

# **The Alberta Spinal Cord Injury Strategy**

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an initiative of the Alberta SCI Solutions Alliance

Key Informant Interviews

## **SUMMARY REPORT**

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## INTRODUCTION

In 2003, the Federal Government funded the Rick Hansen Foundation (RHF) to provide leadership in bringing together researchers, clinicians, service providers and people with spinal cord injury (SCI) to develop a national vision and shared strategy for improving the quality of life of people with SCI. The Alberta Government has invested \$12 million over five years (2008-2012) to support innovative solutions to the unmet needs of Albertans with spinal cord injury (SCI) and pursue systemic improvements in the areas of research and service delivery in the province.

Provincial funding was provided in response to a proposal, 'Going Forward Together' submitted by the Rick Hansen Foundation (RHF) and Alberta SCI stakeholders in honour of the 20th anniversary of Rick's Man in Motion World Tour (1985-1987). The fund and its related commitments will be administered in Alberta by The Alberta Paraplegic Foundation (APF) through an agreement with RHF. The Alberta SCI Solutions Alliance (membership list attached) has been created by the APF to provide the strategic advice and leadership required to ensure excellence.

The Canadian Paraplegic Association (Alberta) performs the duties of secretariat to the Alliance.

Through the proposal and related agreements, a portion of the fund has been dedicated to creating an SCI strategy for Alberta. This strategic plan will:

- identify priorities of critical importance to Albertans living with SCI;
- engage the entire SCI community (researchers, service providers and people with SCI) in the process of addressing identified priorities; and
- inform decision making processes related to present and future investments in SCI related initiatives.

The Alberta SCI Strategy planning process will build on, rather than duplicate, related planning initiatives.

Ultimately, we are working toward making Alberta the best place in Canada for a person with a SCI to live. On behalf of Albertans with SCI, this initiative will focus on identifying and launching collaborative efforts resulting in:

- improved functional and health outcomes;
- improved quality of life in supportive communities
- improved economic outcomes, including participation in employment opportunities; and
- improved care and support systems that allow Albertans with SCI to live in their community of choice.

The initiative will engage stakeholders (people with SCI, service providers, researchers) who share a commitment to improving outcomes for Albertans with SCI. We will work together to:

- **develop a comprehensive policy, planning and delivery framework** integrating institutional and community-based treatment, care and support;
- **identify priority unmet needs**, gaps, challenges and issues to be addressed;
- **develop detailed action plans** for each of priority area;
- **build implementation teams and plans** throughout the process to ensure ongoing commitment and momentum; and
- **bring available evidence to the decision making process** and identify related translational research priorities (for future work).

The strategy will be developed in four phases:

**Phase 1: Research and Analysis:** identify priority issues affecting people with SCI in Alberta, best practices for addressing them, and successful models for collaboration and service delivery.

Key Activities: interview key informants, review related documents, conduct a Delphi process (see definition attached).

**Phase 2: Framework Development:** generate a list of priority needs and/or gaps to be addressed in phase 4 and refine principles, policies, and models/frameworks based on stakeholder feedback.

Key Activities: draft model/framework for service and support for Albertans with SCI, conduct a stakeholder meeting to vet model.

**Phase 3: Action Plans:** develop action plans in priority areas that include implementation strategies.

Activities: assemble advisory teams, facilitate process to develop action plans, steering committee workshop.

**Phase 4: Engagement:** Finalize an Alberta SCI Strategy that outlines priorities, processes, and required resources and which has the support of stakeholders in SCI.

Activities: hold meeting to address leadership and commitment, draft strategy and circulate for final input, finalize strategy and implementation plans.

This report summarizes the findings of the Key Informant Interviews which were conducted between September 18<sup>th</sup> and October 23<sup>rd</sup>, 2009. Under the direction of CPA (AB) (as secretariat to the AB SCI Solutions Alliance), 46 interviews were conducted with 54 key informants between September 18<sup>th</sup> and Oct. 23<sup>rd</sup> with the goal to gain opinions and direction at the beginning of this Strategic/Policy Planning process. Findings will be used to inform the Delphi process, which is the next Strategy development phase.

Respondents represented a range of organizations and interests. In an effort to focus on issues relevant to the Alberta picture, all but one were Alberta-based. Some were chosen for their insight into SCI related issues, and others for their knowledge of strategic planning and factors affecting the success of such plans within the Albert context. All are individuals with an interest in disability issues, and who may be affected by, or have clients who would be affected by the end-results of this process. Many represent groups who would be potential partners in the action-planning process. Eight are individuals who have an SCI. A list of respondents is included as Appendix A.

Consultations such as this are never undertaken solely for the purposes of gathering information. They are also a means of announcing an initiative and the intentions behind it, establishing the credibility of the lead organization, identifying the strengths, expertise, and experience of potential partners, and building interest among others in the community which, if fostered, grows into a momentum that sustains the initiative through its various stages of growth and development.

This consultation served these purposes well. We heard many positive comments about the initiative, referring both to its importance and to the way in which it has been conducted thus far. We were told that it was great that we are seeking input from many stakeholders. Many expressed confidence that we had probably already identified everyone we should be speaking with and were confident that we'd choose the right people to be on the Delphi panel. A comment was made that our initial communication gave the impression that we were honest and earnest in our approach. In a few cases, the Strategy was perceived by respondents as a CPA initiative. In those cases, the

interviewer clarified that the initiative was being led by the Alberta SCI Solutions Alliance and that CPA's role is as a key informant and secretariat to the Alliance.

The following is a summary of the respondents' comments by question, organized into major headings. Further analysis of the data will be conducted. This knowledge will be combined with information on best practices, models and frameworks in place world-wide in the area of SCI. The Delphi process hone in on the major findings of the key informant interviews and background research and will lead us closer to consensus on what an AB SCI Strategy should look like.

### **SUMMARY OF COMMENTS BY QUESTION**

#### **Question #1: Reflecting on similar strategic planning and policy development processes in the past, do you have any general advice? Are there critical success factors? What pitfalls should be avoided?**

Responses can be divided into four broad categories:

1. **Principles:** respondents' ideas about the general principles that underlie a successful initiative of this type, and the principles that respondents value.
2. **Partnerships:** with whom respondents feel we should be partnering and what the partnerships would look like.
3. **Processes:** what respondents feel we ought to do or not do to increase the quality of the information we gather and increase our success in implementing desired actions.
4. **Political relations:** respondents' comments on how to work with government and what to be aware of in the current political climate.

#### **Principles**

Respondents identified a number of principles that they feel would underlie a successful strategy:

- **Involve people with SCI in all parts of the process** – consult them to find out what the priorities are.
- **Bridge gaps that exist in the SCI continuum** between the various sectors such as those that exist between acute care, rehab and community supports – enhance relationships / agreements and reduce fragmentation.
- **Take a holistic view of the individual with SCI** – they are people with unique needs depending on their age, socio-economic status, culture, beliefs, community of residence, etc.
- **Increase alliances and recognize common interests among service providers** – there are similarities among the priorities of organizations within the SCI community and those of other communities (e.g. MS, Cerebral Palsy, Spina Bifida, Parkinsons, CNIB); build on the commonalities but recognize also the differences (there is no “one-size fits all” plan); realize that we (SCI) can't do it on our own; battle isolation and silos.
- **Foster strong leadership** – need leadership with passion and commitment; support leadership from among individuals who have SCI; foster a spirit of give and take between partners; have a clear vision; clearly outline roles and responsibilities; others need to buy in to whoever takes the leadership role.
- **Empower people with SCI to take action** – enable them to become more effective self-advocates and engage them as leaders in implementing solutions.
- **Break down brick walls and resistance to change** – be innovative; learn from the past but don't let it stifle creativity.
- **Recognize that change needs to come from the bottom up** with a coherent message.
- **Commit to transparency and accountability.**
- **Support the idea of people staying in their own communities** – people with SCI should have access to recreation in their neighbourhoods rather than having to travel to another neighbourhood.

