



Discussion Paper - DRAFT 1

Towards an **ACTIVE LIVING STRATEGY** for Albertans with Spinal Cord Injury: 2008 to 2012

Context

In response to a proposal from the Rick Hansen Foundation, the Province of Alberta has provided \$12 million to support the work of the Alberta SCI Solutions Alliance over the five year period from 2008 to 2012. \$500,000 from this fund has been dedicated to 'Active Living' for Albertans with SCI.

In early February, interviews were conducted with 25 Alberta organizations interested in active living for persons with disabilities. A 'response summary', along with this discussion paper will provide the foundations for two workshops to be held mid-March.

Our next report will develop a vision to guide the active living strategy, define strategic focus and priorities; and establish guidelines for expenditure of the half million dollar fund.

March 7, 2008

Reflection



The Alberta Centre for Active Living describes 'active living' as a unique Canadian approach to physical activity. A way of life in which physical activity is valued and integrated into daily living. Active living recognizes the benefits of many different activities: from walking and simple tasks to more vigorous activities such as running. In this context, **the nature, form, frequency and intensity of physical activity is related to each person's ability**, needs, aspirations and **environment** (1).

The Active Living Alliance for Canadians with a Disability has attracted over 500,000 contacts interested in addressing accessibility issues for persons with special needs. They share a vision: **a society where all Canadians lead active and healthy lives** (2).

“While an active lifestyle is important for all Canadians, it is particularly important for those with a disability. Research has demonstrated that active individuals can enjoy better overall health, improved quality of life, elevated self-esteem, prolonged independent living in later life, and increased mobility. For individuals with a disability, these benefits help make coping with the everyday challenges of life easier, and can even prevent relapses of certain disabilities or health problems.” (3)

We know that people with spinal cord injury (SCI) represent one of the most physically inactive segments of society (4). Note a definition for SCI used by CPA Alberta is listed with references. Physical activity participation rates are substantially lower than in the general population (5) and it has been estimated that 50% of people with SCI participate in no physical activity whatsoever, compared with about 35% of Canadians without a disability (6). One study reports that people with SCI were completely inactive for 76% of their waking time (7) and (8).

The economic costs of inactivity alone justify intervention - particularly related to reduction in health care costs. Moreover, we live in a Province committed to the concept of full citizenship; persons with disabilities will be valued and included in all aspects of Alberta society (9). Participation in community based physical activity inevitably also involves social, intellectual, emotional and spiritual dimensions. A caring society can not tolerate excluding people with SCI simply because they cannot afford to participate (fees, attendant care), cannot find the required transportation, or because we have not thought to provide specialized staff or equipment required to address special needs and out public facilities.

This discussion paper paves the way for interventions that will accelerate improvements to the quality of life of Albertans with spinal cord injury, through active engagement in physical activity and community life. What we learn through this initiative and workshops will hopefully both develop and demonstrate best practices in Active Living that can be adopted for the broad and growing disability community.

Active Living through an SCI Lens



For a person with a high level quadriplegic injury (C6 and above), with no grip and unable to lift his or her arms above the head, any physical activity that expands breathing capacity or enhances existing muscle movement will have immense value to health, function and independence; singing and chess might be ideal. Others (quadriplegic C7-T1) might be interested in Wheelchair Rugby.

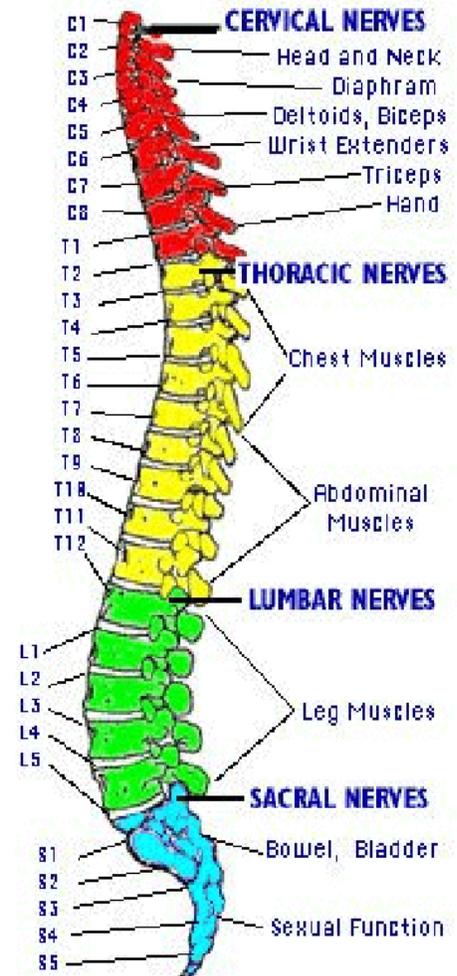
Albertans with paraplegia might have trouble maintaining balance in a kayak even though they have full use of their arms (T5) while others (L3-S2) will have full use of trunk and arm muscles and could thrive on the transfer to a sledge for an aggressive game of hockey. One disability category (SCI) – but not a full range of opportunity.

