Policy & Advocacy Engagement Project

Final report

SCIA Policy & Advocacy Team

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Contents

Summary

This report on Spinal Cord Injuries Australia's (SCIA) Engagement Project provides valuable empirical insight, directly from people with spinal and neurological conditions and their family members and carers, into their current and future needs and the barriers they encounter in fulfilling them. It also provides recommendations as to specific advocacy priorities SCIA's Policy and Advocacy Team could adopt to best support people with spinal and neurological conditions and promote better outcomes for them. The project focussed on gaining insight into the demographic breakdown of this group, determining the most significant issues facing this group and establishing possible measurable outcomes the Policy and Advocacy Team could achieve in its advocacy work.

The report's findings indicate that the population of people with spinal and neurological conditions is diverse. While the majority of people who participated in the project were aged over 55, lived in metropolitan areas, particularly in NSW and were SCIA members, several other groups provided feedback for the project. These included people from regional and rural areas, every state and territory (except for Tasmania and the Northern Territory), and every age group (except those aged under 19). Additionally, the interviews highlighted the diversity of spinal, neurological and physical conditions that people experience and the different issues they encounter.

The project also offered a long list of possible issues and associated positive outcomes the Policy and Advocacy Team could strive towards. Some of the most significant issues and outcomes that the team[1] could actively prioritise include:

1. The National Disability Insurance Scheme (NDIS) process remains overly complex and often fails to provide adequate supports to participants.

   → *With upcoming changes to the NDIS,[2] SCIA should ensure that the voices of NDIS participants with spinal and neurological conditions remain active in consultations and recommendations relating to planning and independent assessments.*

2. Several gaps exist for people aged over 65 years who require daily disability supports.

   → *SCIA should promote increases in funding for over 65s receiving support through the aged care system to a level equivalent to NDIS participants.*

3. There is insufficient access to affordable assistive technology and equipment that allows user choice for many groups.

   → *SCIA should advocate for the establishment of a national assistive technology and equipment scheme.*

4. Accessing housing that is disability accessible remains a challenge across different housing categories.

   → *SCIA should promote platforms to find disability accessible housing and advocate for the construction and allocation of more disability accessible accommodation in social housing.*

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[1] Note that some of the findings from the report relate to other SCIA services and teams and the above list of priorities refers directly to issues that could best be addressed or collaborated on by the Policy and Advocacy Team.

[2] National Disability Insurance Agency (NDIA), 'Improving the National Disability Insurance Scheme: Better Participant Experience and Improved Access and Planning', information paper, 24 November 2020.

5. A lack of employment opportunities for people with disability presents a significant barrier to economic participation and autonomy.

→ *SCIA should actively advocate for improvements in government disability employment services and supports.*

6. Communities remain inaccessible for many people with spinal and neurological conditions, which discourages greater social and economic participation.

→ *SCIA should lobby state, territory and local governments as well as the building industry to ensure that universal design is adopted and enforced in development projects.*

The report also provides specific case studies and highlights future research and partnership opportunities for SCIA to engage with its members and others in the community of people with spinal and neurological conditions

1 Research objective and questions

The research objective of this project is to better understand the key advocacy needs of SCIA's Policy and Advocacy Team's target audiences. The primary audience for this study is individuals with spinal cord injuries (SCI) or other neurological and physical conditions. The secondary audience includes these individuals' families and carers. A collateral objective of the project involves active engagement with SCIA members and potential members, and the development of partnerships that may be developed to inform future advocacy campaigns and SCIA work.

In order to achieve this objective, the following research questions have been developed:

1. *What are the basic demographics of individuals with spinal and neurological conditions, and their families and carers?*
2. *What are the key themes or issues individuals in the study population raise in relation to advocacy and their other needs?*
3. *What are the expectations and measurable outcomes individuals in the study population wish SCIA to achieve and focus on in their advocacy and other work?*

2 Methodology

The project was conducted in two stages, using two empirical methods: a survey and interviews. Quantitative data from the survey's closed questions provided results to respond to the first question. Further conclusions to address the second and third research questions were derived from other open and closed questions from the survey, as well as the trends identified during analysis of the interviews.

Survey questions were divided into three parts: demographics, advocacy issues and peer support. An additional four questions were included to gauge enthusiasm to engage in future advocacy campaigns, use peer support services and register interest in joining the second stage of the study by registering interest in participating in an interview. Respondents could register their interest in participating in an interview to discuss either or both advocacy or community support.

The survey was designed using templates from SurveyMonkey and questions were drafted by SCIA's Policy and Advocacy Team, SCIA's Peer Support Team, with further feedback and input from other SCIA staff members. The survey was open for a period of three weeks from 30 September 2020 to 22 October 2020. Invitations to complete the survey were sent out via electronic direct mail to SCIA's members and partners, and the social media platforms Facebook, Twitter and LinkedIn.

There was a total of 134 responses to the survey, with 58 registering interest in participating in an interview. This response rate significantly exceeded initial estimates. As such, to accommodate as many interested interviewees as possible, due to the team's limited capacity, it was decided that interviews could be conducted in focus groups.