### Partnerships

Build partnerships with:

1. **Organizations serving other disabled or disadvantaged populations** whose clients have similar needs in the areas of housing, home care, etc. (e.g., CNIB, MS Society, Alberta Association for Community Living).
  - Bridge gaps; avoid stove-piping; coordinate common ground; get different sectors involved with related partners; broaden the scope of the target group; bring in several cross-disability groups with common goals to reach for more; create a shared vision together with all community groups and define an action plan to deliver solutions; break down turf protection and territoriality; create a coherent message; organize around services such as home care and universal design for homes/communities; avoid the perception that this is a strategy developed by a few people for people with SCI.
  - Consultation is paramount to success; the consultation group doesn't have to be really large as long as you have committed organizations who are ready to take action.
  - We must act together when we have common interests in areas like housing, attendant care, and direct payments to clients within a comprehensive system.
2. **People with SCI.**
  - Engage them as leaders so they understand the issues and are involved in the solutions.
  - Empower people with SCI to take action, be advocates and support "change from within."
3. **People who can help move a specific action plan forward.**
  - Think outside the box – involve developers in strategies to address housing, hospital administrators of SCI programs, community leaders (in Aboriginal communities); decide on the types of people you need around the table rather than relying on a list of people you know; decide first what kind of expertise and leadership we need at the table; involve non-traditional partners such as developers, banks.
  - Involve really resourceful people.
  - Involve people in with a budget and with control.
  - Successes have been achieved when communities are allowed to manage their own affairs, e.g. Tsuu T'ina Nation, Town of Jasper – in both cases the partnerships needed to provide services are formed and managed at the local level.

### Processes

A successful plan will:

- **Be goal-oriented** – it will focus on solutions that address the gaps in services.
- **Address the challenges and barriers** against the triple bottom line (social, economic and environmental).
- **Be client-driven** – it will involve people with SCI in identifying the issues and implementing the solutions – ensure you have a broad sample of the population with SCI represented.
- Include **input** and solutions with community partners.
- Ensure decisions are **evidence-based**.
- Include business plans with a clearly articulated **vision, goals and outcomes** – the focus is on **implementation** and the **resources** required for implementation – resources are critical and on-going.
- Contain a strong, succinct **vision** statement that people can remember and relate to and that everything else in the plan ties into.
- Have an outside **facilitator** to guide the process and do the work that others are too busy to do.
- Define the **roles and responsibilities** of each organization in the strategy – show common areas of concern and ensure all partners are on the same page.
- Focus on complementary, common and **top priority needs** of the collaboration.
- Identify recognizable and high profile **champions** in all areas of the SCI continuum, within government, on the front-line, and in First Nations Communities.
- Keep outcomes **manageable** – plan for a reasonable time frame (3 years); revisit and revise the plan periodically; keep the thing going.

- Be **realistic** with time frames – consider the fact that people need time to figure things out before jumping into the action; there will be turnover and new people will need to be oriented to what is going on.
- Have consistent **definitions** – e.g. Quality of Life
- **Identify what we have** influence over and what we don't have control over.
- Create a separate review process and action plans for **First Nations**.
- Incorporate **best practices** into the model of how the system will flow.
- Objectively determine what the **unmet needs** of people with SCI are – could have a large public **forum** or conduct a **survey** of a cross-section of people with SCI; such work is being planned by the Research Network of the SCISN.
- Link **theory and practice** – look at theories from various disciplines: health, sociology, psychology.
- Have a strong **communication plan** – utilize the web to share information widely; keep everyone informed even if they aren't part of the consultation; information is valuable; leverage the knowledge we gain throughout this process by making presentations to other groups and at policy conferences.
- Follow a sound **methodology** and have clearly outlined **processes** that stick to the tasks at hand and move position papers, strategies and policies through a system of changes from collaborative community leaders to standing committees to ministries and MLA's to achieve desired changes and outcomes.
- **Measure outcomes** and **revisit/revise** the plan regularly – have evaluation embedded in the plan.
- **Avoid duplication** – use data and information that are already available to plan our strategy.
- Have a **dedicated administrator** to continue to facilitate the Strategy and implementation of outcomes.

### Political Relations

Success requires knowledge of the following:

- **Success** comes when you frame [your] purpose with [the] political agenda of the time.
- We must create a **political will**.
- Any plan taken to government must address **economic impact** (what will it cost? how much will it save?) and show **grassroots** community support.
- It's important to gain the **early support** of the Minister/s, Deputy Ministers, or ADMs – important to involve key decision-makers early on as sponsors; don't come up with a plan and then try to compel decision makers to support it.
- We need to **work closely** with decision makers to implement new policies and solutions.
- It's a good idea to present the plan to **Standing Policy Committee** – they have a lot of power; you need to go in with strong recommendations and things that add credibility (e.g. economic arguments, outcomes statements).
- We need to be able to show government that we **want to help them** achieve their goals.
- It takes **evidence** to become a priority with government – clearly demonstrate need; demonstrate the difference that community organizations can make to quality of life.
- It is critical to have the government's ear – works best to have a **champion / sponsor** from within (or closely linked to) government, e.g. Rick Hansen.
- **Avoid "pilot projects"** – they are not well received as they imply that, if successful, the sponsoring government department will pick up the tab for on-going implementation.
- **Legislation is powerful** – provinces and nations with legislation (e.g. USA, Austria, Ontario) have noticeably better accessibility.
- This is a good time to look at initiatives that are **Alberta-wide**.
- Chances of success are improved by linking the strategy to government priorities, e.g. the three pillars referred to in Alberta Health Services: **Accessibility, Sustainability, and Quality**.
- If additional dollars are needed, do a careful environmental scan and be sure to choose an **optimal time** to approach government.
- **Reflecting** on what has/has not changed in the status of people with SCI over the last number of years may be a good way to begin a presentation to government.

**Question #2: In your view, is this a good or bad time to launch this type of planning or policy development process? Why?**

A majority of the respondents (79%) provided reasons why this was a good time to develop policy, re-evaluate and clarify the vision, get prepared, define quality services, and look for creative ways to do more with less.

- It's a good time in some respects – need to show that you can offer something that doesn't cost – that if applied properly can save money. I think there is money to be saved.
- The political environment is supportive of change - government priorities are changing; major restructuring and strategic planning is underway in Alberta Health Services; there is the opportunity for self-directed solutions that hit on government priorities, demonstrate savings, strive for equity in service delivery across Alberta, are backed by supportive partnerships and have clear strategies for community engagement.
- The needs exist now, the funds are available now, the work ought to be done now.
- The three pillars within Alberta Health Services are "Access, Quality and Sustainability." It should be possible to frame a strategy that addresses these three areas.

Just over a third (33%) noted that there were challenges associated with proceeding at this time, primarily related to the economic situation and cutbacks to existing programs.

- There's never a right time. This could be the most opportune time because there's talk of change – a strategy could be implemented as a cost-saving method.
- This would not be a good time to initiate a project that may cost Health dollars.
- Keep your eye on the political timetable – if funds are needed, be strategic about when you ask for them.
- There is no new money for new programs today.
- Existing programs must prove their worth.
- Reality is cutbacks are happening to existing contracts ...
- Alberta Health Services needs a few months to stabilize ...