For many, the effort involved in getting to a social event is a workout in itself. Others will be the first on the dance floor, perhaps even thinking about the possibility of international wheelchair dance competitions.

One person's workout would challenge a typical Ironman; for example, a wheelchair athlete speeding along roads or pathways with serious competition in mind. Another's experience would be much like anyone else's in the fitness club, except that the equipment might look just a little different; all engaged in traditional strength and endurance exercise. Others would be expanding their physical, functional and career horizons using electrical stimulation (FES) during their exercise regime.

For some, it's just about deciding on the spur of moment to go for a spin in a nearby park. For others, active living involves arranging for transportation, scheduling an attendant, and finding related dollars to support an outing to a fitness facility/program.

For most, if not all, the AL experience is about more than just the physical activity and related health benefits. It is also about building self – esteem, confidence, making friends and enhancing quality of life. It's really about participating fully in a welcoming community through the opportunity of leisure.



FOCUS for Active Living with the SCI community:

Active living is a way of life that integrates physical activity into daily living so as to optimize health and wellbeing; also,

- health & wellbeing is viewed from a holistic perspective encompassing physical, social, intellectual, emotional and spiritual dimensions
- the nature, form, frequency and intensity of physical activity is relative to each person's ability, needs, aspiration and environment
- AL Strategy values a population-health approach to active living communities with a behavioural perspective towards creating the social and physical environments that promotes and supports participation by Albertans of all ages, abilities and cultures.

Priority Outcomes - Keeping our eye on the ball!



People with disabilities select discretionary or leisure activities to improve their quality of life. Choices are made for personal reasons. However, when a community decides to invest together to improve social good, decisions are purposeful and designed to achieve relatively specific outcomes or results.

Canada has invested in health promotion interventions since Mark Lalonde, then Minister of Health, spoke of the 'Health Field Concept' in the early 1970's and supported the launch of ParticipACTION. In the late 1990's, the current Minister of Health Allan Rock re-emphasized the importance of the physical activity strategy:

"The Federal Government recognizes that regular physical activity helps Canadians get healthy and stay healthy.

Two thirds of Canadians today are at increased risk for heart disease, obesity, high blood pressure, adult onset diabetes, osteoporosis and other serious diseases because of inactive lifestyles."

The Canadian Fitness and Lifestyle Research Institute showed that a 16% increase from 1981 to 1995 in Canadians who were physically active translated into savings of \$9 billion because of reduced costs in health care, life insurance, sick leave, disability coverage, group life insurance, and lost tax revenues.

In 1997, the Canadian Parks/Recreation Association, with support from Health Canada, published the Benefits Catalogue that reviewed over 700 research studies demonstrating the following benefits or outcomes of active living or physical activity (10).



Proven Benefits or Outcomes of Active Living

Enhanced Function	Physical Health	Mental Health	Social Wellbeing
<ul style="list-style-type: none"> ▪ prolongs/supports independent living ▪ motor skill development ▪ increased strength and endurance ▪ increased lung volumes and flow ▪ higher educational, occupational and athletic aspirations ▪ improves general cognitive functioning ▪ increases disability adjustment ▪ improves work performance 	<ul style="list-style-type: none"> ▪ helps people live longer ▪ reduces risk of heart disease and stroke ▪ helps prevent colon, lung and breast cancer ▪ combats diabetes ▪ combats osteoporosis ▪ prevents and rehabilitates back problems ▪ significantly reduces health care costs through prevention and/or faster recovery 	<ul style="list-style-type: none"> ▪ reduces stress and anxiety ▪ relieves depression and risk of depression ▪ contributes to emotional and psychological wellbeing ▪ enhanced self-concept and self-esteem ▪ improves coping behaviours 	<ul style="list-style-type: none"> ▪ improves social skills, socialization, cooperation and interpersonal interactions ▪ reduces isolation, loneliness and alienation ▪ stimulates participation in community life ▪ enhances life satisfaction levels and perceived quality of life

Physical activity is a proven therapeutic tool, utilized in hospitals, rehabilitation centres, clinics and communities everywhere to help restore physical, mental and social capacities and abilities. People with disabilities who practice active living can enjoy better overall health, enhanced immune function, increased function and mobility, and increased independence. These benefits can make coping with the everyday challenges of life easier; can prevent health relapses and secondary complications; and increase the energy a person has to deal with the physical and mental challenges of a disability.

