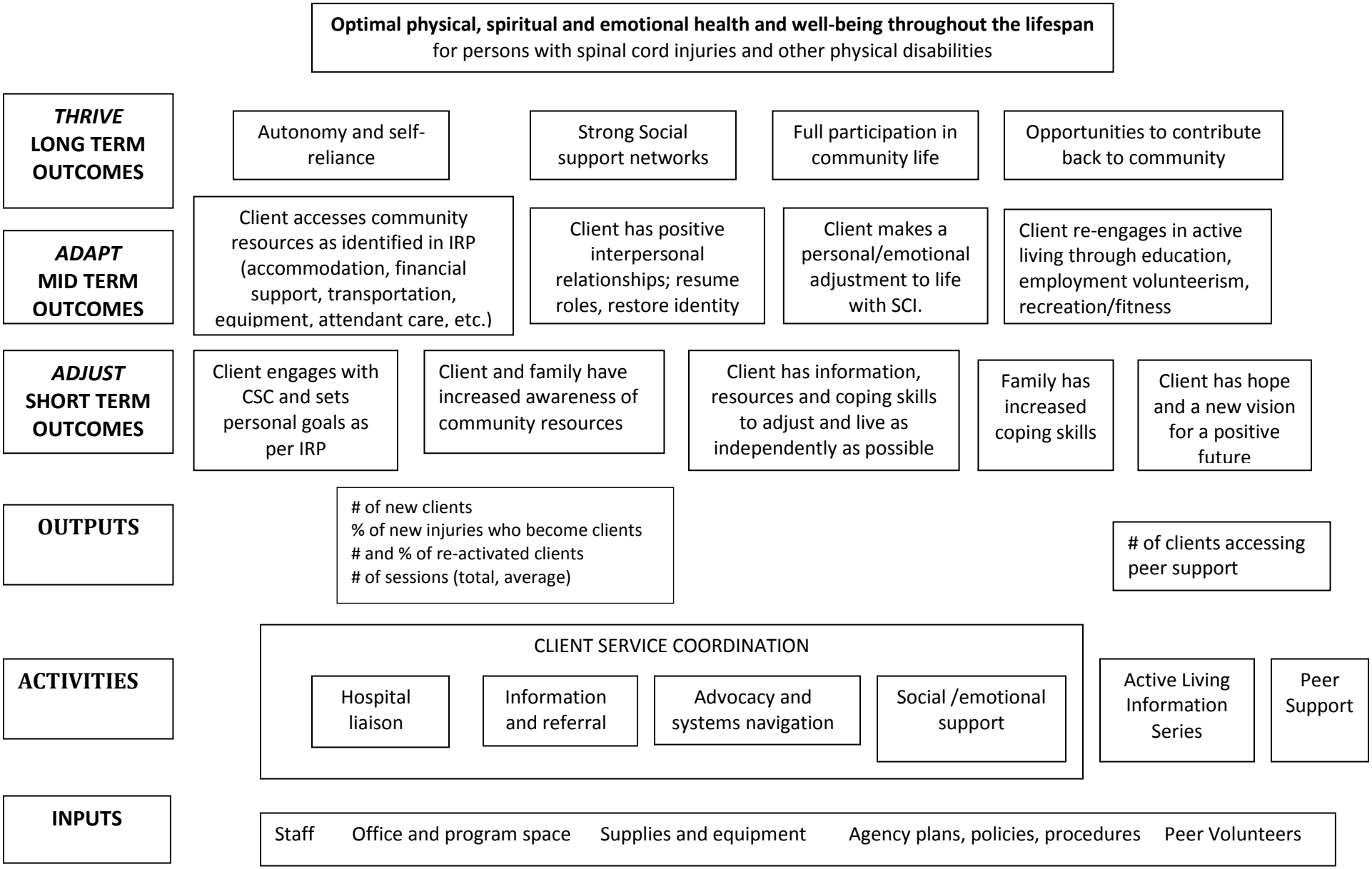
7.0 Interventions and Strategies

Interventions	Strategies	Outcomes
Engagement & Transition Support	• Earliest possible CSC Hospital Liaison contact with client and/or family while in hospital or rehabilitation. Build trust. • Emotional support and encouragement for client and family members. • Information provided to client and family members re community resources and options, "Life After SCI" booklet. • Six week, 12 unit Spinal Cord Education series offered while client is in hospital/rehabilitation. • Offer client peer support connection. • Increase hope for a positive future through role modelling, peer support, CPA (Alberta) inspirational videos.	Client and/or family is connected with CSC and knows about CPA (Alberta) services. Client and family have increased awareness/knowledge of community resources and options. Client has information, resources and coping skills to adjust and live as independently as possible. Family has increased coping skills Decreased anxiety re unknown – client has hope and a new vision for the future.

