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**REPORT ON CONSUMER FOCUS  
GROUP CONDUCTED FOR PEOPLE  
WITH SPINAL CORD INJURIES  
LIVING IN THE COMMUNITY**

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# **INTRODUCTION**

The Spinal Outreach Service is a NSW Department of Health initiative to address the ongoing and complex needs of people living with spinal cord injury in the community. It promotes health maintenance and recognises the need to build capacity among consumers and health care providers in order to create long-term sustainable outcomes. The Spinal Outreach Service partnered with two Non-Government Organisations (NGOs) – ParaQuad and Spinal Cord Injuries Australia (SCIA), for the purpose of these focus groups. The aim of the focus groups was to gather information from consumers on the topics of health education and community participation. The information that is collected was de-identified and analysed to determine the needs of consumers in terms of health education and community participation. It is hoped that this will result in more targeted service delivery to consumers and better utilisation of resources.

# **METHODOLOGY**

Two focus groups were conducted in May & July 2009. The groups were held in two different geographical locations in the state of NSW. The locations selected were one large rural town (Ballina) and one urban city (Sydney).

## **Selection Criteria:**

- ◆ People with a spinal cord injury
- ◆ Living in the community
- ◆ Between the ages of 18 – 67 years

The questions were prepared with an objective of gaining information about the needs of the consumer, the self-efficacy of the consumer and the likelihood of compliance by the consumer. The two main topics covered were health education and community participation.

A pre-focus group one-on-one interview was conducted. This was done as a face-to-face interview or over the phone. The aim of conducting a pre-focus group interview was to save time at the focus group meeting and to give participants a better idea about the process.



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All of these participants were then invited to attend a consumer focus group for a face-to-face group interview session.

The answers from the pre-focus group interviews were de-identified, tabulated and shared with the group at the beginning of the session. The group was provided with an opportunity to comment or add anything more to these responses.

Respondents could not participate if they:

- were unable to understand and speak English
- had an associated brain injury with cognitive impairment
- were medically unstable

## **GOALS**

- Assess awareness of health maintenance as a critical element of improving quality of life
  - Attitudes towards health maintenance
  - Awareness of health education resources
- Test creative concepts for health education and health promotion
  - Attitudes towards health education
  - Preferred method of information dissemination
- Assess willingness to engage in social and economic participation
  - Attitudes towards community participation
  - Awareness of direct relationship between participation, quality of life, health and well-being

## **OBJECTIVES**

The purpose of the report was to provide an understanding of the needs of the community in terms of health education and community participation in terms of intensity and numbers.

Creative solutions provided by the two groups were explored and summarised.



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The report will be used to plan service delivery to people with Spinal Cord Injury living in the community in NSW so that they can maintain their health and participate to the best of their ability within the community.

## **EXECUTIVE SUMMARY**

Each of the two groups had their own unique dynamics and personalities. Both groups responded well to the questions and were appreciative of the opportunity to participate and to present their views in terms of health education and community participation.

The following bullet points summarise the major commonalities and differences among the two groups.

- The urban group demonstrated a higher level of awareness of the various government and private facilities available to them. They were also more aware that it was important to keep up to date with the latest developments on health maintenance issues. They were able to articulate strategies to formalise ways of distributing information to people with spinal cord injury. They demonstrated a better understanding of how to access services and make the best use of the opportunities available to them in terms of funding and care. This is likely to be a factor of their geographic location and the fact that they are more connected to organisations and facilities. They also used community health professionals as a source of information.
- The rural group felt very strongly that they were disadvantaged due to their location and agreed that there was “nothing” available to them to help them to maintain their health and participate in the community.
- Access was a major barrier for both groups.
- Lack of after-hours care was also an issue raised by both groups.
- The Internet was a common tool to access information, but this was used more by the younger members of the rural group as the urban group were sceptical about the information on the net.
- Both groups displayed awareness about the link between community participation and health and well-being. Both groups were interested in pathways to paid employment, education and training. The urban group



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also displayed interest in staying connected with the community via voluntary work and peer support.

- Most people want to maintain health but do not necessarily take an active part in doing so. The major barriers were lack of facilities and access issues.
- Awareness of health maintenance as a critical element of improving quality of life was high in both groups and the concept of being able to access information in relation to their health was welcomed.
- A unifying factor among both groups was that they would like regular updates on issues relating to health promotion and community participation.
- Peer support groups were identified as a valuable source of information by both groups
- Both groups felt that vocational counseling services should be provided in rehab.

There is a need for a systematic targeted service delivery approach to build capacity for consumers. It is recommended that we target the following areas:

- Peer Support Networks should be made available during the inpatient stay and continue post discharge.
- Vocational rehab. services should be provided during the inpatient rehab. stay.
- Annual consumer events should be held in both urban and rural areas to provide an opportunity for education and networking.
- Consumer education resources should be developed using a variety of user friendly vehicles to disseminate information.