The following table provides evidence from the literature that many of the benefits mentioned above have been demonstrated in analysis of populations with SCI.

Proven Benefits or Outcomes of Active Living for Persons with SCI and their Communities

Enhanced Function	Physical Health	Mental Health	Social Wellbeing
<ul style="list-style-type: none"> ▪ higher educational, occupational and athletic aspirations (Hopper, 1985) ▪ average improvement in VO2 max of 20% after 4-20 weeks of training (Hoffman, 1986) ▪ significant increase in strength and endurance using voluntary exercise protocols (Bjerkefors, 2006; Hicks, 2003; Jacobs, 2001 reported in Ginis and Hicks, 2007; Durstine, 2000) ▪ significant increase in strength and endurance using involuntary or assisted exercise using FEW or BWSTT (Belanger, 2000; Hicks, 2005; Johnston, 2003, reported in Ginis and Hicks, 2007) ▪ increase flexibility (Durstine 2000) ▪ improvements in satisfaction with functioning (Hicks, 2005, Semerjian, 2005) 	<ul style="list-style-type: none"> ▪ reduce heart rate and blood pressure (Dustine 2000) ▪ maintain and enhance healthy bone density, muscles and joints (Dustine 2000) ▪ lower incidence of secondary medical complications (urinary tract infection, pressure sores, hyperextension) (Hjeltnes & Jansen, 1990; Rimmer, 1999) ▪ reductions in shoulder pain after 6-9 months of strengthening and stretching exercises (Curtis, 1999; Hicks, 2003; Nawoczinski, 2006, reported in Ginis and Hicks, 2007) ▪ improvements in satisfaction with health (Hicks, 2005, Semerjian, 2005) 	<ul style="list-style-type: none"> ▪ higher self esteem (Hopper, 1985) ▪ higher scores on vigour subscale and lower on depression subscales (Noreau, 1995) ▪ stronger self-image, higher level of self-satisfaction, fewer suicidal tendencies, and more independent attitude (Noreau, 1995) ▪ reductions in stress and depression after combined strength and endurance training (Hicks, 2003; Latimer, 2004, Martin Ginis, 2003, reported in Ginis and Hicks, 2007) 	<ul style="list-style-type: none"> ▪ gaining valuable social experiences (Blinde & McLung, 1997; Sawler, 2005; Sherril, 1984, 1998; reported in Sawler 2005) ▪ improvement in overall life satisfaction including social wellbeing (Hicks, 2005, Semerjian, 2005) ▪ using experiences that have supported their participation to challenge negative stereotypes about their disabilities (Blinde & McLung, 1997; Sawler, 2005; Sherril, 1984, 1998; reported in Sawler 2005) ▪ physical, functional and social inclusion (NCPAD, 2008)

This Active Living Strategy for Albertans with SCI is inspired by and focused on:

- 1) the urgent need to optimize health/overall benefits to individuals
- 2) cost savings to society in each of these critical outcome areas and most important
- 3) enhanced function, physical health, mental health, social wellbeing, individual quality of life



Vision



Full and equitable access to active living opportunities for Albertans with disabilities.

Active Living Alliance
for Canadians with a Disability
(Alberta)

All persons with disabilities, including First Nations, Metis, Inuit and other Aboriginals with disabilities, are valued as full citizens in all aspects of Alberta society - fully participating in the social, economic and political life of Alberta communities.

Albertans with disabilities receive the support they need to achieve a standard of living and quality of life that ensures health, safety, comfort and dignity.

Alberta Disability Strategy

Albertans with spinal cord injury and other physical disabilities will enjoy optimal physical, spiritual, economic and emotional well-being within fully accessible and welcoming communities free of physical, attitudinal and systemic barriers.

Canadian Paraplegic
Association (Alberta)

More than 100 organizations committed to making sure that the environments where we live, learn, commute, work and play support regular physical activity.

Coalition for Active Living

Persons with disabilities participate as full citizens in all aspects of Canadian society. The full participation of persons with disabilities requires the commitment of all segments of society. The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation.

In Unison
A policy and commitment
signed by Federal and Alberta governments

ParticipACTION's vision is to work with its partners to ensure a Canadian society where people are the most physically active on Earth.

ParticipACTION

Alberta has already made commitments to visionary outcomes that promise inclusive communities and equitable access to all aspects of community life. The AL vision below revises the focus of the broader policy promise on the SCI community specifically.

AL Vision Statement

Albertans with SCI will value active lifestyles and have the support they need to participate fully.

The expanded version below provides 'the meat' required to help us focus initiatives and interventions designed to make the vision live as our reality:

Albertans with SCI will value active lifestyles and have the support they need to participate fully.

- achieving enhanced function, health and wellbeing
- delivering significant return on investment, primarily through health care cost savings
- opening doors with and for other disability groups
- building inclusive communities in the process .