Interventions	Strategies	Outcomes
Community Adjustment	• Assign personal CSC worker. • Visit to home or place of residence within first month post discharge. • Individual needs assessment and assessment of the client's environment/barriers/accessibility. • Set up Individual Rehabilitation Plan (IRP) with client directed goals. • Support client to access community resources and address goals identified in the IRP. • Provide information on Active Living services and options. • Connect client with Peer Support for increased social support, coaching, positive role modelling, social/emotional support. • When all goals on IRP have been addressed, file is moved from "Active" to "Service on Request" status	Individual and family needs are identified. Client sets personal goals in their Individual Rehabilitation Plan (IRP). Client accesses community resources (accomodation, financial support, transportation, equipment, attendant care, etc.) needed to meet personal goals in their IRP. Client has positive interpersonal relationships resumes roles, restores identity. Client makes a personal/emotional adjustment to life with SCI.
Service on Request	• Client initiated and client directed service request. • Provide information to help client address their own need/situation. • Connect client with CSC for individualized support where service needs exceed 3 hours of support/intervention – initiate IRP with client directed goal setting. • Support to access information or community resources to meet self-identified goals.	Client access information, support, resources to meet identified needs and goals. Client's independence and physical/social/emotional wellbeing is improved or maintained.

Interventions	Strategies	Outcomes
Community Participation	• Client is encouraged to give back through CPA (Alberta) membership and/or peer support activities (e.g. volunteerism, community involvement, one on one or peer group activities, activism, service planning, CPA (Alberta) Board, etc.)	Over time, client re-engages in active living through education, employment, volunteerism, recreation/fitness. Client makes a contribution in their community

8.0 CLIENT SERVICE COORDINATION PROGRAM LOGIC MODEL



CPA (Alberta) Rehabilitation and Client Services Program Logic Model Target Group: Individuals with SCI or other physical disabilities and their families					
Goal	**Short Term Outcomes**	**Mid Term Outcomes**	**Long Term Outcomes**	**Indicators**	**Measures**
	ADJUST	**ADAPT**	**THRIVE**	STO#1: % of potential clients and/or families contacted who engage with CPA (Alberta) and have active goals	Rick Hanson Registry and CORE Database[149]
Optimal physical, spiritual and emotional health and well-being for persons with SCI or other physical disabilities	Client and/or family sets personal goals in their Individual Rehab Plan (IRP) Client and family have increased knowledge of community resources. Client has information, resources and coping skills to adjust and live as independently as possible. Family has increased coping skills. Client has hope and a new vision for a positive future.	Client accesses community resources they require as identified in their IRP (e.g. accommodation, financial support, transportation, equipment, attendant care etc.) Client has positive interpersonal relationships; resumes roles, restores identity Client makes a personal/emotional adjustment to life with SCI. Client re-engages in active living through education, employment, volunteerism, recreation/fitness.	Client experiences autonomy and self-reliance Client has strong social support networks. Client is a full participant in community life. Client contributes back to the community.	STO#2: % of clients who say they have increased knowledge of community resources STO#3: % of clients who made progress on their goals (i.e. attain at least one goal other than "Family" category during the reporting period) STO#4: % of families with goals who make progress on goals in category Family & Other Significant (attain at least one goal during reporting period) STO#5: % of clients who feel more hopeful because of CSC MTO#1: % of goals attained by type of goal MTO#2: % of clients who report that they have positive and supportive interpersonal relationships in their life MTO#3: % of clients who attain goal re personal adjustment, understand and cope with injury MTO#4: % of clients who reconnect with education, employment, volunteer activities or recreation/fitness LTO#4: examples of clients who give back to their community	Exit Survey CORE Database CORE Database Exit Survey CORE Database Exit survey CORE Database CORE Database and Exit Survey Success Stories