The focus groups were organised thematically, based on the most prevalent issues identified in the survey. These themes included: National Disability Insurance Scheme (NDIS); supports for individuals aged over 65; employment; assistive technology; housing; community access and community health. Of the 58 respondents interested interviewees, due to logistical barriers or non-responses, it was only possible to arrange interviews with 22 individuals. Of this group, 11 were interviewed individually. In total, a series of 15 individual or group interviews were completed during November 2020, arranged according to the themes already mentioned. These interviews were conducted via Microsoft Teams and via phone, due to both the geographical dispersion of interviewees and the impact of the COVID-19 pandemic. Interviews were recorded, subsequently transcribed and edited.

The accumulated data from the survey and interviews was analysed using basic statistical examination and content analysis. The following sections outline the results and conclusions drawn from the survey and data.

3   Survey results

There was a total of 134 responses to the survey with a completion rate of 68% (91). The typical length of time spent completing the survey was 9 minutes and 33 seconds. For complete responses, the typical time spent was 11 minutes 46 seconds. Within the first 24 hours of the survey opening, 68.7% (92) responses were collected. In terms of completion rate, 96.3% of respondents completed the demographics section, 74.6% completed the advocacy section and 59.0% completed the peer support section.

3.1   Demographics [3]

3.1.1   Gender, age and circumstances

Respondents were evenly split between female and male, exactly 50% (67) for each group. No one indicated an 'Other' gender identity.

Most respondents (59.9%, 79) were aged 55 years and above with the largest group of the total population being 65 years and above (31.8%, 42). Only 1.5% (2) respondents were aged between 18 to 24 years old.

The majority of responses (83.2%, 109) came from individuals with a spinal cord injury or other neurological condition. Carers or family members made up 13.0% (17) of the total number of responses, while five other respondents were categorised as 'Other'. One of the other respondents included a health worker.

3.1.2   Residence

Just over three quarters (75.4%, 98) respondents resided in NSW. The second largest group of respondents were from the ACT, but made up only 6.9% (9). The ACT was followed by WA (6.2%, 8), VIC (4.6%, 6) and SA (4.6%, 6). Finally, there were 3 respondents from QLD (2.3%). There were no responses from TAS or the NT.

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[3] See Appendix A for full survey results in response to demographics questions.

Almost two thirds (63.1%) of respondents resided in a metropolitan area, while 25.4% (33) lived in regional areas and 11.5% (15) came from rural areas.

3.1.3   SCIA membership

SCIA members made up the majority of respondents (79.1%, 102), but 13.2% (17) were unsure whether they were members or not. As such, the minority of respondents (7.8%, 10) were not SCIA members. This represents a response rate of approximately 4.1% of all SCIA members.

3.2   Advocacy issues [4]

The top five issues that respondents reported as being among the most important to them included:

1. National Disability Insurance Scheme (48.7%)
2. Spinal cord injury research to find a cure (43.7%)
3. Improving supports for over 65 year olds (34.45%)
4. Assistive technology (30.3%)
5. Housing (27.7%)

Respondents were also asked to rank the three most important issues and similar results were produced as above (see the ranked chart in Appendix B). The three issues that respondents were least likely to rank among their top three were sexuality support services (10.1%), patient-centred care (10.1%) and educational or vocational training (8.4%).

Several respondents (13) cited other issues among the most important, including:

- Access to SCIA or other spinal rehabilitation services in rural areas
- Regulation to housing
- Peer support in rural and regional areas
- Psychosocial care for individuals and their family members or carers

3.2.1   Why were these issues important?

The following section describes trends and insights from the 105 open-ended responses to the above question. It focuses on comments related to specific issues, as well as providing insight into general comments concerning the impact of removing barriers.

3.2.1.1   NDIS

The most common issue cited by respondents as being important to them was improving the NDIS. For many respondents, NDIS funding was "crucial to improving quality of life" for people with spinal cord injury. The current issues with the NDIS identified in responses included: navigating and understanding the NDIS system; receiving adequate levels of funding in plans; excessive waiting times; complex administrative processes; better training and understanding among LACs and planners in the specific needs of participants; and simplified review and appeals processes. As one respondent noted the "**NDIS is a great idea- don't let bureaucracy kill it**".

3.2.1.2   SCI research for new treatments and a cure

Promoting research to find new treatments and a cure to spinal cord injury was the second most common issue ranked by respondents. Many described the vital, universal impact of finding better treatments and a cure, for example: "**[A] cure will mean [the] solution to all the problems**". Another described the importance of funding research as "**even if it is just to reduce pain, numbness and**

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tightness [it] would give [them] a better life". Generally, many respondents expressed that "**everyone with a SCI would like to walk again**".

3.2.1.3 Supports for over 65 year olds

Supporting people aged over 65 was often mentioned by respondents, including those that did not choose it as one of their top three priority issues. Respondents noted the intersectional nature of age discrimination, housing and access to disability supports, particularly assistive technology. As one participant expressed, "**Over 65 [sic] seems forgotten and when existing on a single age pension doing so with a disability is difficult and expensive**".

Eight respondents explicitly cited the ineligibility of people aged over 65 years for the NDIS as being discrimination and a major area for concern. Additionally, many respondents noted the difficulties for older people accessing appropriate housing. One respondent recounted how the care needs of their family member with a spinal cord injury were too high to remain in private housing, and as a result they had no option but to move to an aged care facility.