Conceptual Frameworks to guide the Strategy



Framework 1: The SCI Journey

From moment of injury, a person with SCI begins a journey along a continuum involving acute care in a hospital, active rehabilitation in a specialized centre, transition back into the community, and progress to full participation and citizenship. Many issues and challenges must be addressed along the way: psycho-social adjustment, assistive technologies, housing, personal and financial supports, educational support, vocational support, to name but a few. The framework below speaks only to the active living components along the way. It combines the SCI Rehabilitation and Quality of Life Service Continuum (from the RHF proposal to the Alberta government), with the CPA Rehabilitation Counselling Framework, with the essential steps taken in social marketing or health promotion.

The Active Living Journey for a Person with SCI

	Phase 1: Recovery	Phase 2: Transition to Community	Phase 3: Full Citizenship	Phase 4: Sustainability
General Challenge	In the acute care hospitals and active rehabilitation centres focus is on surgery, psycho-social adjustment, physio-therapy, assistive technologies, personal rehabilitation planning, and preparation for discharge.	Independent living adjustment related to home, transportation, finances, attendant care, equipment and family support. Also involves community service coordination and continued affective counselling.	Full participation in the social, economic and political life of Alberta communities. The supports required to be able to make and access choices related to education, employment and recreation opportunities.	Ongoing challenges related to health, family situations, employability that can require temporary or transition support. Advocacy to help communities recognize and address systemic barriers.
Active Living Support Required	<ul style="list-style-type: none"> physio-therapy therapeutic recreation exposure to peer experiences and role models awareness of the active living imperative, opportunities and potentials after SCI opportunity to experiment and take first steps 	<ul style="list-style-type: none"> outreach in support of ongoing physio-therapy home exercise program encourage more first steps support for active outings (transportation, attendant) continuing opportunities to try physical recreation and sport – trained staff, adapted equipment 	<ul style="list-style-type: none"> a mix of specialized and integrated opportunities access to any specialized equipment and staff required the means to participate (cost, attendant care, transportation) exercise, recreation and sport programs open to all peer support for regular participation 	<ul style="list-style-type: none"> ongoing health promotion to reinforce regular participation financial support for ongoing, regular participation specialized training for advanced levels competitive leagues supportive AL community
Examples	<ul style="list-style-type: none"> Bridging the Gap – ‘Have a Go’ events at rehab centres CPA peer visits and video vignettes Glenrose, Foothills Rehab 	<ul style="list-style-type: none"> Home Support Exercise Program Community ‘Have a Go’ Days developmental programs CRH ‘Living Well’ programs Steadward Centre Adapted Fitness Programs for Adults 	<ul style="list-style-type: none"> Wheelchair Loan Program accessible facilities and receptive staff at Talisman, Mt. Royal, leisure centres Rotary Challenger Park wheelchair sports programs 	<ul style="list-style-type: none"> Steadward Centre Athlete Development Programs wheelchair competitive sport leagues Special Olympics

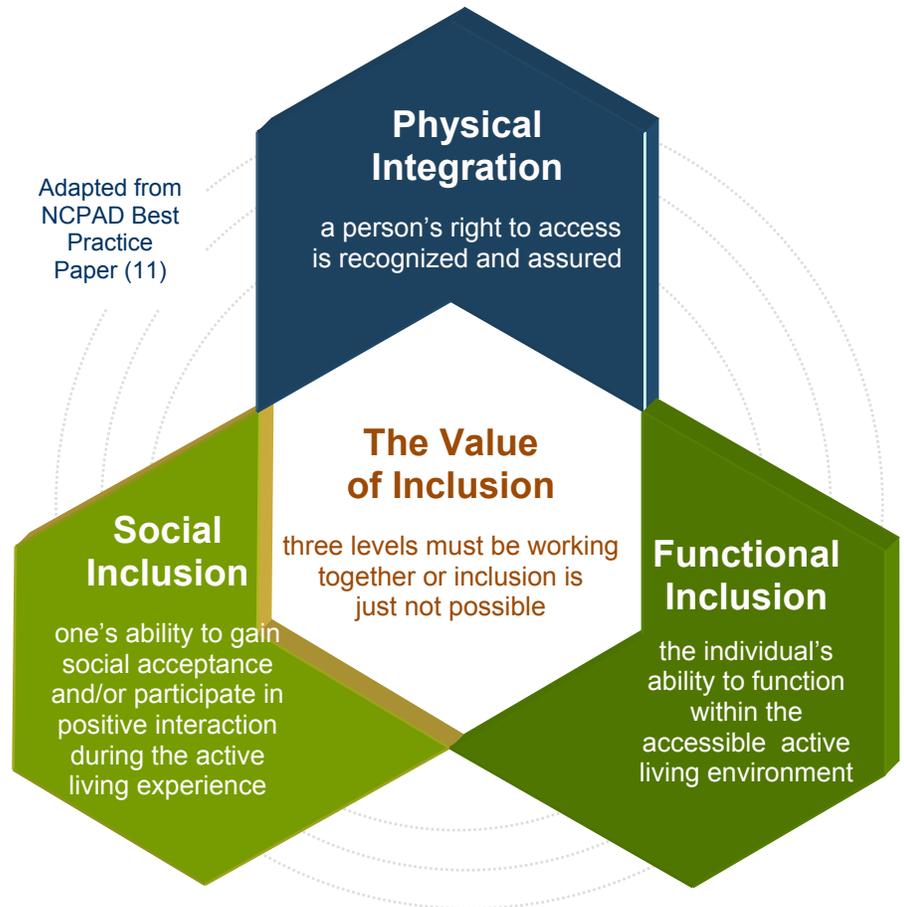
Framework 2: Best Practice of Inclusive Services