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# **SECTION 1**

## **QUESTIONS ON HEALTH EDUCATION / HEALTH PROMOTION**

### **PRE-FOCUS GROUP QUESTIONS**

#### ***Associations with health***

#### **1. What would you associate with the word “health”?**

*Group participants were asked what they would most associate with the word “health”. Respondents offered words that were both physically descriptive of health and words that were associated with the functions and quality of health.*

- “Being well enough to do my daily routine”
- “Looking after myself”
- “Being well”
- “Quality of life”
- “Exercise and eating right”
- “Coping mentally”
- “ Good immunity”

*There were some negative associations with the quality of health across both groups. Words used were:*

- “Rescue”
- “Staying out of hospital and not depending on doctors”
- “Pain management and ability to sleep at night”
- “Bed rest”
- “ Fixing problems as and when they arise”



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## 2. What does staying healthy mean to you?

*Group participants were asked what staying healthy meant to them. Respondents offered words that were both physically descriptive of fitness and well-being as well as words that were associated with activities of day-to-day living.*

- “Being strong”
- “Sense of well-being”
- “Keeping fit”
- “Good nutrition”
- “I can be active and relatively independent”
- “Being fit and well”
- “Being independent in my daily activities”
- “Exercising”
- “Getting some routine in my life”
- “Pacing myself”
- “Better Quality of life”
- “ Being able to do things and enjoy life”

*There were some negative associations with the meaning of health across both groups. Words used were:*

- “Not being sick”
- “ I don’t have to go to hospital”
- “ Not going backwards”
- “ Not being on bed rest”

## 3. Is staying healthy important to you? – Yes / No; Why?

*All participants were clear that staying healthy was important to them.*

*The physical imagery that is associated with health maintenance mainly revolved around being active, and functioning well.*

- “All round wellness”
- “ Easier to transfer and move around”
- “ Helps me to function”

*There was also a general focus on quality of life when considering health maintenance. Words mentioned were:*

- “Enjoy time with my family”



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- “So that I can be with friends – not sit at home”
- “ Live a long life and enjoy to the fullest”

*The reasons they provided were mainly to do with their own self-worth and ability to*

- “be useful”
- “ enhance personal pride”
- “enjoy”

*There were a few negative associations with not maintaining one’s health*

- “Life is not much fun when you are sick”
- “ I am aware that things can deteriorate very quickly”
- “ I can stay out of hospital”

## **FOCUS GROUP QUESTIONS**

### **1. What do you know about the resources relating to your health that are available to you?**

*The rural group felt there were not enough resources available in the community. They felt this was the case in terms of health and fitness, equipment, as well as trained and knowledgeable experts in the field.*

*There were some negative associations with the lack of resources across the rural group. Words used were:*

- “As far as spinal cord injury, there is nothing out here.”

*The urban group felt that there was a significant difference between the resources available to compensable clients compared to non-compensable clients.*

- “Being compensable, my case manager sorted out all my problems – I felt a bit spoiled compared to other people in rehab.”

*The urban group also felt that if the government provided free appliances and health needs it would reduce the number of hospital admissions.*

- “Cause people who are paying for things themselves will naturally want to save wherever they can by sterilising and reusing disposable things.”



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- “Why would you use more than necessary? You would use the best appropriate, and I feel it would save the government a lot of money in the long run.”

*Respondents in the urban group felt that there were resources in the community, but it was hard to know how to access these resources.*

*Another area of concern for both the groups (but expressed more in the urban group) was the lack of after-hours care and the lack of availability of respite care.*

- “Now we’ve got funded for respite, but there are no respite facilities available. ParaQuad is redoing Ferguson Lodge. They are not available for sixteen months.”
- “The only option is an aged home; now I don’t think that’s a very good scenario.”

## **2. Where / how do you normally access information?**

*There was a distinct difference in the preferred method of accessing information. The older participants in the rural group accessed health information from their GPs. Words used were:*

- “You go through your GP”.
- “They know everything about where things are around this part of the woods.”

*The younger participants had negative associations with GPs. Words used were:*

- “Yeah, I found that GPs know nothing, ‘cause they have no idea about spinal stuff”.

*They also felt that GPs do not get enough training when it comes to managing people with SCI.*

- “They are not trained in that, so they know nothing.”