Many respondents agreed that the aged care system, and Home Care Packages were insufficient to meet the needs of individuals with spinal cord injury. For example, one respondent highlighted that a Level 4 Aged Care Package would not cover the costs of necessary equipment and assistive technology. Many respondents under the age of 65 were already concerned about the lack of appropriate supports available to them as they get older.

3.2.1.4 Assistive technology

Difficulties accessing assistive technology and equipment for people ineligible for the NDIS was repeatedly raised by respondents as a major issue. One respondent described the need for access to assistive technology as follows: "**There is always new and innovative technology evolving all the time and people with disabilities need access to these technologies**". Several people highlighted the financial difficulties for those not receiving NDIS funding to access appropriate equipment, even those with Home Care Packages. One respondent characterised the need for assistive technology as a "**critical survival matter**" and another noted that as Australian society integrates new technology on a wider scale, "**technology is becoming a major part of life therefore the cost…should not be a barrier**". Many respondents highlighted the direct impact of assistive technology as providing independence for people with disability. There was also a desire from some participants to receive more up-to-date knowledge about available assistive technology.

3.2.1.5 Housing

Many respondents highlighted the challenges finding appropriate housing. Three respondents specifically mentioned the difficulties they had had on finding accommodation following their discharge from hospital, and also mentioned how there was no support in navigating this process. One noted how "**in many cases nursing homes are the only option for housing after hospital discharge. They do not provide the appropriate level of care and stimulation for young people**". Other respondents highlighted that people with spinal cord injuries and other neurological conditions are more limited in accessing affordable public and social housing, particularly if they could not access Specialist Disability Accommodation through the NDIS. Another respondent mentioned the further limitations on housing availability in rural areas. Others anticipated the future difficulties they may have with housing as they get older.

3.2.1.6 Public Transport

While public transport did not rank as highly as other issues statistically, in open-ended responses, many cited the impact of poor accessibility to public transport as a major barrier to agency. For

example, as one respondent described it, "**better access to public transport is a good way to allow people with SCI to integrate into the broader community**". The issues accessing public transport raised by respondents included: non-wheelchair friendly buses; limited space on trains; lack of training among public transport staff in providing assistance to wheelchair users getting on and off of buses and trains; large gaps between trains and platforms; discrimination accessing certain subsided travel cards; and a scarcity of trams accessible to powered wheelchair users in metro areas, leading to excessive wait times.

One respondent suggested that ride sharing could resolve many of these issues, however it would rely on users going to destinations in a similar area. Another alternative to public transport, wheelchair taxis, was highlighted by one respondent, however they mentioned the long wait times associated with using taxis and the possible 'dangers' for people with disabilities waiting long into the evening.

3.2.1.7 Other issues

Respondents also raised other issues affecting access to services. Many respondents highlighted the difficulties accessing public transport, community health services and peer support in regional and rural areas. One respondent was critical of some disability service providers as "**many organisations majority [sic] are just tick box organisation[s] with no substance for producing good outcomes**". One respondent also highlighted the decreased services offered in response to the COVID-19 pandemic. A lack of knowledge or accessibility to relevant information or support persons was mentioned as a major barrier by nine respondents. As one respondent characterised it, "**There is a lot to learn and navigate…Knowing what questions to ask is a huge advantage**". Finally, community access and a lack of direct path of travel was mentioned by eight respondents and again one described the major impact that this would have as "**Affordable community access IS quality of life**".

3.2.2 Removing barriers

Generally, respondents noted that resolving many of the specific issues they had chosen would remove barriers that prevented them from living full, independent, dignified lives, as well as being truly socially and economically empowered. This hope was echoed by one respondent who stated that "**without the worry [of barriers it] would help me feel more 'like everyone else'**". Another participant summarised it as follows: "[these issues are] about improving quality of life, independence and [the] ability to be part of the community without needing extra assistance". One respondent described the universal impact of resolving many of these issues as "**they are key to feeling safe and supported and ensuring positive change for people impacted by neurological disease**".

3.2.3 What outcomes would you like to see SCIA achieve?

There was a total of 100 responses to the question above. Many respondents made a variety of recommendations for possible outcomes SCIA should strive to achieve. Some of these suggestions are outlined in the table below, categorised thematically:

NDIS	Housing
- Advocate for simplification of the NDIS process - Advocate for more personalised assessments for participants, with a single assessor who understands the specific needs of people with different disabilities in different personal circumstances - Improve transparency between participants/applicants and the NDIA - Improve access via alternative methods (i.e. phone) to LACs	- Ensure social housing includes options for people with disability - Advocate for more long-term accommodation options - Promote supports to enable people with disability to live in their own homes (through home modifications) - Promote information pathways to find appropriate housing