Active living for persons with a disability requires opportunity and rights to have physical access to fitness, sport and recreation facilities

The US National Centre on Physical Activity and Disability (NCPAD) has published a Best Practice statement on inclusive recreation services. It speaks to three levels, all of which must be in place for an opportunity to be fully inclusive.

Alberta is far from achieving the goal of providing inclusive active living best practices and opportunities for citizens with disabilities. A February 2008 phone interview survey with 25 related organizations identified the following top needs and priorities of Albertans with SCI related to active living:

- more **accessible facilities** with **adapted equipment**
- addressing the reality that many do not have the **disposable income** required to participate in active living opportunities (fees, transportation, personal trainers, equipment)
- **transportation** – basic supports to get to the active living opportunity
- funding for **attendant care** support while engaged in fitness, recreation, sport is critical to participation
- more **trained health/wellness specialists** to work with Albertans with disabilities
- more **communication and awareness** initiatives designed to connect those in need with the opportunities that already exist
- more programs on **self motivation and empowerment** to encourage people with SCI to take more control of health and make commitments, customize lifestyle to include active living



Physical Integration	<ul style="list-style-type: none"> ▪ a way to get to the opportunity (transport, attendant) ▪ the opportunity or facility has wheeled access, appropriate change rooms, etc. ▪ facilities or programs are available when wanted or needed – responsive scheduling
Functional Inclusion	<ul style="list-style-type: none"> ▪ adapted equipment is available ▪ supportive, trained staff – able to understand and respond to any special needs ▪ appropriate activity (specialized or integrated) ▪ programs provide accommodations for participants with disabilities to give them the same enjoyment and success as those without disabilities
Social Inclusion	<ul style="list-style-type: none"> ▪ self-confident participant (with a disability) ▪ welcoming community that values diversity and sees ability rather than disability ▪ inclusion embraced as a value

Alberta Situation Assessment

Active Living (AL) for Persons with SCI



Active Living Alliance for Canadians with a Disability - Alberta
Alberta SCI Alliance
Alberta Centre for Active Living
Alberta Recreation and Parks Association
Alberta Northern Lights Wheelchair Basketball Society
Association of the Inside Out Integrated Theatre Company
Between Friends Club
Calgary Disabled Sports Club
Calgary Flash Track Club
Calgary Grizzlies Wheelchair Basketball Society
Calgary Health Region - 'Living Well'
Calgary Parks and Recreation
Calgary Power Hockey League
Calgary Public Library - Diversity Services
Calgary Rotary Challenger Park
Calgary Sledge Hockey Club
Calgary Society of Community Opportunities
Camp Health, Hope and Happiness (HeHoHa)
Canadian Association of Disabled Skiers
Canadian Paraplegic Association
Central Alberta Sledge Hockey Association
Central Alberta Special Equestrians
Challenger Little League
Disabled Sailing

Many Opportunities - Many Best Practice Models

As is obvious from the list of about 50 organizations to the left, there are lots of different opportunities for Albertans with disabilities to exercise, recreate and participate in a range of sports. Many positive examples of AL were described during the interviews with the twenty-five respondents from these organizations; the **'best practice models are'**:

- **Bridging the Gap** – a social marketing, recruiting and development initiative; Canadian and the B.C. Wheelchair Sports Associations
- **Living Well with a Chronic Condition** – Calgary Regional Health in partnership with Talisman Centre and City Leisure Centres providing fitness programs to over 4000 new clients every year
- **MS ActiveNOW** – an MS Society health promotion initiative to increase awareness of the benefits of daily physical activity, to help fitness provider design appropriate programs, and to increase access to active living and exercise opportunities
- **Rotary Challenger Park and Challenger Little League** – providing fitness, recreation and sport activities for persons with disabilities in the Calgary region - outdoor)
- **The Steadward Centre for Personal and Physical Achievement and University of Calgary** – providing adapted fitness programs for adults and high-performance athlete development and training support
- accessible fitness, recreation and sport programs at Mount Royal College, Calgary, Glenrose and Foothills Rehabilitation centres.
- Specialized arts living programs and therapeutic riding bring significant joy/benefits

Persons with SCI who are interested in sport opportunities are fairly well served by a range of general and specialized wheelchair sport organizations. While services exist, these groups generally report high levels of unmet demand/need for resources to grow/expand.