[149] Community Outcomes Reporting and Evaluation (CORE) Database

9.0 Data Collection Plan

CPA (Alberta) Rehabilitation and Client Services – Data Collection Plan		
Short-term Outcomes	**Indicators of Success**	**Measurement Tools**
STO #1 ADJUST Client engages with CSC and sets personal goals in their Individual Rehab Plan (IRP).	% of potential clients contacted who engage with CPA (Alberta) and have active goals	Take potential client numbers from Rick Hanson registry or Foothills/Glenrose Hospital stats. # of active files from CORE program data
STO#2: ADJUST Client and family have increased knowledge of community resources.	% of clients who say they have increased knowledge of community resources	Exit survey (volunteers could assist with exit survey implementation)
STO#3: ADJUST Client has information, resources and coping skills to adjust and live as independently as possible.	# of clients who made progress on their goals (i.e. attain at least one goal other than "Family" category during the reporting period)	CORE program data
STO#4: ADJUST Family has increased coping skills.	% of client families who make progress on goals in category Family & Other Significant (attain at least one goal during the reporting period)	CORE program data (need to know # of families with a service goal and those who make progress on goals)
STO#5: ADJUST Client has hope and a new vision for a positive future.	% of clients who feel more hopeful because of CSC involvement	Exit survey Success stories

CPA (Alberta) Rehabilitation and Client Services – Data Collection Plan		
Short-term Outcomes	**Indicators of Success**	**Measurement Tools**
MTO#1: ADAPT Client accesses community resources they require as identified in their IRP (e.g. accommodation, financial support, transportation, equipment, attendant care etc.)	% of goals attained by type of goal	CORE program data
MTO#2: ADAPT Client has positive interpersonal relationships; resumes roles, restores identity	% of clients who report that they have positive and supportive interpersonal relationships in their life	Exit survey
MTO#3: ADAPT Client makes a personal/emotional adjustment to life with SCI.	% of clients who attain goal re personal adjustment, understand and cope with injury	CORE program data – Health and Wellness: personal adjustment; understand and cope with injury
MTO#4: ADAPT Client re-engages in active living through education, employment, volunteerism, recreation/fitness	% of clients who reconnect with education, employment, volunteer activities or recreation/fitness	CORE program data Exit survey reports volunteerism
LTO#1: THRIVE Client experiences autonomy and self-reliance	Not measured at this time.	Not measured at this time.

CPA (Alberta) Rehabilitation and Client Services – Data Collection Plan		
Short-term Outcomes	**Indicators of Success**	**Measurement Tools**
LTO#2: THRIVE Client has strong social support networks.	Not measured at this time.	Not measured at this time
LTO#3: THRIVE Client is a full participant in community life.	Not measured at this time.	Not measured at this time.
LTO#4: THRIVE Client contributes back to the community.	Examples of how clients thrive and give back to their community.	Success stories.

10.0 Outputs Summary (2014)

United Way Reports	Edmonton	Calgary	Red Deer	Medicine Hat	Grande Prairie	Fort McMurray
# Total Unique Participants (0-17, 18-64, 65+) + gender for Medicine Hat	√	√	√	√	√	√
# Aboriginal Participants (0-17, 18-64, 65+)	√	√				
# Immigrant & Refugee (0-17, 18-64, 65+)	√					
# of unique family units	√	√	√	√	√	
# of unique individuals "new" to your program		√				
# of contacts served		√	√	√	√	
# of Volunteers	√	√	√	√	√	
# of Volunteer Hours	√	√	√	√	√	
Areas served			√			
Types of activities/services provided						√
# of requests received						√
# of service hours completed						√

Alberta Human Services	Cross Disability Supports	CAPCC
# of clients served (active files)	√	√
# of new client files opened	√	
# of client files closed	√	√
# of client files "on hold"		√
# of clients on wait list		√
# of clients whose needs could not be met and why	√	
Primary and secondary diagnosis of client served	√	
# and type of CSC strategies used		
# and type of information inquires	√	
# of referrals to CPA and source	√	
Success stories and narrative report	√	√

Aboriginal Program *(assuming this is sorted by Aboriginal clients only?)*	**First Nation Inuit Health Branch**	**Aboriginal Affairs & Northern Development**
# of clients new to the program (signed application or service)	√	√
# of client with goals in progress	√	√
# of clients with goals attained	√	√
# of active goals by category	√	√
# of hours spent on information service	√	√
# of information requests by category	√	√