• Protect funding for support coordinators and individual advocates • Promote decreased wait times for decisions • Improve staff training to adopt a more empathetic approach	• Advocate for simplified processes to access public and social housing and avoid waiting lists • Promote greater access to SDA
Supports for Over 65s • Expand access to the NDIS for people aged over 65 years or ensure that all over 65s with a disability receive the equivalent level of support that they would if they were on the NDIS • Ensure over 65s have sufficient support to remain at home, without being forced into aged care facilities • Advocate for better awareness of disability among aged care service providers and across My Aged Care staff	**Employment** • Improve supports for people with SCI accessing employment • Promote supports to increase participation in employment • Promote different pathways to employment, including: on-the-job training, work experience, voluntary work
Assistive technology • Promote research and development of new equipment and technology • Promote universal access to assistive technology and equipment at reasonable prices (particularly powered wheelchairs) for those living in nursing homes (irrespective of age) • Promote the establishment of a national equipment scheme	**Community access** • Advocate for universal access to public places "**without worrying if the area is suitable for persons with a disability**" • Seek input from people with disability in developing building regulations and considering development applications • Promote greater accessibility across all forms of public transport in metro, regional and rural areas
SCI research • Promote funding for SCI research for a cure and new treatments	**People in regional and rural areas** • Promote access to face-to-face services in regional and rural areas • Facilitate proactive outreach to people living in regional and rural areas to increase awareness about available services
Community attitudes • Improve community attitudes and understanding of the experiences of people with spinal cord injury and other neurological conditions • Promote joint campaigns with private stakeholders (i.e. businesses) to increase awareness and education to better equip employers and others with an understanding of SCI	**Access to information** • Improve access to knowledge about available supports • Provide information on latest technology accessible to people with disability • Act as a hub for information and supports for people with SCI and other neurological conditions
Expansion of services • Promote home visits by personal trainers • Improve awareness of SCI-specific needs among all healthcare professionals (including GPs) • Expand peer support services into the home following discharge from rehabilitation and hospital	**General** • Improvements to "**quality of life for citizens with disability**" • "**To be a guiding force ensuring we don't get overlooked or have ridiculous & unreasonable restrictions placed upon [us]**" • Increased engagement with people with disability (including via surveys)

• Psychosocial support for family and informal carers	• Further collaboration with other organisations working across similar issues (i.e. NGOs working on expanding access to social housing)

3.3   Peer support [5]

Of the participants that finished the advocacy section of the survey, 84.7% chose to complete the peer support section.

When asked who would be most useful to speak to following a traumatic injury, 39.8% of respondents favoured a 'person in a similar circumstance'. This was followed by a peer support worker (25.3%), clinical professional (19.3%) and family member or carer (7.2%).

Respondents were fairly definitive that the most appropriate time to receive advice and assistance following an injury was during rehabilitation (weighted average of 4.32). The second most favoured time to receive advice was during the 1st year after discharge (3.59), followed by the period spent in the Intensive Care Unit (2.68), between the 1st and 5th year following the injury (2.6) and finally after 5 years post-injury (1.82).

The most favoured form of receiving advice and information for 54.4% of respondents was a series of structured information sessions. Other popular forms included face-to-face meetings (44.3%) and volunteer-led mentoring (43.0%). One respondent recommended that virtual meetings should be held.

3.4   Future engagement with SCIA [6]

Two thirds of respondents (66.0%) wished to participate in future SCIA advocacy campaigns in some capacity. Of this group, the majority (65.6%) would be willing to sign petitions, 56.3% would consult SCIA in the future and 34.4% would co-design solutions with SCIA. 14 respondents (21.88%) suggested other forms of participation, including media appearances, providing further advice and consulting with government officials. Five respondents offered to help in any way they could.

Of the 93 respondents who completed the question regarding participation in an interview, 49.5% were interested in discussing advocacy issues and 43.0% indicated that they would like to discuss community support. Approximately one third (34.4%) did not wish to participate in an interview at all.

4   Interviews and focus groups

The qualitative feedback from the interviews and focus groups provided richer insight into the majority of thematic issues identified in the survey as well as providing an opportunity to hear from a variety of different demographic perspectives.

Of the 22 interviewees, 15 identified as female, 18 were individuals with a spinal or neurological condition, 4 were family members, 17 came from metro areas and 12 resided in NSW. Interviews were also conducted with people in the ACT (4), SA (4), VIC (1) and WA (1). One interviewee resided in a rural area, while 4 resided in regional areas. The majority of interviewees were aged over 55 (15), and of this group 7 were aged over 65. Two interviewees were aged between 35-44 and 4 were aged 35-44. Only one interviewee was aged between 25-34. Interviewees and their family members experienced a range of conditions, including, among others, SCI, acquired brain injury, spina bifida,

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[5] See Appendix C for full survey results in response to peer support questions.
[6] See Appendix D for full survey results in response to questions related to future engagement with SCIA.

spinal tumours and cerebral palsy. For those with traumatic injuries, some acquired their injury within the last 12 months while others acquired theirs over 40 years ago.

Each interview was categorised under a single theme, but often many other issues were also discussed. Of the 22 people interviewed, 7 were interviewed on the issue of supports for people aged over 65 years, 4 on the NDIS, 3 each on housing, employment and community access and 2 on community health. However, for example, in the course of interviews, the NDIS was discussed in 8 other interviews. As such, the following analysis includes observations from all interviews in which different issues were discussed.