During the interview process, community leaders rated both the availability of **specialized** active living opportunities (primarily for persons with disabilities) and **integrated** active living opportunities as average/OK, mid range or 3 on a 5-point scale. When asked about the optimal balance between the two approaches (specialized and integrated), both were deemed to be very important and most respondents spoke to a 50/50 balance.

Comments:

- celebrated Alberta's accessible parks and playgrounds
- mentioned many fitness facilities (public/private) that have good adapted equipment
- observed that the most successful programs tended to be developed for/specialized and targeted at specific populations (e.g. wheelchair sport, MS, brain injury)
- noted the example of 'Living Well', where specialized support is given to individuals with chronic conditions, co-existing with other programs and clients at the facilities
- a general feeling that municipal parks and recreation departments were not doing nearly enough to make their fitness, recreation and sport opportunities truly inclusive (as opposed to just physically accessible).

Association of Alberta
 Easter Seals Camp
 Horizon
 Edmonton General -
 Community Outreach
 City of Edmonton
 Community Services
 Edmonton Public
 Library - Access
 Division
 Edmonton Sled
 Hockey Club
 Edmonton Thunder
 Track Club
 Glenrose
 Rehabilitation
 Hospital
 Grande Prairie
 Wolverines
 Wheelchair Sport/Ass
 In-Definite Arts
 Society
 Lethbridge
 Therapeutic Riding
 Association
 Lethbridge Steamers
 Wheelchair Basketball
 Little Bits Therapeutic
 Riding Association
 Mount Royal College
 Mountview S.R.A.
 Paralympic Sports
 Association
 Peace River Riding
 Disabled Society
 Stage Left
 Productions
 Steadward Centre
 Steel Wheels Quad
 Rugby Club
 Talisman Centre
 University of Alberta
 University of Calgary
 Wheelchair Curling -
 Alberta
 Wheelchair Sports
 Alberta Association
 Wheelchair Tennis

And to the other AL
 providers not yet
 noted and need to be

Need for Increased Collaboration

When asked about current levels of collaboration among active living groups in Alberta, those working in Edmonton and Northern Alberta reported a good rating (2 on the 5-point scale) while those in Calgary and Southern Alberta gave an average rating (3).

Comments:

- some excellent examples of cooperation: Wheel Chair Sports GO DAYS, partnerships within the Arts Community, CPA/Mount Royal, MS/Steadward
- need more collaboration to avoid duplication, to fill gaps and to reach smaller and more remote communities
- need municipal recreation staff/facilities to do more in partnership with the disability community (specialized and integrated opportunities)
- need more collaboration of programs and services between physio, therapeutic recreation, and fitness/recreation professionals to create/expand opportunities
- challenges/barriers to collaboration include: competition for limited funding and the fact that volunteer time is limited and people focus on service delivery vs discussion.

Top Needs and Priorities

The interview process asked about the top needs and priorities of Albertans with SCI related to active living (already reported on page 7); the top needs and priorities of the organizations who are doing their best to respond.

Top Needs of Persons with SCI	Top Needs of Organizations
<ul style="list-style-type: none"> ▪ more accessible facilities with adapted equipment ▪ addressing the reality that many do not have the disposable income required to participate in active living opportunities (fees, transportation, personal trainers, equipment) ▪ transportation – basic support to get to the active living opportunity ▪ funding for attendant care support while engaging fitness, recreation, sport ▪ trained health/wellness specialists to work with Albertans with disabilities ▪ more communication and awareness initiatives designed to connect those in need with opportunities already existing ▪ more programs on self motivation and empowerment to encourage people with SCI to take more control and make commitments to active living 	<ul style="list-style-type: none"> ▪ sustained, multi-year funding to cover the basic operating costs of running active living, recreation and sport organizations and supporting or leveraging the volunteer energy required ▪ funding to provide for program subsidies in cases where costs of specialized staff and/or equipment makes participation prohibitive ▪ increased access to space – the policies of most public and private facilities limit use and support for persons with disabilities. Need either policies that require response to need and demand OR increased investment in specialized facilities ▪ help in recruiting and training staff and/or volunteers to ensure that participants have the support they need to participate

The Strategies

to enhance active living for Albertans with SCI



The following strategies were inspired by comments and recommendations made during the interview process with leaders representing 25 organizations with an interest in active living for Albertans with disabilities. They are proposed here as a foundation for discussion at the two workshops planned for March 17th in Edmonton and March 18th in Calgary.