**Question #3: Can you think of any models or frameworks from related fields (health, social policy, disability policy) that we would be wise to review?**

Models suggested fall into two categories: 1. those that could help inform the strategy as a whole; and 2. those that are more issue-specific and would assist us in developing strategies in priority areas. Some fall into both categories. (Please note: proper titles of strategies have not been verified).

**Those with broad applications:**

- Alberta Provincial Stroke Strategy (addresses the continuum from care to community supports) (2 mentions)
- Alberta's Clean Air Strategic Alliance
- Alberta Bone and Joint Strategy
- Alberta Breathes ("has done some remarkable work to coordinate government fragmentation" and got a higher level of buy-in)
- Alberta Life 4 Sciences Strategy
- Alberta Cancer Control Strategy
- Canada's 2010 Legacy Now program
- Saskatchewan Population Health Promotion Strategy
- City of Calgary "Triple Bottom Line" policy framework (considers social, economic and environmental impact of all programs)
- Alberta Injury Control Strategy
- Alberta Traffic Safety Plan
- Alberta Suicide Prevention Strategy
- MS Advisory Council



- SCI Solutions Network (has developed various frameworks)
- ONF – Ontario Neurotrauma Foundation
- Models and resources developed by Disabled Veterans of America

**Those that apply to best practices and knowledge translation:**

- Social policy work being done in Ontario
- US department of Education (best practices project for involving people with disabilities)

**Those that apply to advocacy or legislation:**

- Americans with Disabilities Act
- Christopher Reeve Foundation
- Ontarians with Disability Act
- Disabled Persons International
- Alberta Association for Community Living

**Those relating to personal care models:**

- Canada's attendant care model / legislation
- Alberta's Self-Managed Care Model piloted in 1981
- Alberta Continuing Care Strategy

**Health and disability models:**

- Research at U of C
- Research by the Rick Hansen Foundation / SCISN
- The WHO International Classification of Functioning, Disability and Health
- Alberta Health and Wellness Vision 2020
- Alberta Continuing Care Strategy
- Community Living Framework (Alberta Health and Wellness)
- CPA Alberta Strategic Plan
- AQAL – Ken Wilber's categories of human consciousness
- Alliance Business Plans
- The Alberta Active Living Strategy
- Pharmaceutical plans and strategies (well funded)
- Rehab hospital in Toronto (respondent couldn't recall name)
- WCB Alberta has continuum for areas other than SCI
- Alberta Health Services Strategic Plan
- Craig Hospital in Denver
- Chicago Rehab Institute
- Paralyzed Veterans of America
- Shepherd Centre in Atlanta

**Models for accessibility:**

- LEEDS
- Canadian Urban Transit Association

**Continuum of care models:**

- Manitoba model for referrals to Peer Support
- CPA peer support program
- Models in England and Australia that have had success with direct payment / individualized funding
- MS clinic at Foothills Medical Centre – MS has done very well to recruit therapies to the OPTIMUS program – OT/PT are in one place – they make nice connections with other disciplines.
- Spina Bifida adult clinic at Glenrose
- models of multidisciplinary teams operating at the rehab stage (in general)

**Community care/support service delivery models:**

- Oklahoma's Model of Community Based Providers
- Jasper Community Team model (Community Outreach Services – all agencies came together and pooled resources - work jointly to provide human services for Jasper residents)
- Brain Injury Initiative (contracts with community-based multi-service agencies)
- CPA National

**Question #4: To what extent would you advise us to relate our work to established policies, plans or strategies, such as the Disability Strategy created by the Premier's Council on the Status of Persons with Disabilities or the 'In Unison' accord? Which ones should we consider carefully?**

Regarding the Alberta Disability Strategy (ADS), most respondents felt it is a good foundation document and reflects principles that we should reference in the AB SCI Strategy, but that our strategy needs to be more focused and action-oriented with clear deliverables. Most stated that the recommendations in the ADS are too broad. There was disagreement about how much weight it actually carries in government. There was also disagreement on whether or not aligning the strategy with the Premier's council is good (ie. could help us get the government's ear) or bad (they are under the control of the government). One respondent warned against being locked into a particular way of thinking and being limited by the past. Another felt that it was a good strategy to look at accepted policies and hold government accountable to them.

There were no recommendations to relate our work to the In Unison document. Most respondents were only vaguely aware of it or unaware of it at all. In general, it was considered too old and not directly relevant to Alberta. Only one respondent recommended considering it.

The Broda Report on long-term care conducted in Alberta was mentioned by one respondent as a good document that is still being referenced by departments.

**Question #5: To what extent should we consider precedents such as the provincial commitment to persons with developmental disabilities or brain injury?**

A strong majority (80%) of respondents did not feel we should try to replicate the PDD model. Negative comments were that it created an isolated community (persons with developmental disabilities) that was treated differently from other disability groups, it is very expensive to administer, it hasn't eliminated service gaps, it is driven by political agendas, and it's not innovative. One respondent noted that s/he was not sure what evidence there is that they have achieved improved outcomes with that particular model. It was also noted that PDD is now becoming more restrictive about who is eligible for funding.

Respondents did not feel that PDD is a model that would be currently supported by government.

One positive aspect of the PDD model that was noted is that they have an appeal process for applicants. Individuals under PDD also receive more funding than would have been available to them under the self-managed care program.

With respect to Brain Injury - only half the people had any comments; of the half that did comment there was a split in opinion as to the validity or need to reviewing this model.

Some respondents felt that the Brain Injury service delivery model has some good things to offer: they use a model of contracts with local service providers that seems to work well for them; they were able to create housing spaces for people with Brain Injury; they made things happen even though they didn't have strong support from the health authorities in some regions.

One respondent stated that both the Brain Injury service delivery model and the PDD model both have limitations, with Brain Injury service providers being caught in intergovernmental gaps with no

one department taking financial responsibility. Another commented that the approach of contracting with community-based services has created some rifts. The comment was made that, given the resources available through “Rick Hansen” [the Rick Hansen Solutions movement], SCI is probably better poised than either of these two to create a better approach.

One respondent also recommended looking at models from other disability areas such as Developmental Disabilities and Fetal Alcohol Spectrum Disorder.

### **Question #6: In your view, is there a model community, province/state or nation anywhere in the world that has set a high standard in their commitment to persons with disabilities?**

Respondents mentioned the following:

**Canada:** Rick Hansen Foundation

**Alberta:** Self-managed care model; Alberta Health Strategy – Vision 2020; Safety Code Act; Mount Royal University (inclusion policy); Glenrose administrative model; Mayors’ Round Table on Universal Design; Red Deer (housing models); Town of Jasper (Jasper Community Team Model); employment initiatives at Tsuu T’ina Nation, Medicine Hat, Siksika Nation, and Morley (Chiniki First Nation); Red Deer (Collegeside).

**British Columbia:** SAIL program (provides equipment and coaching); transportation; GF Strong (their doors are always open for people to come back and they are involved with clients after they are discharged); have a tight network of people in chairs; seems to be a good model for home care/support services in Vancouver.

**New Brunswick:** outreach program; community inclusion is a priority.

**Ontario:** Ontarians with Disabilities Act; Local Health Integration Network; policies recognize accessibility and visitability; municipalities work well with the province to provide effective supports; Thunder Bay strategic plan to address community access and barriers to success; Toronto Rehab.