4.1 NDIS

The NDIS was the most prevalent issue raised in both the survey and interviews. The following section discusses various aspects of navigating the NDIS and experiences with the National Disability Insurance Agency (NDIA).[7] It is interesting to note that most interviewees who applied for the NDIS, who had not received funding previously via a state or territory disability program, were aware of the Scheme via the media, word-of-mouth or advice from a health professional. While many interviewees had concerns about the NDIS, many made positive comments about the Scheme generally, describing it as "**life changing**". Another summarised is as follows: "**[The] NDIS has changed your day to day services for the better. It's amazing what I can do now…[it's] a major change**".

4.1.1 Access process

Interviewees had variable experiences joining the NDIS. For one interviewee the transition was automatic as they had previously received state-run disability services. For others the process was made easier through the assistance of social workers, former case managers and occupational therapists (OTs). This was particularly the case for interviewees who recently acquired SCI, as some felt that they "**didn't know the questions to ask**". For some, the process was longer simply due to the logistics of obtaining medical reports. One interviewee spent approximately a year preparing documentation.

Another interviewee encountered several difficulties during the access process. While receiving acute care they applied for the NDIS. They had a diagnosis of SCI and during rehabilitation they gained a degree of mobility. However, according to the interviewee "**the problem I have is I've got a spinal cord injury but I can walk…They initially couldn't understand that…'His walking is ok', so that seems to be the attitude**". As a result, their initial and second applications were rejected. Following the second rejection, the interviewee contacted an NDIA staff member and "**read [them] the Riot Act. I was furious**". Following this exchange, they received an email the following day confirming that their application had been successful. As the interviewee put it, "**Ring them, harass them with emails, whatever it takes, but don't give up and don't be put off, 'cause they will put you off**".

For one interviewee who had been receiving disability supports previously through state government, they found the process of joining the NDIS very longwinded as they were first contacted by three different NDIA representatives and Community Partners. One representative initiated the application process via telephone, which was disappointing as the interviewee felt that "**people can't see my disability over the phone**". Many others agreed that face to face appointments were the preferred method of conducting meetings with staff from local NDIA Partners in the Community during the access process or later during planning meetings.

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[7] Note that Specialist Disability Accommodation (SDA) will be discussed in Section 4.4 Housing.

4.1.2   Planning, supports and management

The following section examines the various issues and feedback provided by interviewees once they had been accepted onto the NDIS.

4.1.2.1   Plans and scheduled plan reviews

Many interviewees had had several difficulties with the planning process and the supports included, or excluded, in their first plans. As one described it, "**My first plan was a nightmare. It was a perfect storm of lots of things going wrong**". Supports in first plans often did not reflect the needs of many interviewees or their family members.

During one interviewee's planning meeting for their family member, the NDIA planner, with a background in accounting, left the interviewee feeling that their family member did not have any of the much needed supports included in their plan. Another interviewee reiterated the difficulties involved in ensuring a plan reflects a participant's needs: "**it's really hard to make them understand…what [their] needs are…They need to be trained, before they ring, they need to know exactly what is wrong with them and then look that up to know that maybe what [the participant] is saying is legit, it's what [they] need**".

One interviewee could not understand why the NDIA would ask for an expensive OT report and then challenge its findings when it was used to justify a support in their plan. Another was unaware that they had funding for a plan manager and felt that it was not required. One interviewee was concerned that due to the fluctuating nature of their young family member's needs it was impossible to determine exactly what supports they might need in 12 months' time. By contrast, some older interviewees with established routines advocated for getting longer plans.

Some interviewees experienced a prolonged period from a successful access decision to approval of their first plan. Most issues arose because supports were allocated inappropriately. Also, some interviewees did not utilise their first plans and due to this some people's second plans were dramatically reduced. For one, they "**barely used any of it because I didn't know what I could use it for and what I couldn't**". Utilisation was also affected when funds were misallocated: "**I have trouble spending all the funding that's allocated to me…there are other things that I would like which are not covered**".

4.1.2.2   NDIS specific supports – case studies

The following case studies illustrate some of the difficulties involved in ensuring the right supports are included in a participant's plan:

Home modifications

A person who had recently acquired SCI required home modifications after transitioning home following recommendations from their LAC. They described the process of getting funding via their plan:

It took several attempts to finally get the funding approved for the modifications to my bathroom. It was a big job. It was a new bathroom…I did all the costing and got quotes. And it was high. It was a lot of money and I said, 'Well just stick it in…and we'll see'. Whatever we get, I'll just make the difference up. But the NDIS can't cope with that. They have an exact amount. So, you put your quote in for 'x' dollars…and if you go over that, it's a 'No'. I had to just organise the quote so it was exactly [the suggested amount] and you know what? As soon as I did that it just went straight through and then I paid the builder another 'x' dollars on top of that because that's what it actually cost. It just seems crazy that they should just have a fixed maximum amount which is not readily disclosed …Just tackle one thing at a time, because if you try and tackle too many things it is just to difficult for the NDIS to grasp.

Support workers

A person uses a specific hoist to support their neck, which requires two support workers to operate, however their plan did not allow for this:

I need two carers and the NDIS funded me one carer and then a second carer for like an hour...but funding the carer for one hour is absurd, so they really underfunded me and I couldn't understand the logic of why they'd done that...whoever was reviewing my file, to them, that was reasonable. To them, they couldn't see any reason why I need two carers...The support we need, it is so subjective. You've got this really fixed system to provide care and support...they try and put people in broad categories, but it doesn't work like that.