*One participant felt that the information given to him when he left spinal rehabilitation unit was useful, but would have liked more information to be sent to him on an on-going basis.*

*The general feeling was people would appreciate regular updates even in the form of an email.*

*A great emphasis was placed on experiential learning:*



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- “You learn as you go”

*People also benefited from formal services that they could contact like the Spinal Outreach Service. They expressed gratitude that they were given an opportunity to participate in a focus group so that they could express their thoughts and feelings.*

- “This is the first chance I had to participate in a focus group”

*Hardly anyone in the rural group used community health professionals to access information about health resources. It was generally felt that there was not enough support from community-based organisations in rural NSW compared to Queensland - there were some negative feelings expressed.*

- “We chose ParaQuad because they are a large organisation but they are based in Sydney. There’s been very little here”.
- “The services in Queensland are phenomenal”

*The urban group was more open to using community health professionals as a source of information.*

*Respondents in the urban group identified the following magazines as good sources of information:*

- SCIA quarterly publication
- ParaQuad quarterly publication

*Words used were:*

- “There is a lot of information in there.”
- “You can just skim through them. You pick up little things and it is so helpful.”

*One participant in the urban group also identified SCIA as a good source of information.*

- “SCIA have people who are employed to help you with every problem in every direction, to direct you to where there is help and such.”
- “Not only that, but if you don’t want to ring up, they have a website and a blog area where you can go in and ask questions and chat things over and such. That sort of thing can be tremendously helpful.”

*Peer support was identified as a valuable source of information both in intensity and numbers by both groups.*



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*A participant and peer support worker from the urban group felt that consumers do not get enough information about continence management in hospital.*

- “I go around every week, I know they don’t because that is what I spend most of my time doing – teaching people independent management of their continence equipment – they don’t have a clue, what’s out there, even in rehab.”

*Another participant also seemed to agree.*

- “I found that the things they were telling me in hospital were completely and utterly useless.”
- “Why would you ask a nurse as opposed to someone who is living with it?”
- “There are limits on advice they can give you for legal reasons as well. They’ll tell you never to reuse a catheter.”

*This feeling was shared by the rural group*

- “Word of mouth....talking to other people in chairs is the easiest way”

**4. On a scale of 1-10, 10 being the highest confidence level, how confident are you of being able to access all the information you need about your health?**

*Here again the confidence level was higher (7-10) amongst the younger participants, and this was directly related to their ability to access information from the Internet. This was more evident in the rural group.*

*An interesting comment by a participant in the urban group was that it was difficult to access information about care agencies on the Internet.*

- “They do not seem to want to advertise themselves on the Internet. Even my case manager who’s a professional found it difficult to access an agency in the North Shore area.”

*The urban group felt that it was easier to use the Internet to get more information about the things that they were aware of.*

- “It does not help you learn about new options.”
- “It is pretty bad if you have to sit with Google to find out what’s available to you.”



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*Respondents in the urban group were also more sceptical of information they obtained from the Internet, particularly about wheelchair accessible facilities.*

*Interestingly, the older respondents in the rural group rated their confidence level as (3-5). This was because they only tended to access information from local health professionals when they were in trouble and they felt that “the local doctors don’t know anything”. However one older participant in the rural group who felt he had a low confidence level, was confident enough to access the spinal specialist in Sydney for information.*

*The AD card was also mentioned as a good educational tool for the local ED staff: “I pull out the card and say ‘read this before you do anything’ to my husband; at that point he is really sick”.*

*Respondents in the urban group generally rated their confidence level as “mediocre” (5-6). They identified magazines, SCIA phone line, website and blog as useful source of information.*

*Peer support was identified as a valuable source of information both in intensity and numbers by both groups.*

#### **4. Are there any issues relating to your health that you would like more information about?**

*Group participants were asked if they wanted any information on issues relating to their health. Respondents identified areas where generic information would help such as:*

- “Skin care”
- “Bladder management”
- “Pain management – drug free pain relief”
- “Exercises to maintain my health”
- “Sexuality and fertility – I still don’t know if I can have kids”

*They also expressed an interest in getting information about equipment and accessing tests.*

- “Accessing tests to understand physically what is happening with my spine”
- “Equipment maintenance”

*A unifying factor both in intensity and numbers in the rural group was a desire that information be provided to local health care professionals on management of emergency situations in people with SCI.*



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*One participant in the urban group displayed an interest in gaining information about technological improvements.*

- “When I was in hospital a guy used to speak to me about some wacky bionic inventions and stuff, these things might actually be really valuable solutions.”
- “I don’t know how accessible they are, but at the very least people should know about them.”

5. How would you like to receive information on health maintenance?

*The group was provided with the following options:*

- Lectures
- Mail outs – printed mail outs / magazines
- DVDs – could be mailed out to interested consumers
- Internet / web-based
- Trade shows / workshops

*All of these were identified as useful ways of dissemination information.*

*Participants also mentioned information hotlines.*

*Electronic letters were preferred over printed letters as they had links to other useful sites. One participant cited various cancer groups that send out electronic letters on a regular basis.*

*Lectures were also preferred as it was felt that they could be customised to the needs of the target audience present on the day.*

*Respondents felt that trade shows were valuable as one could see what new products were available. It was explained that a trade show would be more about health and community organisations presenting information and having a stall where people could visit and ask questions about issues relating to health maintenance and community participation. The general consensus was that such an event held once a year would be good.*

- “You have to be careful that you don’t end up with lots of people showing wheel chairs or whatever.”
- “So maybe you could have it health related but could cover care agencies and appliances.”
- “For people who can’t come down to Sydney you could move it to the regional areas.”
- “People who travel to Sydney for the show could get some kind of financial support.”