**Manitoba:** disability policies; new provincial housing initiative and funding announcement; motor vehicle insurance system in Manitoba (system is excellent – instead of a payout, people are offered rehab for life; they support people at all levels of disability; they look at what a person needs to participate in life; the injured person doesn’t have a lot of hassles to get what they need; it’s a very dignified and validating system for people who are injured).

**The United States:** Americans with Disabilities Act (has teeth and is backed up with funding); Respite Care Act; accessibility standards in California, Nevada, Washington and Hawaii; First Nations reserves in Nevada; excellent employment rates for people with disabilities in Washington.

**Australia and New Zealand:** dedicated to inclusion and provide funds to help with integration and accessibility; strategies to address the need for transitional housing in Australia; Stephen Duckett co-authored report in Australia on outcome therapy measures – AusTOM, which looks at impairment, activity limitation, participation restriction, and wellbeing; western Australia.

**Europe:** accessibility forum in London; UK in general; Scotland building codes in various EU countries; Britain has system of direct payments to individuals for their health care costs; Scandinavian countries (Sweden, Norway) have an excellent care system, high commitment, and good policies and funding for services that support community integration and independent living; Beitestolen Healthsport Centre in Norway gives individuals a week of adaptive physical training and respite for families; Switzerland has novel ways to deal with disability issues.

**Question #7: From your perspective, what are the priority unmet needs facing Albertans with SCI – priorities that should be addressed during this process?**

See Appendix B, attached, for details. Issues are ranked according to the number and percentage of interviews where this item was mentioned. A denominator of 46 was used to calculate percentages.

1. Accessible and affordable housing (28; 61%)
2. Home care and attendant care (27; 59%)
3. Employment and education training and motivation supports (22; 48%)
4. Improved access to in-patient rehabilitation services, including transition to and from rehab (14; 30%)
5. Transportation accessibility and independent driver training/adaptations (14; 30%)
6. Access to rehabilitation and health services over the long-term (13; 28%)
7. Adapted equipment and aids to quality of life (12; 26%)
8. Funds for SCI active living / access to recreation and leisure opportunities (9; 20%)
9. Psychological supports (8; 17%)
10. Advocacy with one voice and en masse – make lots of noise (7; 15%)
11. Financial supports (7; 15%)
12. Peer support (5; 11%)
13. Basic and translational research (3; 7%)
14. Aging in place for persons with SCI (2; 4%)
15. Other (12)

**Question #8: Can you suggest any high level strategies, approaches, policies, programs or services that we should consider during this process that can really make a difference for Albertans with SCI?**

**1. Work cross-disability**

- Engage stakeholders from other organizations but having similar priority needs (e.g. Cerebral Palsy, Spina Bifida, MS, CNIB).

Advantages:

- Collective efforts are more appealing to funders.
- It's a better use of resources.
- There's reduced duplication.
- A unified voice is more effective at bringing about change.
- There's more sharing of information and expertise (e.g. Seniors are an effective advocacy group).
- It reduces competition for funding.

Disadvantages:

- Not all agencies are at the same level of organization – SCI has the funds and may experience more successes on its own.

**2. Identify champions**

- Have champions lead the way with new initiatives and bring others on board.
- Back champion/s up with a firm, clear action plan with specific solutions.

**3. Focus on community transition**

- Focus on the community transition piece, as it differentiates SCI from other disability groups – their adjustment needs are unique (loss of mobility, loss of ability to provide self-care, etc.).
- Create formal agreements between rehab centres and CPA to provide Peer Support – need to establish clear roles and responsibilities for CPA staff.
- Consult best practices in this area.
- Move from a medical model to a community based model focusing on accessibility/inclusion.

**4. Establish a government relations plan**

- Keep the initiative top of mind with politicians.
- Attend meetings with government ministers.
- Communicate regularly with the broader community to keep everyone in the loop (there will always be those who say they weren't informed) – utilize the internet.
- Ensure the strategy recognizes the three pillars of Alberta Health Services: Access, Quality and Sustainability.
- Review the policies of the different departments involved – look for ways our work supports what the government has said it would do; find out what they are doing to fulfill their mandate and remind them of their commitments.
- Create a new combined economic/health model that shows how government investment pays off in the short and long term; demonstrates benefits such as fewer/shorter hospital stays.
- Ask for the best – we're always asked "what can you do without?" and often we negotiate down before we even get going – let's go for quality – don't compromise.
- Make the government aware of how many people under 65 require long-term care.

**5. Advocate for legislation and policy changes**

- need legislation in areas of public transportation, community accessibility (e.g. sidewalks), accessible housing (set a goal of 10 – 15%); legislation makes a significant difference – guidelines alone are often ignored
- review and establish rehabilitation policies and procedures and propose improvements that are based on best practices
- advocate for new provincial guidelines, policies and services that are flexible around individual preferences
- advocate for an SCI Medication Benefit Plan

**6. Improve access to existing funding**

- increase awareness of and reduce barriers to accessing available funding sources such as: Helping Way Fund, community Access Program, SCI Solutions Fund, Solutions for Active Living funds, Affordable Supportive Living Initiative
- bring greater equity: ensure all people in need know how to access available funds; consider a CAP funding program that provides everyone with and SCI with \$10,000 every three years for personal aids of their choice

**7. Utilize cutting-edge theory, innovation and technology**

- Recognize the value of technology in helping us reach our goals – technology can be used in communications as well as in service delivery (e.g. telehealth).
- Recognize that technology has huge possibilities for improving quality of life of people with SCI.
- Step outside the box and partner with or obtain input from kinesiologists, social workers, psychologists, social science researchers, engineers, business people, chambers of commerce, educators.
- Be creative – Germany reduced their high school drop out rate after abolishing school boards.

**8. Other**

- Create a separate but parallel process to meet the needs of First Nations - deal separately with the needs of First Nations – work with willing communities and create a specialized action plan together that has the endorsement of Band Councils.
- Coordinate efforts with Solutions movements in other provinces - each province could identify its strengths and what it is doing well and then they could coordinate their efforts / share knowledge and lessons learned – when each province tries to do it all, it dilutes what can be achieved.
- Make sure approach is provincial and transcends all regions.
- There is something about stories – important to raise images in people's minds that are real and connect them to an issue.

**Question #9: Reflecting on the questions we have just asked, can you suggest other individuals or organizations that we should be approaching at this early stage – to ask the same questions?**

Respondents recommendations were reviewed and acted upon as part of the interview process. A list of those who were not already on our list of contacts is given below. Some may be invited to participate on the Delphi panel or in the development of area-specific action plans.