Mobility/transport allowance/vehicle modifications

A person described the experience of fighting for funding to use their own car, following a rejection in their first plan:

I'm very dependent on my car...I work across the opposite side of the city from where I live... I need the flexibility of driving...I can't use taxis and I can't use buses because of the unstable nature of my continence issues and my diabetes. I can't be stuck in an environment where I can't deal with my issues...But me saying that, wasn't enough. I had to get letters from everybody...I got my Job Agency to write me a letter, I got my doctor to write me a letter, I got my boss to write me a letter to send through to review.

A family member described the process of obtaining supports for vehicle modifications for their child:

We had to wait nearly two years with NDIS, for [my child] to be out and drive [their] car and we had to prove why [they] needed it. Well, to get in and out of [their] flipping car and into [their] chair! But because it was $28,000...they thought that we were just riggin' it. And we had to wait two years for that, poor kid...I kept saying...'We are legit. [We] wouldn't be paying top dollar driving lessons with a specialised driving instructor if [my child] didn't need [vehicle modifications]'. And so we had to prove and get photos taken, and then we actually had to go to a friend who had [a car with vehicle modifications] and get [my child] to sit in the car and use this [friend's car] to show them what it was for [my child] to be able to get one [with vehicle modifications].

Assistive technology – hand controls

A person outlined the difficulties associated with accessing assistive technology when it does not fit within the NDIA's line items:

One of my stated goals was to explore hand controls...so I had to go to these driving instructors and try the different controls...But because I was plan managed, they have to charge to a line item and there's only one line item – driving lessons. It wasn't a driving lesson, it was trying hand controls with the driving instructor. I've been driving for 20 years. I didn't need the lesson, I just needed the person with the car... [The] invoice went through to the plan manager and the plan manager got really prescriptive and was like, 'You're not funded for driving lessons'...They said, 'We'll get in trouble', and I'm like, 'So, what do I do?'. And they're like, 'Well, you shouldn't have done it'. I said, 'Well, my goal is there. How am I supposed to know that that was supposed to be a stated support?'. I went to my LAC and I got a letter from my LAC saying this is fine and the plan manager still came back to my LAC and said, 'Well, this is what somebody from the NDIA has said and they disagree with that decision...I'll do it, but it's on your head if you do get in trouble'...So I had this breakdown.

4.1.2.3 Management

The 12 interviewees who discussed the NDIS, had different management arrangements, which in some cases had changed over time. For 4 interviewees they had been self-managed from their first plan. Of this group 3 had acquired injuries at least 5 years ago. This group cited the benefits of self-management: flexibility, control and greater awareness of their plan's status. For one interviewee who

switched from plan management to self-management, they felt more empowered following poor experiences with plan managers as one-off purchases allowed them more flexibility and ensured they always had sufficient funding.

In contrast, two interviewees appreciated that they did not have to concern themselves with management and could rely on their plan managers. One interviewee, who had recently acquired SCI, thought "**I haven't got the foggiest about any of this…chances are they know more about it than I do**". One interviewee had been self-managed but was concerned that they did not have enough supports and opted for plan management for their second plan. Another interviewee felt that their plan manager understood their needs and the NDIS process much better, particularly as they had personal experience with a family member with disability. They appreciated that "**[after] years with my disabilities…I am not having to do all that running around**".

Three other interviewees are, or had been, Agency managed in full or in part. One of these interviewees had transferred to plan management to gain greater flexibility.

4.1.3   Complaints, reviews and appeals

Despite many concerns regarding plan reviews, none of the interviewees appealed to the Administrative Appeals Tribunal. However, many did submit a participant requested review of their plan or review of a reviewable decision. One interviewee requested an internal review of both their access decision and their first plan and was successful in both instances. During the period in between submitting the reviews and receiving a decision the interviewee did have sufficient funding to meet their needs.

Another interviewee was similarly disappointed with the lack of supports in their first plan and submitted a request for an urgent review. After a significant delay they received a call from the NDIA advising them to withdraw the review as it was unlikely to be approved and recommending that they go for an early planning review instead. The interviewee noted that "**what I found out later…[was that] a lot of people receiving these calls and what they were trying to do, was get you to withdraw it, because then if you withdrew your review, it showed that they weren't rejecting it…so you can't escalate it…to the AAT**".

One interviewee submitted a review of their family member's plan and sought assistance from multiple stakeholders, including local Members of Parliament (MPs) and advocacy organisations. The interviewee "**just bombarded them…I did everything and just kept sending them in. Kept going and ringing and sending stuff in**". During this time, their family member had insufficient funding and the interviewee had to take on more responsibilities as a carer.

A recurring theme in many interviews was confusion over the NDIS process and communications with the NDIA. One interviewee received a cut in their funding in a new plan as they had not utilised their full supports as they had spent an extended period in hospital. Following discharge and a new meeting with the NDIA, the interviewee and their family members were very confused regarding the next step as "**we were under the impression that that was my proper plan review…but it was just a…chuck a flick, tick on the paperwork**". While they had thought it was a full new plan review, it was instead a light touch review, to consider the non-utilisation of funds, however this had not been communicated properly to the interviewee.