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- “It is a great way because then you can really go up and talk to people – they’ll give you contacts.”
- “It is very informal and not intimidating.”

*Videos and video clips were identified as a good way to be informed about a subject.*

- “An exercise video where a physiotherapist demonstrates different exercises on people with different levels of SCI would be useful.”
- “Small video clips like on You Tube would be good- I am a You Tube freak.”

*A small directory of locally available resources was also suggested.*

*One participant / peer support worker indicated that SCIA had just put together a kit of all the latest information on continence management.*

- “We will be passing on this information via rehab centres.”
- “We are hoping that this will encourage people to keep themselves informed of what’s out there.”

*When participants in the urban group were asked if they had used peer support groups as a source of information, the response was:*

- “Well, there aren’t any out there.”

*Another participant in the urban group identified life skills days as a very useful source of information.*

- “In Royal Talbot Melbourne they do have life skills days where they invite ex- participants to come back.”
- “They set up little areas where you can get to talk together.”
- “I haven’t heard of anything up here at all.”

*A unifying factor among group participants was that they felt that peer support groups would be great way to gain access to useful information.*

- “In some ways it’s the most obvious sort of information.”

*Another unifying factor in both groups was that they preferred information dispersal on a regular ongoing fashion.*

- “Little information sheets that would lead us to these resources could be piggy-backed on a ParaQuad magazine”

*Participants were reminded of the changes that they felt they could make to improve their health at the pre-focus group interview, viz:*



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- “Nil at the moment – I am happy with my health”
- “Attend physiotherapy sessions”
- “Get my seating checked”
- “More exercise”
- “Better diet”
- “Get better pain relief”
- “Establishing a routine”

*And then asked.....*

## **6. Are you able to identify some of the barriers that stop you from implementing these changes?**

*Respondents in the rural group unanimously agreed that a major barrier for them was how much more difficult it was for them to get things done.*

- “You have to go through the rigmarole to get things done and then there is the distance”.
- “So in the end you give up.”
- “Just put it in the ‘too hard’ basket.”

*One participant identified lack of confidence to go to meetings after dark as a significant barrier.*

*Another unifying factor amongst the rural group was the lack of expertise in the local area.*

- “ I don’t trust the experts”

*It was also felt that health care providers needed to adopt a more holistic approach.*

- “They should look at the whole picture.”

*The group also identified lack of motivation and Queensland NSW border issues as barriers.*

*Respondents in the urban group identified access and cost as barriers.*

- “Even without an injury it is extremely expensive to stay fit – even council pools get refurbished and cost a lot of money.”
- “When you have special requirements, you need a chair lift to get into the pool. That restricts the number of pools you can go to and then you have to get there!”



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## SECTION 2

# QUESTIONS ON COMMUNITY PARTICIPATION

## PRE-FOCUS GROUP QUESTIONS

### **1. What would you associate with the words “community participation?”**

*Group participants were asked what they would associate with the words “community participation”. Respondents offered words that were both physically descriptive of participation activities and words that were associated with personal satisfaction and quality of life.*

- “Being involved in the community in whatever way you can”
- “Caring for the elderly”
- “Going to the shops”
- “Interacting with people outside one’s home”
- “Meeting friends and doing things with them”
- “Helping others”
- “Getting out of the house”
- “Leading a normal life and doing whatever I want outside my house.”
- “Inclusion in activities or opportunities”
- “Volunteering”
- “Going to clubs”
- “Attending music concerts”

### **2. Do you feel it is important to be an active member of your community?**

*A unifying factor, both in intensity and numbers in the rural group, was that they all felt it was important to be active in their community. This sentiment was echoed in most of the participants in the urban group.*

- “My family outings are very important to me”
- “To prevent social isolation”



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- “Important for one’s mental and emotional health”
- “A busy person is a happy person”

*There were some negative associations with the lack of participation in the community across both groups words used were:*

- “Not being a recluse”
- “Not being a hermit”
- “One does not want to be solely a client on a dozen lists”

3. What areas of everyday life are most important to you to participate in?

- “Work”
- “Family”
- “Church”
- “Volunteer boards”
- “Sailing”
- “Socialising with friends”
- “Chatting with new friends on the Internet”
- “ Volunteer work”
- “ Attending music concerts”

4. **Is there anything in your life that, if taken away, would feel like a major participation loss?**

- “My car”
- “My computer”
- “My Environmental control unit (ECU)”
- “ Public transport”
- “My wife”

## FOCUS GROUP QUESTIONS

**1. What issues or barriers most affect your participation?**

*Respondents in the both groups agreed in terms of intensity and numbers that a major barrier for them was wheelchair access.*



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- “More than half the local shops, you can’t get in.”
- “A lot of buildings try and squeeze under the heritage thing so that they do not have to change anything.”
- “You can’t even get out of Martin Place which is the closest station to the State Parliament.”