Suggested contacts (neither spelling nor affiliations have been verified):

- Acting ED for policy innovation and partnership, ASCS
- Barraclough, Bob - formerly of Office for Disability Issues
- Coupal, Tina - Rec therapist at Foothills Medical Centre
- Craven, Cathy - Toronto Rehab
- Curtis, Rick - Alberta Parks and Recreation
- Easton, Susan - formerly of AHRE
- Fritzsche, Lynette - Administrator for Brain Injury Services at Foothills Medical Centre
- Giles, Wayne - Dean of Kinesiology at U of C
- Harris, Colleen - MS Clinic at Foothills Medical Centre
- Hauser, Doug - Universal Rehabilitation Services Association (involved in the Brain Injury Initiative)
- Hogarth, Doreen - Alberta Council of Disability Services
- Hurlock, Deb - undertook a study of people with physical disabilities and inappropriate housing
- Iantko, Mark - Accessible Housing Society
- Kendrick, Michael - from Mass. In the U.S.; see web site
- Kirk, Deanna - formerly of Calgary Accessible Housing
- Knox, Darren - Stroke Program at Foothills Medical Centre
- Mallon, Bernie - Glenrose Rehabilitation Hospital
- McEwen, Sean - Calgary Alternative Career Employment Services
- McLeod, Norm - former CEO of PDD
- McPherson, Gary
- Noreau, Luc - SCISN Research Practice Network
- O'Brien, John - U of Syracuse
- Olson, Denise - Community Access Program, Central Alberta
- Plumite, Mary Ellen - outpatient nurse for SCI at the Glenrose
- Prochazka, Arthur – University of Alberta
- Stacey, Helen – involved in disability community throughout her career
- Stodler, Jennifer - OT at Foothills Medical Centre
- Turnbull, Patricia - Canadian Mental Health Association
- Wheeler, Garry - MS Society
- Dr. Zaki - Glenrose Rehabilitation Hospital
- Representative/s from:
  - AUMA and AAC&MD (urban and rural municipalities)
  - Canadian Active Living Alliance for Persons with Disabilities
  - People with brain injury who are also in wheelchairs
  - Line workers in brain injury (e.g. ARBI)
  - Manitoba Insurance
  - Employers
  - Educational institutions
  - School boards (child/youth needs) – Laurie Clifford or Patricia Erinburg
  - Christopher Reeve Foundation (someone in fund development)
  - Alberta Disabilities Forum
  - Cerebral Palsy Association
  - Nurse educator at the U of A
  - Special needs department at WCB (works with vendors) – Laureen Lozinsky, Kevin O'Neill, Denise Beaupre

- Yang, Janie - Faculty of Rehab Medicine, U of A
- Baird, Mary Ann – AADL
- Occupational Therapists, both in hospital and outside
- CPA National
- Other provincial CPA offices
- Long-term care facilities and home care
- Mayors

**Question #10: Following this round of interviews, we will be using the Delphi Method to reach consensus on what direction the SCI Strategy should take. Are there any experts in the areas of priority unmet needs that you would recommend we include on this panel?**

Experts recommended by participants in alphabetical order are (neither spelling, nor affiliations have been verified):

- Adams, Jeff – paralympic athlete
- Albers, Jacqueline – Alberta Health Services
- Boyd, Eric - CEO of the SCI Solutions Network
- Broad, Robert – Division of Neurosurgery, University of Alberta
- Burns, Tony - Rehabilitation Practice Network lead with SCI Centres of Excellence
- Cardinal, Oliver - Aboriginal and experienced in medical services in western Canada
- Christopher Reeve Representative - Project Walk re Community Based Rehabilitation
- Clarke, Teren (3) - ED with CPA Alberta
- Conquest, Margaret - Community Access Program (427-9146)
- Craggs, Michael - SCI Unit at Royal National Hospital in London, England – Orthopedic/transitions
- Craven, Cathy – Toronto Rehab
- Earl, Dianne - a Quality of Life Counsellor
- Ferguson-Pell, Martin – Dean, Faculty of Rehab Medicine, University of Alberta
- Fox, Richard – Division of Neurosurgery, University of Alberta
- Gabriele, Tina - a professor at U of C in Kinesiology and Adapted physical education
- Guthrie, John – Glenrose Rehabilitation Hospital
- Harper, Stephen representative - Federal gov't rep from Health (i.e. MLA Cal Ballas)
- Hill, Denise - Calgary Physician
- Hirsch, Braden (2) - Seniors and Community Supports
- Hehr, Kent (4) - Liberal MLA
- Hughson, Anne - University of Calgary - Cross Disabilities Expert
- Iantkow, Mark - Vision impaired and an expert on barrier free housing and accessibility; see Accessible Housing in Calgary or call home at 403-271-7488
- Kendrick, Michael - from Mass. In the U.S.; see web site
- Legg, David - Mount Royal College Professor and Advocate for Disability ( on Active Living Committee)
- Lai, Vivian - Alberta Health & Wellness
- Lunney, Marg - Director of Physiotherapy at Foothills Medical Centre
- MacPherson, Gary (4) - Alberta ( See PCSPWD)
- Manderville, Doug – Canadian Paraplegic Association, Red Deer office
- Milligan, Vance - Chair of Alberta Paraplegic Foundation
- McGladdery, Pam - URSA in Calgary - employment services
- McKowen, Dan - Calgary Physician
- Morris, Betty Lynn - Alberta health Services
- Noreau, Luke - SCI Solutions Network – National Community Integration Practice Network
- Norton, Ross - CPA Alberta and SCI Solutions Alliance Coordinator
- O'Brien, John - Responsive Systems Association - Lives near Georgia
- Peers, Danielle – paralympic athlete
- Pempeit, Larry - CPA Alberta – Community Development
- Pierce, Neil - ED of MS Society – Alberta Chapter

- Prochazka, Arthur - In Edmonton doing research with in home rehab devices
- Ragnarsson. Dr. - Mt Sinai Hospital in new York - lead at the Centre of Excellence
- Representative from Manitoba Insurance
- Russell, Tom - Blood Reserve
- Squire, Leanne - City of Calgary Accessibility
- Steadward, Bob
- Stein, Dick - Edmonton advocate and develops new devices to improve function
- Styner, Marlin (4) - Premier's Council on the Status of Persons with Disabilities
- Sturdy, Barb - Alberta Culture and Community Spirit
- Thomson, Audrey – Multiple Sclerosis Society, Red Deer office
- Ulanicki, Roxanne – advocate with the Spina Bifida and Hydrocephalus Association of Northern Alberta
- Whelan, Patrick
- Wheeler, Garry - MS Society, Alberta Chapter - Director of Community Services
- Wight, Eilleen – Instructor at Mt. Royal College in Social Work and Disabilities Studies

### **General Comments:**

- Recommend all Executive Directors of ADF to ensure cross-disability thinking.
- Get government on side and keep them totally in the loop and in the know of results.
- Use either a face to face or phone conference to begin process; people are very busy and just e-mail may not get a response or go to the right people.
- Highlight SCI focus within broader perspective of physical disabilities & people with mobility impairments.
- Include a variety of experts from different sectors relating to our issues like the building sector, medical community, seniors re aging in place and other with mobility impairment.
- Don't miss the medical perspective.
- Aim to get buy-in from different disciplines and the different influencers and decision-makers – those with control of dollars.