Despite one interviewee feeling that they had been underfunded in their first plan, they were reluctant to request a review, as they suggested "**I don't want to be throwing a temper tantrum and saying, 'You aren't giving what I want'…I didn't want to presume that I knew better**". Instead, following advice from a support person, the interviewee spent the funds in the plan and determined

that if they were insufficient they would request an urgent plan review. Due to the impact of the COVID-19 pandemic, the interviewee had sufficient funds to cover their expenses.

4.1.4 Independent assessments

In August 2020, the Minister for the NDIS announced that independent assessments (IAs) would be introduced to better "support access and planning decisions".[8] In light of these changes, interviewees were asked their opinion on the introduction of IAs in general terms.[9] Of the six interviewees who provided feedback on IAs there were mixed responses.

Those with positive feedback suggested that the benefits of costs saving, assessment of medical functionality and simplification of obtaining medical reports was very appealing, particularly during the access process. These interviewees had acquired SCI or experienced degenerative spinal issues relatively recently. Another interviewee appreciated the in-person nature of IAs "**because when you're initially…overwhelmed…if you're talking to someone it's very easy to absorb information**".

The interviewees with negative responses suggested that having an IA with an assessor who had not previously treated them, or was unfamiliar with their needs, would produce unfavourable results. As one interviewee stated "**[I] won't talk to anyone unless I know them and I won't talk about my life so openly with complete strangers**". They further suggested that there were already so many health professionals, support workers and others supporting them that it was unnecessary to see an assessor outside of this group. For one interviewee, they distinguished between IAs for people seeking to access the NDIS and existing participants who enjoy choice and control. They noted, "**I feel it's important not to be dictated to about how you get [an IA]…Once a person is on the NDIS, they should be able to choose their therapists…it stands to reason that those people are the ones that do reports on you…it makes no sense to go to see some independent person who meets you for four hours**".

Another interviewee had a mixed response agreeing that "**an understanding of what your needs are would be helpful**". However, they also noted that "**as long as both sides were open and honest…If they're counting dollars…then that could come back and hurt people**".

4.1.5 NDIA staff and LACs

Eight interviewees discussed past experiences they had had with NDIA staff and LACs. Those with positive experiences often interacted with staff with lived experience or knowledge of disability. As one interviewee commented their first LAC "**was far more connected…[they] could pick up on the issues and really [understood]**".

For one interviewee living in a rural area, poor communication made them feel that they were "**very low in the priorities**". As they suggested, face to face contact is vital to ensure that staff understand their needs and how they live. Many other interviewees agreed with this.

All eight interviewees agreed that they would appreciate a single point of contact at the NDIA, preferably with expertise or at least knowledge of participants' primary disability. Without this, one interviewee highlighted the frustration "**when we have to tell our story again and again**". Due to multiple contacts at the NDIA with varying levels of knowledge, "**you'll get as many answers as you**

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[8] National Disability Insurance Agency (NDIA), 'Improving the National Disability Insurance Scheme: Better Participant Experience and Improved Access and Planning', information paper, 24 November 2020, p. 3.
[9] Note that interviews were conducted prior to publication of the information paper referenced in n 6, which included specific details related to the IAs. As such, their answers were based on general observations on the process.

do people". Others emphasised the difficulty when staff turnover is so high, which complicates participants' ability to build relationships with people so that they best understand their needs.

4.1.6 Service providers

Two interviewees found that most difficulties they had encountered was not in relation to the NDIA or the NDIS process, but rather with NDIS service providers. As one interviewee described it, "**Most of my problems are from the ground up…only because someone isn't doing their job properly…by not doing what I've asked them to do**". This included service providers offering support coordination. It seemed that while the interviewee had made complaints to their care agency, past complaints had not been escalated to the NDIS Quality and Safeguards Commission. Another interviewee had found it "**virtually impossible**" to find an appropriate provider in their area, as when "**you mention NDIS they run for the hills…they just think 'I'm not dealing with that because I've heard it takes six months to pay'**".

4.1.7 Support coordination

Several interviewees discussed the significance of support coordination in providing links to service providers, information and relief from the stress some felt navigating the NDIS process. One interviewee described their support coordinator as "**the one that's just made such a difference to me**".

4.1.8 Navigating the NDIS system, information and advocacy

Interviewees' experiences of the NDIS largely depended on the support persons, advocates and information they had to navigate the system.

For one interviewee who recently acquired an injury, they found that without knowing the right questions to ask, they had to be guided by their social worker, OT and physiotherapist. They described how they had asked peers for advice and found that many had poor experiences, but the interviewee is "**not interested in the dramatic stories, I am interested in finding out how it works and how to best access what's available, or find out what's available**".

Numerous interviewees had contacted MPs to intervene on their behalf at various stages, and had had positive outcomes due to their influence. However, as one interviewee observed, the process should not be so antagonistic "**In my last contest with the NDIS…they also got me a Legal Aid solicitor…I didn't think it had to be so adversarial…it's so stupid because it'd really frighten a lot of people**".