*They did point out that any new submissions to the council had to be accessible to people in wheelchairs.*

*Lack of access to public toilets was also identified as a barrier.*

- “Well, a lot of places like the airport disabled toilets, with an electric wheelchair you can’t get into them.”

*Respondents in the urban group identified difficulty in accessing affordable transport as a major barrier.*

- “Financial barriers are a concern with people going on the DSP after their injury and being unable to work.”
- “It is ridiculous trying to get a license now, you know 120 hours, and if you don’t have someone in the family to teach, you have to pay a lot of money per hour.”
- “You have already spent \$65,000 getting a new vehicle you can get into, and then you have got to pay more in terms of stamp duty and charges in NSW.”
- “The taxi subsidy is not enough.”
- “I mean 50% of an expensive cab ride is still expensive.”

*Respondents in both groups agreed in terms of intensity and numbers that there should be separate parking spots for people with wheelchairs.*

- “You don’t want to drive for half an hour only to find you can’t park anywhere.”

## **2. What do you feel are your biggest supports to participation in the community?**

*A unifying factor, both in intensity and numbers in the rural group, was that family and friends were their biggest support to community participation.*



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*Lightweight portable ramps were also identified as an important element that aided community participation.*

*One participant identified their physiotherapist as being really supportive and another acknowledged the organisations that conducted the focus group for being interested in enhancing their level of participation.*

*Organisations like ParaQuad, SCIA and SOS were identified by the urban group.*

### 3. Why do you feel it is important to participate in the community?

*Respondents were reminded that in the pre-focus group question almost everyone had acknowledged that it was important for them to participate in the community.*

*The link between health and well-being and community participation was explored.*

*All the participants agreed that there was a direct relationship between their health and well-being and their ability “to stay connected with people.”*

- “If you sit at home by yourself, you feel sick and depressed.”
- “I’m starting to get a bit itchy at home.”
- “I’m getting a bit depressed; I’d like to get out more.”
- “I’d like to get out there and help other people.”
- “I still don’t know my limitations but I’m looking for part-time employment or voluntary work.”

*One participant further elaborated that he felt it was important to make other people aware that just because he was in a wheel chair it did not mean that he interacted differently with people.*

- “Before I had my accident I would see someone in a wheel chair and did not know if they would be sociable.”
- “You are wheeling down a street and you see people avoiding...”

### 4. What strategies are most needed to promote and support your participation in society?

- At an individual level
- At the level of society
- At a policy level

At an individual level respondents identified the following:



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- “Get a driver’s licence if possible.”
- “I am lucky to get a van with modifications that I can drive straight to the steering wheel, it locks the chair in, you know, electric head rest etc and I just drive off with the hand controls.”
- “Need to make time to participate in the community.”
- “Have the will to do it.”
- “Take part in wheel chair sport.”
- “Be part of an access committee.”
- “Come along to groups like this one.”
- “Make an effort to be self informed.”
- “Be self advocates with Individuals and Government bodies.”
- “People in wheelchairs need to be more informed of their rights, to be able to tell a person you know the law requires you to do a better job.”
- “Helps to be properly informed about things like Mobility Allowance, travel concessions, health care card etc.”
  - “Get involved in peer support groups.”
  - “When in rehab we met people who had been in rehab, it was good to note that they had gone home and were getting on with their lives.”
  - “It is very motivational to see somebody achieve something from a chair - it gives hope.”

*At a level of society an interesting suggestion from the rural group was a “wheelchair swap”.*

- “You should put able-bodied people into wheelchairs and just send them out.”
- “Good eye-opener for them.”

*Respondents also felt that it was important to raise awareness with school children about people with disabilities.*

- “In Queensland they have a seat program, where they pay ‘paras.’ and ‘quads.’ to visit schools.”

*Respondents also felt that it was “odd” that in NSW the Youth safe program focused on how not to get a spinal injury.*

- “Because you can get a spinal cord injury in many ways, not just by risky behavior.”

*They felt that the focus should be on teaching school children what a spinal cord injury is and what to do when you see someone in a wheelchair.*

- “Disability awareness should be a mandatory course in schools.”