Appendix A: List of Interview Participants

| Last Name     | First Name | Title  | Organization   |
|---------------|------------|--|--|
| Albers        | Marcy      | Inpatient Coordinator  | Glenrose Rehabilitation Hospital                               |
| Andrews       | Alan       | Contract Specialist  | Community Partnerships, Seniors and Community Supports         |
| Avdagovska    | Melita     | Provincial Coordinator   | Alberta Disabilities Forum                                     |
| Bagg          | Christian  | Member   | Alberta SCI Solutions Alliance                                 |
| Belton        | Kathy      | Executive Director   | Alberta Centre for Injury Control and Research                 |
| Brown         | Alicia     | Program Manager  | Spina Bifida and Hydrocephalus Association of Northern Alberta |
| Clarke        | Teren      | Executive Director   | Canadian Paraplegic Association (Alberta)                      |
| Coulombe      | Guy        | Manager, Client Services (Edmonton)  | Canadian Paraplegic Association (Alberta)                      |
| Currie        | Barb       | Supervisor, case management team   | Workers' Compensation Board – Alberta (Edmonton office)        |
| Dunne         | Donna      | Coordinator of Inclusion, Post-Secondary Education                               | Mount Royal University   |
| Ferguson-Pell | Martin     | Dean   | Faculty of Rehabilitation Medicine, University of Alberta      |
| Forrester     | Charmaine* | Case Manager, Special Needs  | Workers' Compensation Board – Alberta (Calgary office)         |
| George        | Tammy      | Manager, Trauma Program  | Royal Alexandra Hospital                                       |
| Goodwin       | Donna      | Executive Director   | The Steadward Centre for Personal and Physical Achievement     |
| Graham        | Bonnie     | SCI Inpatient Manager  | Glenrose Rehabilitation Hospital                               |
| Hessler       | Guy*       | Case Manager   | Workers' Compensation Board – Alberta (Edmonton office)        |
| Hill          | Denise     | Physiatrist  | Foothills Medical Centre                                       |
| Hirsch        | Braden     | Manager, Community Partnerships  | Alberta Seniors and Community Supports                         |
| Hsieh         | Jane       | Director of Environmental Scans & Manager, Rehabilitation Practice Network       | SCISN  |
| Hubele        | Ralph      | Manager, Health & Housing Initiatives, Supportive Living & Long Term Care Branch | Alberta Seniors and Community Supports                         |
| Kwakernaak    | Johanna    | retired Director of Rehabilitation and Specialized Clinical Services             | Foothills Medical Centre                                       |
| Lafreniere    | Winona     | Client Services Coordinator  | Canadian Paraplegic Association (Alberta)                      |
| Manderville   | Doug       | Manager, Regional Services   | Canadian Paraplegic Association (Alberta)                      |
| Matthiessen   | Bev        | Executive Director   | Alberta Committee of Citizens with Disabilities                |
| McDonald      | Kim        | Executive Director   | Paralympic Sports  |
| McGowan       | Dan        | Physiatrist  | Foothills Medical Centre                                       |
| Mers          | Debbie*    | Coordinator, Trauma Program  | Royal Alexandra Hospital                                       |
| Milligan      | R. Vance   | Barrister and Solicitor  | Bennett Jones LLP  |
| Morrice       | Betty Lynn | VP Allied Health Strategies  | Alberta Health Services  |

| Last Name  | First Name | Title  | Organization   |
|------------|------------|--|--|
| Page       | Marion*    | Case Manager   | Workers' Compensation Board – Alberta (Edmonton office)      |
| Pellegrino | Patrick    | Member   | Alberta SCI Solutions Alliance                               |
| Pempeit    | Larry*     | Director, Community Development  | Canadian Paraplegic Association (Alberta)                    |
| Pierce     | Neil       | President  | MS Society of Canada, Alberta Chapter                        |
| Red Gun    | Johnathon  | Disability Coordinator   | Community Futures Treaty 7 (CFT7) Disability Program         |
| Redfern    | Toby       | Aboriginal Services Coordinator  | Canadian Paraplegic Association (Alberta)                    |
| Robertson  | Ian        | Supervisor, case management team   | Workers' Compensation Board – Alberta (Calgary office)       |
| Ross       | Marc       | Member   | Alberta SCI Strategy Steering Committee                      |
| Royan      | Carl       | Director, Lottery Funding Programs   | Alberta Culture and Community Spirit                         |
| Saliba     | Soraya     | Executive Director   | Accessible Housing Society, Calgary                          |
| Saunders   | Iris       | Executive Director   | EmployAbilities  |
| Saunders   | Sandy      | Business Services Advisor, Business Expertise Unit   | Service Canada   |
| Schamber   | Chris      | Member   | Alberta SCI Solutions Alliance                               |
| Squair     | Leanne     | Issue Strategist   | City of Calgary  |
| Stoesz     | Barbara    | Administrative Director, Adult Rehabilitation  | Glenrose Rehabilitation Hospital                             |
| Stuffer    | Sarah*     |  | Royal Alexandra Hospital                                     |
| Styner     | Marlin     | Chair  | Premier's Council on the Status of Persons with Disabilities |
| Thornly    | Angela*    | Case Manager, Special Needs  | Worker's Compensation Board – Alberta (Calgary office)       |
| Tweedle    | Patty      | Young Adult Rehab Program Assistant  | Bethany CollegeSide  |
| Uditsky    | Bruce      | CEO  | Alberta Association for Community Living                     |
| Walsh      | Simonne    | Executive Director   | Champions Career Centre                                      |
| Weinkauf   | Tim        | Senior Manager, Program Quality and Evaluation   | Seniors and Community Supports                               |
| Whelan     | Patrick    | Associate Professor & AHFMR Senior Scholar; Co-leader Spinal Cord and Nerve Regeneration Program | Hotchkiss Brain Institute                                    |
| Woodroffe  | Avonda*    | Case Manager, Special Needs  | Workers' Compensation Board – Alberta (Calgary office)       |
| Yuzwak     | Cathy      | Social Worker  | Foothills Medical Centre                                     |

\* this person is counted in the total number of respondents, but not in the total number of interviews as they were interviewed with another person or other persons on the list.

Twelve other individuals who were contacted indicated an interest in participating, but were unavailable during the allotted time frame.

Appendix B: Detailed Responses to Question #7 – Priority Needs

**7. Participants were asked - “From your perspective, what are the priority unmet needs facing Albertans with SCI – priorities that should be addressed during this process?”**

(Number in parentheses indicates how many respondents mentioned that item and the percentage of interviews where that item was mentioned.)

| PRIORITY NEEDS   | COMMENTS AND DESCRIPTION OF NEEDS  |
|--|--|
| <p>Accessible and affordable housing<br/>(28; 61%)</p> | <ul style="list-style-type: none"> <li>• Huge need for housing for people coming out of rehab – creates backlogs in the system.</li> <li>• Municipalities must establish by-laws that ensure at least 10 to 15% of housing is accessible; developers need building codes and by-laws to follow and procedures to ensure they uphold same.</li> <li>• Provide subsidies/incentives for people to make their homes visitable.</li> <li>• Affordability is key; some people need rent assistance; need action now.</li> <li>• Need more variety of housing options and fuller access to the community. (2)</li> <li>• There are issues with eligibility for the housing that is available.</li> <li>• Need more transitional housing for people while they wait for modifications to be completed on their permanent residence. (4)</li> <li>• Available funding through Affordable Supportive Living Initiative is not being accessed b/c it's not in the mandate of many service providers to operate a housing unit and they don't have the dollars required to operate the units once they are built.</li> <li>• The seniors population and the goal of aging in place will increase need for no/minimal stairs and/or ramps. (2)</li> <li>• More residential care units with mixed ages &amp; attendant care on site.</li> <li>• Accessible housing needs to be integrated in the community.</li> <li>• More long-term care units with appropriate programming for younger adults – there are a lot of people in Alberta under 65 who require long-term care.</li> <li>• Few long-term options for people who are vented.</li> </ul> |
| <p>Home care and attendant care<br/>(27; 59%)</p>      | <ul style="list-style-type: none"> <li>• Goes hand in hand with accessible housing – people can't move into their own home if they can't get care.</li> <li>• The freeze on self-managed care funding is having a devastating effect on families – young people are being discharged into long-term care – affects people psychologically.</li> <li>• Self-managed care was ideal; agencies are too restrictive; what you get depends on who you have to go to bat for you. (2)</li> <li>• There aren't enough skilled home care workers, even if you have the money to pay for one.</li> <li>• Need flexible, self-managed attendant care to allow people freedom to live a normal lifestyle (e.g. go out for the evening, attend family events). (3)</li> <li>• Good access to primary care to ensure prevention of pressure sores (2) and address underlying issues; people need access to appropriate health services.</li> <li>• Support to SCI individuals with more home care services that help people to live in the home and to be healthy and fit. (2)             <ul style="list-style-type: none"> <li>- People need to have the choice - they have different needs for</li> </ul> </li> </ul>   |