The suggested strategies all build on the fact that we are dealing with a relatively small community. If we focus exclusively on Albertans with SCI, the target audience is about 4000 in number with approximately 140 new injuries annually. However, what we learn from active living initiatives can be easily transferred to others with physical disabilities, particularly those involving mobility impairment.



Strategy	Examples/Suggestions for OUTCOMES
<p>Learn More</p>	<ul style="list-style-type: none"> ▪ An Active Living (AL) Survey – the Alberta SCI Solutions Alliance will be facilitating development of an Alberta SCI Strategic Plan over the next year. Assuming/hoping a survey of Albertans with SCI will be a first step in that process, a section could be devoted to questions helping us better understand current participation levels, barriers and priority needs/interests of AL. ▪ Host an Active Living Think Tank – a collaborative initiative led by Wheelchair Sports, the Steadward Centre, Mt. Royal, U of C and CPA; essentially a special Odyssey Peer Event to develop innovative responses to the priority needs confirmed in the abovementioned survey
<p>Strengthen Collaboration</p>	<ul style="list-style-type: none"> ▪ An Active Living Task Team – create/facilitate a leadership group under the auspices of the Alberta SCI Solutions Alliance with the joint mandate to work together to develop AL solutions AND to recommend allocation of active living funds available over the next five years from the 20th Anniversary Legacy Initiative ▪ Create/facilitate a collaborative health promotion team and initiatives involving all of Alberta SCI organizations with an interest in active living, the Alberta Centre for Active Living, and the Active Living Alliance; modeled after MS ActiveNOW with the mandate to increase awareness of the benefits, help providers design appropriate programs, and increase access to community based active living opportunities for persons with SCI. Note that these two recommendations can be combined.

Strategy	Examples/Suggestions for OUTCOMES
<p>Build an Active Living Community</p> <p>defined by the Alberta Centre for Active Living as one that fosters health and active lifestyles</p>	<ul style="list-style-type: none"> ▪ Create an Online AL Social Network – under the auspices of the proposed health promotion initiative, employ readily available groupware to provide a moderated forum for the SCI community to share active living enthusiasm and experiences, develop directories of supportive services, create opportunities for sub-groups with like interests and needs. It could essentially develop into a self-directed, virtual parks and recreation department owned by persons with SCI; forming interest groups and connecting them to any facilities, equipment and/or support staff they need. ▪ Build Active Living into the Odyssey Program – the CPA Peer Program could develop an AL stream that helps peer groups meet and create their own opportunities. Could be the ‘face to face’ component of the online social network proposed above. ▪ Develop a collaborative volunteer recruitment capacity as part of the proposed health promotion initiative and/or online social network to link those that might need help with their active living agenda and those that would enjoy sharing their time and/or activity related expertise. Recruit for organizations that need support and for matches with individuals that need help.
<p>Build Service and Program Capacity</p>	<ul style="list-style-type: none"> ▪ Negotiate an MOU with every major facility in Alberta – negotiate inclusive exercise, recreation and sport agreements with Alberta’s colleges and universities, major sport centres, and larger leisure centres. Agreements could be promoted by the collaborative health promotion team. ▪ Reaching New Heights in Fund Development Success - a new AL initiative to develop fundraising capacity in all organizations specializing in various aspects of active living for Albertans with SCI. Modeled after a Health Canada/Lupus Canada initiative by the same name that trained teams from nine national health charities. Negotiate the possibility of a joint resource development initiative supported by RHF. ▪ An Adapted Equipment Endowment – whether part of the above or separate, create an endowment fund with the interest going to matching grants to groups or providers needing specialized exercise, recreation or sport equipment.
<p>Provide Direct Support for Individuals</p>	<ul style="list-style-type: none"> ▪ Home Support Exercise Program – work with the Alberta Centre for Active Living to find ways of expanding HSEP from its current focus on older people to include Albertans with high level quadriplegia. ▪ An AL Pilot Program for the Newly Injured – modeled after the Hamilton Health Science/CPA (Ontario) demonstration project, providing a supportive solutions team (AL) and an Active Living Solutions Coordinator to work with every newly injured individual. The pilot would be a partnership between one of Alberta’s SCI rehabilitation centres, specialized fitness facilities like Mt. Royal, Univ. of Calgary and the Alberta SCI Solutions Alliance. Research validation would be built into the design of the program. Examples of possible interventions: 1) the provision of outreach therapeutic recreation services focused on transition from rehab centre to community, 2) expansion of Bridging the Gap type initiatives, 3) development of customized exercise and adapted physical recreation equipment (Tetra style), 4) negotiation of free memberships in health clubs and/or subsidized passes to public, educational facilities. ▪ AL Training for Attendants – clinics and workshops sponsored by the organizations involved in the collaborative health promotion initiative ▪ Equipment Loan Program – with a focus on first steps and entry level engagement (exercise, recreation, sport) ▪ Access Funding – as part of the fund development initiatives proposed above, develop a fund that can assist those in financial need who face high access costs (e.g. transportation and extended attendant care contracts). Temporary funds until advocacy efforts convince health authorities of the wisdom of investing in prevention rather than medication. ▪ see recommendations for a CPA Odyssey ACTIVE LIVING Peer program as above.