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*A parent in the rural group mentioned that his daughter had just started kindergarten and all of the children had loads of questions, so the school organised for him to hold a question answer session at the school, a kind of 'show & tell'. A unifying factor, both in intensity and numbers in the rural group, was the need to educate young children before they developed prejudices.*

*The group also felt that the dangers of skateboarding should be highlighted.*

- “It is not just knees and elbows that need to be protected.”

*A need for protective gear for the spine was also mentioned.*

- “I was not wearing my spine protection when I crashed my motorbike as it was too bulky.”
- “I now have found light flexible protection that I wear whenever I ride my bike.”

*At a policy level the issues that emerged were:*

- Wheel chair parking
- Ramps
- Lights on wheelchairs
- Accessible and affordable public transport
  - “Review of the taxi subsidy.”
  - “It is very difficult to get the subsidy, the spinal specialist has to fill out a section and they are aware that it is very strict.
  - “They are very upfront they say they know that many deserving people won’t get it.”
  - “It is not free, there is a 50% co-contribution, and 50% of an expensive ride is still expensive.”
  - “It goes to a maximum of \$30.”
- Removal of stamp duty on new vehicle.
  - “NSW is the only state, that you pay stamp duty of \$1800 on a modified vehicle. You don’t get any concessions.”
  - “You have already spent \$65,000 getting a new vehicle you can get into, and then you’ve got to pay more.”

*The general feeling was that there should be more spots for wheelchair parking and they should be of a different colour. Respondents also felt that there should be a uniform policy across the country instead of having different regulations from state to state. An example of car park colour coding was*



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sited. Increasing time limits for free parking was also recommended. A disabled parking card that could be displayed on the windscreen was suggested.

- “It is a chronic problem with people in wheelchairs being able to know that they can go into a car park and get a spot.”
- “Unlike other disabled people who have a choice of parking in a regular spot, a person in a wheelchair has to have a wide spot.”
- “It would be great if there was a national coding like there was red for wheelchair only and blue for walking disabled.”
- “You see someone in a wheelchair, by the time they get out of the car and get back into the car it can take a long time, an hour is not enough.”
- “One of the things we all agreed on was a disabled parking card that is obviously displayed on the windscreen. Anyone who does not want it is obviously not that disabled and does not need it.”

*It was also felt that buildings should be inspected before they put up the wheelchair sign.*

- “If somebody displays a circle with a man in it they have to be inspected to ensure that an actual wheelchair can get in.”
- “People seem to put them up and you run into a step, so you’ve got to run back and get the ramp out of the vehicle.”

*Participants in the rural group felt that sometimes the regulations for ramps were “too strict.”*

- “You could not make a ramp which could be approved because of lack of space.”
- “For me personally it would be much better to have something which isn’t approvable, but you can still manage.”

*Lights on wheelchairs to facilitate safe night travel was also mentioned at a policy level. One participant mentioned that this was standard practice in Queensland.*

*Participants in the urban group felt that the government should fund magazines like ParaQuad and Accord to advertise any changes in policy or new facilities they provide for people with disabilities.*

- “You can’t just rely on these organisations to put it in. I think the government needs to when things become available.”

## **5. What are the specific aspects of participation that you would like more information about?**



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*Respondents were provided with the following choices*

- Leisure
- Sport
- Education
- Training
- Voluntary work
- Paid work

*Participants in the rural group requested information about leisure activities such as:*

- beach friendly wheelchairs
- wheelchair friendly caravan parks
- *Wheelchair sports*

*“I was never a couch potato before my injury, but when I got out of rehab I became one.”*

*Once again the rural group felt the opportunities for wheelchair sports were mainly Sydney based.*

*ParaQuad magazine was mentioned as a good source of information on sports and leisure activities.*

*A Queensland organisation called “Sporting Wheelies” was also mentioned. “They do a lot of trips around Australia; they go skiing and do all sorts of stuff.”*

*Archery was cited as a good example of a sporting activity.*

*The urban group was interested in finding out reliable information on travel.*

- “Wheelchair accessible motels.”
- “The confidence to know that because they say it is wheelchair accessible it really is accessible.”

*As far as education was concerned participants were interested in finding out more about the financial and transport subsidies they could get to “re-educate themselves.”*

*Respondents in the rural group felt that there were plenty of opportunities for them to do voluntary work. Hence they did not see the need to obtain more information on this subject.*

*The urban group displayed an interest in volunteer work especially peer support groups.*



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- “I’m starting to get a bit itchy at home, I’m getting a bit depressed, not to medication levels but I like to get out more and help more people, especially at Moorong or with peer support at SCIA.”

*There was unanimous interest amongst the rural group in getting more information on how to obtain suitable paid employment.*

- “I went through CRS when I got back from rehab.”
- “The only reason I got work was that I had been working at the same place for 2 years and CRS helped to set up my work desk.”