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|  | <p>attendant and home care services; funding must go to person with a disability to purchase priority supports based on individual needs.</p> <ul style="list-style-type: none"> <li>- Consider giving each individual with SCI \$10,000 over 3 years for basic needs such as education, recreation, daily living aids, etc...; equity is a factor for all persons with SCI; some choose to work and others choose or may not be able to work; regardless - all people have needs that are not being met regarding their quality of life.</li> <li>• Need more attendants to help people access and effectively use community resources, public and private facilities and programs.</li> <li>• Need attendant care for personal needs, transportation, coaching new skills.</li> <li>• Provide recognition for family care givers through tax credits plus expenses; family members who provide rehab support/health services need respite programs. (5)</li> <li>• Establish a 'Registered Disability Savings Plan' which allows families to contribute to a savings plan for their disabled family member.</li> <li>• Government prefers to pay institutions rather than home care; people without basic home care supports have nowhere else to go but 'institutions and hospitals'.</li> <li>• Combine/join rehab and homecare to eliminate waiting lists and enhance reach and standards; combine common solutions into 1 clinic in rural areas.</li> <li>• People in the middle zone of health do not get support to be successful.</li> </ul>   |
| <p>Employment and education training and motivation supports (22; 48%)</p> | <ul style="list-style-type: none"> <li>• Goal is full participation at home, at work if appropriate, and in the community.</li> <li>• Access to customized technology for everyone (2) complete with adapted equipment and programs as needed; this is essential for all individuals to overcome barriers to participation and to level the playing field.             <ul style="list-style-type: none"> <li>- Ensure wireless capability and power connections.</li> <li>- Give customized technology and equipment at the right time.</li> </ul> </li> <li>• People needs the tools, skills/abilities and willingness to do the job.</li> <li>• Establish more employment opportunities for work; attitudes of employers and the potential employee need improving.</li> <li>• Need better access to post secondary education with equipment to help success.</li> <li>• Help individuals become volunteers and valued members of their community.</li> <li>• Add more education and training supports to give people the confidence and knowledge to compete with others at work.</li> <li>• Enhance socialization skills and abilities to move outside of comfort zone so individuals can create more allies for themselves; (4)             <ul style="list-style-type: none"> <li>- Need coaching, counsellors and system navigators to support success.</li> </ul> </li> <li>• Support people in pursuing a wide range of employment options (e.g., entrepreneurship).</li> <li>• Encourage employers to keep their workers on in a different role after injury, if that is possible.</li> <li>• SCI individuals need training for new careers and work opportunities are needed; address new knowledge, skills training and help with mental stress; facilitate services that cultivate a positive attitude towards ones abilities.</li> </ul> |

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| <p>Improved access to in-patient rehabilitation services including transition to and from rehabilitation (14; 30%)</p> | <ul style="list-style-type: none"> <li>• More in-patient rehabilitation beds – paras are looking at only 4 to 6 weeks in rehab and they panic and can't focus on their rehabilitation.</li> <li>• Access to rehabilitation services.</li> <li>• Lots of gaps in the rehab process (6); 3 months of rehab is too short plus there's a lack of funds for ongoing prevention rehab ...             <ul style="list-style-type: none"> <li>- Best practice research shows that more intensive rehab in the beginning increases ability significantly and provides for better mobility/abilities in long term; rehab is critical up front and for years. (2)</li> <li>- Rehab is the only thing that helps with improving function; need partnership to obtain greater access to treadmills/exercise/rehab.</li> <li>- Need 100% referral of all SCI persons from rehab centres (3); Peer Support Program is informal in Calgary and referrals are inconsistent from hospitals &amp; rehab centres; turf protection, lack of understanding of the effectiveness of peer support along the way needs to be addressed; bridge the gap here.</li> </ul> </li> <li>• Multiple transitions (e.g. to await rehab or to await home modifications) creates stress on families – will they get proper care in their new environment? – fear causes delays in their transition.</li> <li>• Delays in being admitted to rehabilitation mean that patients can arrive in rehab with more problems (e.g. pressure sores) or they become set in their ways.</li> <li>• People need suites in or outside of the hospital where they can go to see how independent they can be – they need to get over their fears before being discharged.</li> <li>• Bridge community-based organizations' relationships with the medical community; huge benefit to clients when there are good referrals – like the Alzheimer's group that have a formal arrangement - the 'First Link Program.'             <ul style="list-style-type: none"> <li>- Work through the issue of credentials and licensing; Peer Support has a defined scope of practice and supports rehab process in many ways.</li> <li>- Put service standards in place to show the medical system we have knowledge, skills, care and right attitude to help make a difference.</li> <li>- CPA could be involved at a high level in clinics and with rural or mobile clinics to provide peer support, system navigation , etc.</li> <li>- There needs to be management contracts with policies, protocols, goals, roles/responsibilities to coordinate provision of care.</li> </ul> </li> <li>• Support skills, abilities and basic needs to transition to independent living; it can take up to 5 years to build a strong, consistent and health place/life.</li> <li>• Support skills, abilities and basic needs to transition to independent living; it can take up to 5 years to build a strong, consistent and health place/life.</li> </ul> |
| <p>Transportation accessibility and independent driver training/adaptations (14; 30%)</p>                              | <ul style="list-style-type: none"> <li>• All buses should be accessible - no questions asked.</li> <li>• Accessible public transportation is needed all across Alberta.</li> <li>• Provide more vehicle adaptation funds and driver training; personal independence is key to employment help achieve income and quality of life.</li> <li>• Handi-bus is a hassle – especially in rural areas.</li> <li>• First Nations need transportation to move around within the reserve.</li> </ul>  |

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|  | <ul style="list-style-type: none"> <li>• The reason some people can't access health services is that they lack transportation.</li> <li>• Calgary is losing its ability to test/train people for drivers' licenses.</li> </ul>  |
| <p>Access to rehabilitation and health services over the long-term (13; 28%)</p> | <ul style="list-style-type: none"> <li>• Longer-term follow-up care for health needs related to SCI (e.g. urology consult, prevention of skin problems, information on diet).</li> <li>• Need for community-based physio services – perhaps funding for physios to obtain the equipment they need to work with quads, especially.</li> <li>• Need more outpatient services – people have long waits to get into the Glenrose outpatient program, meanwhile they struggle.</li> <li>• Many health care staff at regional hospitals or private care centres aren't skilled at dealing with SCI – telehealth is working but doesn't replace a face-to-face especially if the needs are complex.</li> <li>• need someone who could do referrals and talk with professions and help identify unique care needs – we like people to advocate on their own behalf, but they can't always do it. A centralized person would provide some provincial consistency.</li> <li>• a travelling outpatient team is needed to reach isolated people – or provide a clinic that goes into the community.</li> <li>• Education of family docs and long-term care staff to help address medical needs.</li> <li>• OTs perform an important role in assessing people in the community and identifying things they need.</li> <li>• Shift balance to 'Prevention'; true health care vs current illness response system.</li> <li>• All rehab facilities in Alberta need to be accessible for use; include other physical health/physiotherapy services in sports/recreation centres too.</li> <li>• In Calgary there's a disjointed continuum of care – starts to break down in access to outpatient therapies – services are provided in different facilities located throughout the city.</li> </ul> |
| <p>Adapted equipment and aids to quality of life (12; 26%)</p>                   | <ul style="list-style-type: none"> <li>• Need quicker access to equipment for trial in rehab. (2)</li> <li>• People need availability to existing 'adapted equipment' which allows them to access the outdoors, play sports, use technology, engage in community.</li> <li>• Need better assistance with mobility; different wheelchair. needs/products for different applications, home modifications and work modifications to with person (2); families can't afford power wheelchairs.</li> <li>• Include funds to use Alternative Health Services such as massage, pressure mapping and other prevention options to attain health.</li> <li>• Fund high tech strategies for home base rehab; ensure a computerized home for everyone to be fully activated with the web, lights, TV, phone, etc. (2); better communication devices like adapted computers; better designed wheelchairs (that are adjustable to a person's changing needs).</li> <li>• Need client drive treatment plans in areas (physical, social, emotional, spiritual, intellectual); provide self management workshop to teach injury prevention, system navigation &amp; how to maximize health with exercise, etc.</li> <li>• Include alternative therapies like yoga, massage, acupuncture, active living into mainstream options; incorporate into treatments and funding programs.</li> <li>• So many surgical, drug, physical advancements have been made but not everyone gets access – it needs to be available in the community.</li> </ul>   |

