

NZ SPINAL CORD INJURY ACTION PLAN EVALUATION - SUMMARY OF FINDINGS FOR PARTICIPANTS

“After 2 years 3 months, housing modifications are not done yet, vehicle modification done and still waiting on several bits of equipment to be assessed to get back into social things . . . So in the meantime my partner is waiting and becoming more reclusive, more isolated, extremely frustrated and dangerously depressed each week that goes by! There is nothing I can do to make it better, so I'm now stuck too.”
[Family Member]

“There have been improvements with the service changes implemented through the NZSCIAP; however, there is still significant room for improvement in all areas of delivery - from inpatient to community follow up, to GP management and community care, education, and accessibility [for] people of varying socioeconomic statuses, cultures, location, and funding streams.”
[Healthcare professional working in specialist unit]

KEY THINGS PEOPLE WITH SCI & THEIR FAMILIES TALKED ABOUT

- Generally inpatient and community rehabilitation services are meeting peoples needs. However, psychological and pain management support continues to be an issue. People with non-traumatic SCI have more issues accessing timely acute and community services.
- It can be difficult to navigate and access healthcare and support once you are living in the community.
- Timely provision of equipment, housing and vehicles continues to be a problem for many, especially children.
- At times there is a lack of transparency about how decisions are made, and where the ‘roadblocks’ are.
- Overall, current systems do not see ‘me as a person’ - meaning that the wishes and needs of people with SCI (and their families) are often not considered or prioritised.

WHO WE COLLECTED INFORMATION FROM



151 ONLINE SURVEYS FROM PEOPLE WITH SCI, FAMILY MEMBERS, HEALTH CARE PROFESSIONALS & CARERS



17 INTERVIEWS WITH ADULTS & CHILDREN WITH SCI



DATA FROM FUNDERS, HEALTH CARE PROVIDERS & THE NZ SCI REGISTRY

KEY THINGS HEALTHCARE PROFESSIONALS & CARERS TALKED ABOUT

- The Action Plan helped funders and provider organisations to work together more collaboratively.
- Acute clinical pathways for people with traumatic injuries have improved.
- The NZ SCI Registry makes it easier to determine whether people’s needs are being met and how services could be improved.
- Inequity of access to SCI services, supports and equipment (as influenced by funder, ethnicity and home address) was identified as being a key issue.
- Ongoing training of healthcare professionals is required – sharing the different expertise of inpatient and community providers.

KEY RECOMMENDATIONS

A national forum for ongoing communication and collaboration is required. Include more diverse representation and consultation within this group. Key future strategic directions include:



Improve equitable access to services by develop processes and supports to improve navigation of people with SCI through services. Develop tools and resources to empower the person with SCI (and their family) to more effectively advocate for themselves.



Include people with SCI (and their families) in the design and implementation of service improvements.



Explore innovative health and support services that better meet the needs of people with SCI in timely and responsive ways. Ensure that reassessment services focus on future needs and wishes and not just current ‘problem’ identification.

Specific suggestions for next steps: flexible care pathways, pain management, housing modification processes, transitioning from child to adult service and peer support (*see full report for details*).

NEXT STEPS

The NZSCIAP Governance Group, ACC and the MoH have noted the recommendations of the evaluation report. Planning is now being done to work how best to address the recommendations.

BAIL is working with a range of organisations and people with SCI to start several research projects that could provide more information about how best to provide services to people with SCI.

BAIL is writing up several papers that will be published in international journals.

WHERE CAN YOU FIND MORE INFORMATION?

A full copy of the NZSCIAP Evaluation Report can be found on the BAIL website (www.burwood.org.nz). Video summaries of findings related to each of the NZSCIAP objectives are also available there.

Contact BAIL (admin@burwood.org.nz) if you would like further information or would like someone from BAIL to present findings to your organisation or group.