*The urban group felt that they would like to speak to people with spinal cord injuries in real jobs.*

- “Like people with jobs that are away from the relatively insular injuries community.”
- “How they got their jobs.”
- “Perhaps even some kind of networking.”

*The urban group also felt that as they spent so much time in rehab after their injury, it would be a good idea to utilise that time to get vocational counselling to find out what work they can do.*

- “I was in hospital for nine months and it struck me that it would have been really interesting to learn work skills.”
- “It would be nice if we had some sort of a Job Network Program where you could know if you could do blue collar work, or that kind of thing is over for you and you have to go into IT or something.”

*One participant in the urban group mentioned that in her experience as a peer support worker she felt that very few people in rehab were ready to talk about work initially. The following comments were made about the Pilot Employment Program provided by SCIA.*

- “Through no fault of anybody we find the employment service is under-utilised because people are not ready.”
- “Even when they have had a meeting with an employment consultant they decide that they do not want to talk about this for a while.”
- “The service has put some people in great jobs, but on the whole if we are looking at 20 people there are only one or two that could really utilise the service.”

*However it should be mentioned that people do tend to get back to the service a few months later when they are ready to talk about work or vocational training.*



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*One participant from the urban group requested more evidence based therapy and indicated that he would be interested in getting more information of the latest scientific research.*

- “I come from an engineering background so I get frustrated with hospitals when things aren’t scientific.”
- “For example, there are things to do with FES, electro-stimulation based therapy; some physiotherapy staff don’t like the fact that it is a new thing and others are really into it.”
- “I think a lot could be achieved in the way services are provided if there wasn’t such a strict divide between clinical and research.”
- “The fact that FES has not been resolved one way or another is kind of a bit silly.”
- “I’ve heard similar debates around the Walk On project in Brisbane.”
- “You’ve got to resolve it one way or another.”
- “Health service industry needs to think more creatively about how it goes about providing services in ways that incorporate creativity and improvements, let’s say a total quality management approach.”

## 6. How would you like to receive this information?

*Respondents were provided with the following choices*

- Lectures
- Mail outs
- DVDs
- Internet / web-based
- Trade shows/ workshops

*Respondents in the rural group mentioned they would like a resource directory.*

- “You have a direct route to something that has all of those things put into one.”

*Lectures for local rural GPs came up as another request.*

- “Get someone from the Spinal Unit to give the lecture.”

*The difficulty of getting busy GPs to attend education sessions was mentioned. Hence the prospect of empowering themselves with knowledge was discussed. Participants in the rural group agreed with this suggestion.*

- “That’s the only way you survive.”

*Printed information that people could carry with them like the AD card was mentioned as being useful.*



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- “The best thing that happened to us was we had a young doctor in the ED who admitted he knew nothing about AD.”
- “My husband now always has the card in his wallet in case I am not with him.”

*Participants also felt that to save time in scary emergency situations there should be a single hotline that health care professionals can call to get the right advice.*

*One participant in the rural group mentioned that they call the spinal unit in Sydney and they are really helpful.*

*A participant in the urban group felt that it would be good to have a website or a central spot that would summarise what sort of financial assistance you can get.*

- “It wasn’t until I left Moorong that my financial advisor mentioned that I could apply for a Total Permanent Disability payout (TPD) just by filling out a few forms.”
- “The Super fund is not going to put their hand up and tell you to fill out the forms and get a payout.”
- “After this happened I rang up Moorong and told them to pass this information on to other people with spinal injuries.”

*The urban group also welcomed trade shows and queried if we could look at combining it with a lecture.*

- “In the year 2000 they had ‘Making Connections’ at Darling Harbour. It was just like an expo; the best part I got out of it was meeting people.”
- “I don’t know if you can do something like that on an annual basis.”
- “It is important to have discussions with people who have had injuries for a long time and know pieces of information.”
- “I think we need to have possibly a number of trade shows; one needs to be health related, one for transport and mobility and one for social or whatever. You know if we could have at least a few each year or a very big one in a larger space with a broader range, there is an enormous amount you can gain from them.”
- “Like a pavilion at the Easter show.”
- “I went to one recently at Homebush that was basically on wheelchairs and such, and it was chock-a-block.”

*Web based information was also welcomed by both groups.*

- “The internet is great because you can get the information when you want it, any time at all.”



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*The urban group also felt that it would be helpful to have more articles in magazines like ParaQuad and Accord.*

- “You flick through a magazine without having to actually go looking for information.”
- “A lot of times you don’t go looking for something because you do not know that there’s something to find.”