Client Service Coordination Program	CPA (Alberta) Board	Spinal Cord Injury Canada (National)
# of clients "new injuries" (Disability, Gender, Age, Cause of Injury)	√	
# of client "service agreement date" (Disability, gender, age) then (SCI; non SCI, Injury Dates)	√	
# of clients who received service (isn't this the same as "active")?	√	
# of clients active, service on request, closed, transferred out of province	√	
# of clients by referral source	√	
# of clients with new IRP started	√	
# of clients with IRP closed (isn't this the same as "service on request" above?)	√	
# of clients with goals by goal status: • new goal started; goal attained; in progress; pending; terminated by client; terminated by CSC; not able to complete	√	
# of clients served (SCI, Non SCI) by service Category: • Employment/Vocational • Health and Wellness • Housing and Accommodation • Transportation • Supports for Independence	√	√
# of services provided (SCI, Non SCI) by category (as above)	√	√
# of goals attained by category (as above)	√	
# of hours of service by category (as above)	√	
# of clients seen at Glenrose outpatient clinic	√	
# of clients seen at Foothills Education Series	√	
Success Stories	√	

Peer Support Program	CPA (Alberta) Board	Spinal Cord Injury Canada (National)
# of peer program introductions to persons with new injuries , mobility disability and/or and their families	√	√
# of follow up meetings with new regional members	√	√
# of support calls made to participants and/or family members	√	√
# of support or information requests received/met	√	√
# of hours spent by each Peer Mentor with participant	√	
# of training sessions for Peer Mentor volunteers	√	
# of training sessions attended by Peer Coordinator	√	
# of peer matches CPA Alberta only: location of matches, type of match - peer, family , friend	√	√
# of new participants waiting to be matched	√	
# of group sessions by type: • Informal (social, recreational); Knowledge Seminars (Educational); Conferences; Care Taker/Family/Healthcare Sessions; Webinar	√	√
# of participants at group events • Informal • Webinar	√	√
# of Peer Events (Social) (*hosted by peer coordinator?)*	√	√
# of participants at each event (peer, family, volunteer, staff)	√	√

Adapted Adventures Program	CPA (Alberta) Board
# of participants per program	√
# of new participants (never participated before)	√
# of events	√
# of people at events	√
# of volunteers	√
# of volunteer hours	√
New initiatives	√
# of sponsors	√
new funding	√
New equipment purchased	√

Community Development Program	CPA (Alberta) Board
# of requests received by category	√
# of hours spent on each request	√
# of requests completed; ongoing; pending	√
Success stories	√
Trends and challenges	√

Workers Compensation Board	
# of kilometers Travel time Meal costs	During first 6 month of post injury, CSC may bill up to 6 hours per month per client; during last 6 months of injury CSC may bill 4 hours (*per month?)* per client.

11.0 Client Exit Survey for Client Service Coordination

Instructions: To be completed within three months after client has completed their final goal on the IRP or has discontinued their IRP and moved to "service on request". All surveys are considered anonymous unless otherwise requested by the client.

Date of Survey Contact: _____

Preamble for Phone Surveyor:
My name is _____ and I am calling on behalf of CPA (Alberta) to get your feedback on your experience with our services. Your Client Service Coordinator was _____. Now that you have completed your Individual Rehabilitation Plan, we would appreciate your feedback on your experience with the Client Service Coordination service. I am going to ask you to think about how you are doing now and then compare that with how you were doing when you were first injured.

Using a scale of 1 to 5 where 1 is Poor and 5 is Excellent, how would you rate (read question) **NOW** and how would you rate this **BEFORE** you had Client Service Coordination support when you were in the hospital (e.g. before when I was in the hospital – my knowledge of community supports and programs available to me was . . .)

1 = very poor 5-- excellent	**How I feel now**	**Before when I was in hospital**
My knowledge of community supports and programs available to me.	1 2 3 4 5	1 2 3 4 5
My relationship with my family.	1 2 3 4 5	1 2 3 4 5
My relationship with friends. (have at least one close friend who you connect with)	1 2 3 4 5	1 2 3 4 5
My personal support network – people I can rely on or talk to when needed.	1 2 3 4 5	1 2 3 4 5
My ability to manage my life with a Spinal Cord Injury.	1 2 3 4 5	1 2 3 4 5
My sense of hope for the future.	1 2 3 4 5	1 2 3 4 5

Overall, how satisfied are you with the services you have received from your Client Service Coordinator?

1	2	3	4	5
Very Dissatisfied	Dissatisfied	Somewhat Satisfied	Satisfied	Very Satisfied

Do you have any other comments you would like to add?

Would you be interested in working with us to tell you story on video as an example to others?

☐ Yes ☐ No ☐ Maybe at another time

Would you be interested in working with us as a peer support worker or a volunteer?

☐ Yea ☐ No ☐ Maybe at another time

If yes to video or peer support, can I forward your name and contact number so someone can get in touch with you?

☐ Yea ☐ No

Only insert name if client has given permission for contact.

Name: _____

Contact Information: _____

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