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| <p>Funds for SCI active living / access to recreation and leisure opportunities (9; 20%)</p> | <ul style="list-style-type: none"> <li>• Active Living requires both attendant care support getting to and from programs.</li> <li>• Fees are a barrier and need to be funded by the government or facilities.</li> <li>• Fitness and physical activity options especially needed for those who are aging or are retired.</li> <li>• Need to support notion of people exercising in their own neighbourhoods.</li> </ul>  |
| <p>Psychological supports (8; 17%)</p>   | <ul style="list-style-type: none"> <li>• Peer supports to address emotional needs (emotional problems lead to addictions, which leads to eviction and homelessness).</li> <li>• Family members also need support – some have negative ideas about disability.</li> <li>• The Discovering the Power in Me program is interesting.</li> <li>• Self-esteem is key to making progress – people need to know they are not alone.</li> <li>• Support for people leaving the sheltered environment of the hospital.</li> <li>• Support for marriages and families to deal with role changes.</li> <li>• Need more emphasis on helping people develop their inner strength and capacity to overcome challenges.</li> <li>• Need to institute change from within – talk to the people and get them off the couch.</li> <li>• Focus on how the transition from able-bodied to disabled can be made better and the psychological influence on outcomes – two people with same circumstances can have very different outcomes – why?</li> <li>• On-going coaching to support independence.</li> </ul>   |
| <p>Advocacy with one voice and en masse – make lots of noise (7; 15%)</p>                    | <ul style="list-style-type: none"> <li>• Raise awareness of needs; investigate relaxation to by laws and code; lack of awareness of disability issues on reserve – there’s talk but nobody does anything – it’s not a priority of the leadership.</li> <li>• Lobby for basic human rights with housing, care, education, employment ... it is a constitutional rights issue that needs mass marketing ending up with a powerful presentation to Parliament Hill asking government to deliver a Canadian Disability Act with accessibility, inclusion, etc; put a draft Act on table. (3)<br/>- This would be a group effort to put this agenda on the government’s radar screen.</li> <li>• Help motivate people need to speak up about their needs and take action.</li> <li>• Basic principles like 20% of housing is barrier free is a goal post to rally around together; need to work as a team on strategies and goals.</li> <li>• Basic increases with inflation should be mandatory with AISH, etc.</li> <li>• Let’s go back to the 70’s grass root movement where people are self motivated to improve their own quality of life with efforts and advocacy.</li> <li>• Hire professional lobby/advocates for our priorities to facilitate changes and help people with SCI get involved and learn how to be advocates.</li> <li>• Hire a Communications Expert for public relations and staff training with the common messages/material.</li> <li>• All service providers need to get together with one voice to pursue a strong political agenda of common needs with collective strength and funds.</li> <li>• Work with the Alberta Disability Forum members to achieve common goals; work cross-disability when approaching government and foundations to make macro changes to policy (i.e. ramp program, housing, attendant care).</li> </ul> |

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| <p>Financial supports<br/>(7; 15%)</p>                 | <ul style="list-style-type: none"> <li>• People have to leave the reserve to receive AISH.</li> <li>• People need adequate income so they can access housing supports.</li> <li>• Self-managed care is an excellent program because it gives the person with SCI the control.</li> </ul>   |
| <p>Peer support<br/>(5; 11%)</p>                       | <ul style="list-style-type: none"> <li>• Mentors or life coaches are needed to educate people on how to manage their disability (health issues such as proper use of a catheter).</li> <li>• Need to build a community so people know they aren't alone.</li> <li>• Peers help you see what the future may hold.</li> </ul>  |
| <p>Basic and translational research<br/>(3; 7%)</p>    | <ul style="list-style-type: none"> <li>• Need to know more about how to improve function and paralysis.</li> <li>• More application of pressure sore treatments/procedures already available.</li> <li>• Research on regeneration of brain cells and cell growth.</li> </ul>   |
| <p>Aging in place for persons with SCI<br/>(2; 4%)</p> | <ul style="list-style-type: none"> <li>• Research on facts, trends, and best practices is needed in the impact of aging on persons with SCI; today, there is an earlier onset of aging issues and more SCI persons are living longer.</li> <li>• Facilitate an 'Aging Focus Strategy' across physical disabilities that engage the older people, doctors, community organizations.</li> <li>• Provide a funding program that allows 'Aging in Place' due to modifications in the home such as ramps or home care, etc.</li> </ul>  |
| <p>Other</p>   | <ul style="list-style-type: none"> <li>• Improved system navigation - create an 'Integrated Services Navigation System' with lots of coordinators from different organizations working together providing a full range of services.             <ul style="list-style-type: none"> <li>- Everyone would work with the same case file and management system – one person/1 file; proper referrals would be set up with the medical community and case consultation/reporting procedures.</li> </ul> </li> <li>• If you take care of people's basic needs, then they can stop freaking out and focus on higher things.</li> <li>• Community accessibility (2) – people need to be able to exist in their communities – it's offensive to have to enter establishments through the back door because the front is inaccessible.</li> <li>• Family Planning and IVF services</li> <li>• Vacations (hard for people to feel comfortable leaving their homes)</li> <li>• Access to information on services for people with SCI</li> <li>• Access to emergency information such as where to get their wheelchair fixed</li> <li>• What contributes to quality of life? Family, employment, housing, ability to take a vacation. Need more attention to quality of life issues.</li> <li>• There are no services on reserves – people have to leave to get services.</li> <li>• agree with the needs as described in the Going Forward Together proposal to government</li> <li>• Accessible drug and alcohol addiction programs.</li> <li>• Empower people with SCI - address the apathy with some clients; SCI community need to have more involvement in action plans and include more voices from people with SCI.             <ul style="list-style-type: none"> <li>- Comes down to governance - who owns the organization; SCI need to feel like Ambassadors and that they are the primary</li> </ul> </li> </ul> |



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|  | <p>shareholders.</p> <ul style="list-style-type: none"><li>• Define the opportunities for involvement and show how they can help out.<ul style="list-style-type: none"><li>- Integrate more with the general population and community programs like Bingo, social gatherings and other project opportunities.</li></ul></li></ul> |
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## Alberta SCI Strategy Steering Committee

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