## **SECTION 3**

### **GENERAL QUESTIONS**

#### **PRE-FOCUS GROUP**

##### **1. What are your greatest problems living with SCI?**

###### **Issues relating to health**

- “Urinary tract infections”
- “Mobility”
- “Pain – inability to sit for long periods of time”
- “Constipation”
- “Not being able to walk”
- “Skin”
- “Chest infections”
- “Spasms”
- “Inability to cook for myself”

###### **Issues relating to participation**

- “Access”
- “How long it takes to get to places”
- “How long it takes to do things”
- “Unable to participate in activities that go on for the whole day or weekend”
- “Bowel management”



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- “Not being able to work”
- “Difficult to maintain my independence”
- “Being restricted due to pain and bladder issues”

## **2. What changes do you feel you can implement to make things better for you?**

Participants were requested to restrict their responses to health and participation.

### **Health**

- “Nil at present”
- “Physiotherapy”
- “Correcting my posture”
- “Seating”
- “ Exercise”
- “ Management of spasms”
- “ Stop smoking”
- “ Eat right”
- “ Stop binge drinking”
- “ Get into a routine”
- “ Pain management”
- “ Sort out bowel issues”

### **Community participation**

- “Nil at present”
- “ Be more outgoing”
- “ Get people to motivate me”
- “ Stop drinking so I don’t spend 3 days recovering”
- “ Keep active”
- “ Get a drivers licence”
- “ Explore new social options”
- “ Consider vocational retraining”
- “ Complete education & get a job”



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### **3. If there was one thing that could assist you with changing your health and sense of well-being, what would that be?**

- “Access to a pool”
- “Access to public toilets”
- “More self-operated gadgets to make me more independent”

## **CONCLUSION**

This report discusses the findings of two consumer focus groups conducted for people of workforce age with spinal cord injuries living in the community. Overall, in both groups, the discussions of issues relating to health education and community participation were lively, serious and constructive. Attitudes evolved a good deal during discussions amongst participants, with people remembering relevant examples and reconsidering their views in light of other people’s comments.

The questions were prepared with an objective of gaining information about the needs of the consumer, the self-efficacy of the consumer and the likelihood of compliance by the consumer. The two main topics covered were health maintenance and community participation.

Awareness of health maintenance as a critical element of improving Quality of life was high in both groups.

Attitudes towards health maintenance were positive but the overall feeling was it was too difficult to overcome barriers and take positive steps to maintain their health.

The major barriers identified were lack of awareness of spinal related issues amongst health care providers. Access to services and service providers was also a barrier. Financial constraints were also identified.

Awareness of health education resources was variable and on an average it was mediocre. The general consensus was that there was a need for more resources to be made available to consumers and health care providers with these resources being updated and distributed on a regular basis.

Consumers preferred a variety of ways of disseminating information. Trade shows were popular as it was viewed as an informal means of getting information on a range of topics under one roof. It was also thought to be an opportunity for meeting people. Lectures to GPs, Emergency Department staff and consumers were also suggested. Regular updates via electronic letters and web-based information, as well as more articles in common



consumer magazines such as ParaQuad, SCIA and Accord were requested. Self-paced learning tools such as DVDs were also suggested as good tools to disseminate information to enable people to learn in their own surroundings at their own pace.

Most consumers are aware of the relationship between community participation and health and well-being. Willingness to engage in social and economic participation was high, but the general feeling was that they were not sure of their functional limitations.

Peer support was mentioned as an important means of sharing information in regard to issues relating to both health and participation.

It was suggested that time in rehab could be better utilised to gain vocational counseling and to learn new skills.

Access, finances and lack of awareness were some of the barriers towards participation.

## **RECOMMENDATIONS**

Based on the findings of this report it would seem reasonable to develop a systematic step-by-step targeted service delivery approach to build capacity for consumers so that they feel they are more in control over issues relating to maintaining their health, as well as increasing their ability to participate in the community.

Suggestions for targeted service delivery in the future are as follows:

- Peer Support Networks
  - Need to be formalised and made available across different rehab settings.
  - Ongoing access to peer support networks after discharge from rehab.
  - More forums where consumers and carers could meet and discuss issues informally.
- Vocational Services in rehabilitation.
  - Mainly vocational counselling
  - Information about re-training and re-skilling
  - Identification of realistic options
  - Information about processes
  - Contact list for use when ready



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- Vocational planning to be incorporated into the inpatient rehab plan.
  
- Annual consumer events
  - Trade shows
  - Lectures from experts
  - Lectures on a few topics followed by an opportunity to visit several information stations for consumers
  - Concurrent carer groups facilitated by social workers
  - These events should be held both in rural and metro areas to facilitate access.
  
- Resources
  - Development and dispersal of education resources
  - Target audience should be consumers, GPs , ED staff, ambulance officers and community health providers
  - Suggested resources could be:
    - Web based material with small video clips, consumer fact sheets, newsletters, modular learning packages
    - DVDs
    - Articles in magazines
    - Electronic letters



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