20th Anniversary SCI Legacy Opportunity



In 2006/2007 Alberta SCI stakeholders banded together to help craft and support the Rick Hansen Foundation 20th Anniversary Legacy Initiative. The Alberta Government responded with an investment of \$12m over the five year period from 2007/2008 fiscal to 2012/2013 fiscal. \$500,000 of that amount was protected for active living initiatives – within the ‘Solutions That Work’ portion of the foundation proposal.

Should other stakeholders agree, additional opportunities in fund to explore active living opportunities could be:

- \$2 million has been protected over the five year period to allow for flexible responses to applications from individuals and/or their organization to facilitate customized solutions or innovations responding to priority unmet needs of Albertans with disabilities. Based on previous experience with grant applications for Wheels In Motion funding, we can anticipate that a portion of these requests from individuals could be related to active living priorities that cannot be met without this extraordinary assistance.
- \$2,980,000 has been protected for SCI translational research and infrastructure, to be invested in Alberta respecting the priorities of the pan-Canadian SCI Translational Research Network. It may be possible to convince researchers that a portion of this fund should be used to validate active living innovations, benefits or proposed best practices.
- \$1,160,000 has been allocated to community engagement and support through the Rick Hansen Wheels In Motion annual events and the related Ambassador Program. Both programs could be more fully utilized strategically as catalysts for active living – health promotion opportunities.

Criteria and guidelines for investment of the \$500,000 Active Living Initiative Fund need to be set before recommendations and decisions are made; the two workshops to be held in mid-March will help to shape the AL direction and final decisions of funds; ultimately, an Active Living Task Force makes allocation recommendations to the Alberta SCI Solutions Alliance. The options below are put forward to stimulate discussion.

Option 1: Invest Only in Individuals

The ½ million dollar fund could be handled exactly as the overall ‘Solutions Fund’ is managed, except that only active living related applications from individuals would be considered. This would support the operating philosophies of ‘consumer driven’ and response to ‘self identified’ priority needs. Organizations would benefit indirectly if the individual was applying to support access to their services or programs.

Option 2: Invest Only in Organizations

Given that individuals can apply to the larger provincial Solutions Fund for any need (including those related to active living), protect the AL Initiative Fund for organizations. There simply are not enough dollars available to make a meaningful contribution to operating subsidies; guidelines established encourage proposals related to:

- capital costs required to build capacity
- program development – particularly related to the priorities identified in the anticipated survey of Albertans with SCI
- innovation validation – field or clinical trials of a new way to delivering benefits through exercise, recreation or sport (service models, adapted equipment, motivation/recruitment, etc.).

Option 3: Invest Only in Collaborative Initiatives and Interventions

Select the most important initiatives outlined in this Strategic Plan and invest through collaborative mechanisms such as the proposed ‘health promotion initiative’, building an online SCI Active Living Alliance Community, an equipment loan co-op., etc.

Option 4: A specific Combination of the Above OUTCOMES - the best practices with each option

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Definition of Spinal Cord Injury

Spinal cord injury is an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory, or autonomic function. The Business Plan adopts the International Standards for Neurological and Functional Classification of Spinal Cord Injury as a widely accepted system describing the level and the extent of injury based on a systematic motor and sensory examination of neurologic function.

The following terminology has been developed around classification of SCI:

- Tetraplegia (replaced the term quadriplegia) - Injury to the spinal cord in the cervical region with associated loss of muscle strength in all 4 extremities
- Paraplegia - Injury in the spinal cord in the thoracic, lumbar, or sacral segments, including the cauda equina and conus medullaris

SCI can be sustained through different mechanisms with the following three common abnormalities leading to tissue damage:

- Destruction from direct trauma
- Compression by bone fragments, hematoma, or disk material
- Ischemia from damage or impingement on the spinal arteries

Edema could ensue subsequent to any of these types of damage to the spine.