On first receiving a digital information booklet from the NDIA on which service providers operated in their area, one interviewee felt overwhelmed as "**It's a PDF file and the writing's so small you have to blow it up…this is ridiculous, you're sending this out to people with disabilities? How do you expect them to sit at a computer and scroll through 300 odd pages trying to find someone to help them?**".

One interviewee described the situation of a fellow participant whose support hours had run out and who otherwise relied on their elderly parents. Their LAC could not assist them as they were unavailable to attend their house to assess their condition and as a result "**they are just basically giving up…no one is there to help them to push them, when you're in kind of a depressed mode…maybe they won't access those services**". It also illustrates the pressures on family members to advocate and push to find information and supports by themselves.

4.2 Supports for Over 65s

Eight interviewees discussed the issues faced by people aged over 65 with a disability and identified the current gaps that exist in receiving supports.

4.2.1 Governments' support programs

Of the eight interviewees, seven of them had engaged with government support programs, receiving or applying for different federal and state programs. One interviewee had an NDIS plan, which they had applied for prior to turning 65. The following section examines the various programs different interview participants engaged with.

4.2.1.1 Commonwealth Home Support Program (CHSP) and Home Care Packages (HCP)

Due to ineligibility for disability supports programs, the majority of interviewees had applied for or were receiving support through the aged care system via CHSP and HCP. Level 4 HCP currently provides approximately $52,000 per annum.[10] This compares with an Australian average of $164,00 in NDIS participants' plans with SCI listed as their disability group.[11] In light of this disparity, the majority of interviewees found that the aged care system failed to support their disability needs: "**From day one, we were always underfunded and consequently we had to basically explain or say what we would do without**".

As a result, many relied on self-funding gaps in accessing adequate assistive technology, community health services and support workers: "**We're filling a gap…there's no recognition that you're forking out half of your income just to manage the condition, and then you've got to live on the other half that you've got left**". Additionally, many interviewees who are family members acted as part or full-time carers or supplemented private funds by returning to work.

For most interviewees, the process of applying for CHSP and HCP was relatively easy. However, for a few interviewees the major difficulty was the extended wait time between approval of an HCP and receipt of supports: "**We were warned. Two months, two years before the funding comes through…there's 100,000 or 120,000 or something on the waiting list**". In one instance an interviewee had yet to receive funding after being approved over 9 months ago. For another interviewee, while their family member was eligible for an HCP, choice of service provider was limited to a non-specialist hospital that could not provide specific supports for patients with spinal conditions. Another interviewee had found, that while they could fund their supports themselves, the lack of choice and control in HCP funded supports prevented them from accepting a package: "**You have absolutely no power of making decisions for yourself**".

While many interviewees felt that they could manage under the present circumstances through family support, the overwhelming concern was if circumstances altered. As one interviewee described it:

If I suddenly had a slip and broke an arm or something…then we would need the full [Home Care] package tomorrow…and I don't know what would happen then. Maybe that's when they actually hear me out - when you are at immediate risk of being institutionalised…I don't know how it works. Otherwise, you gotta wait for someone to die, you know? When you're 82 and a quad, you don't want to have to wait too long. Not wanting to be morbid about it, but being realistic, you know. I mean, how many 80 year old quads do you know? There's not that many of us…it just takes one dose of pneumonia or something and you know, you're gone.

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[10] MyAgedCare, 'Home Care Packages', Australian Government, https://www.myagedcare.gov.au/help-at-home/home-care-packages [viewed on 7 December 2020].

[11] NDIS, 'Explore data', National Disability Insurance Agency, https://data.ndis.gov.au/explore-data [viewed on 7 December 2020].

4.2.1.2   Continuity of Support Program (CoS)

One interviewee received disability supports via CoS after first receiving funding through a state-funded program, prior to the introduction of the NDIS. The interviewee described the disruptive transition between the state program to CoS: "**It ended very suddenly, within a matter of weeks. It was gone. And the CoS assessed us and it was a much more rigid program, you don't have the same flexibility we used to have…We were told, quite simply, this is Continuity of Support, this is not the NDIS, this is not [your state program], take it or leave it. You either sign now…or you don't get anything**".

The interviewee has a self-directed funding model and reports monthly. They noted that the general attitude of CoS contrasts with their previous state program. They recounted a situation in which they sought funding for a support worker to attend an overseas trip, however on applying to CoS they were told this was not possible. After writing to a Minister, who agreed that CoS could cover the support worker's costs, their coordinator claimed that they had never denied funding. The interviewee described it as follows: "**It is such a bullying attitude…[it's], we're all naughty little children and we have to be threatened into obedience**".

4.2.1.3   Transition care

One interviewee and their family member received Transition Care from My Aged Care following discharge from hospital. They found the process "**very bureaucratic**" and confusing particularly regarding which services and equipment they had access to. However, they were appreciative of the assistance they did receive on first being discharged from hospital.

4.2.2   Over 65s housing options

Housing was a major concern for many interviewees. Many felt that their current circumstances were sustainable, however a few were critical of aged care facilities and the prospect of finding alternative accommodation as they got older. Note that the following section specifically refers to the situation for over 65s, however housing issues more generally will be discussed later in Section 4.4.

4.2.2.1   Aged care facilities and nursing homes

Many interviewees discussed the situation in nursing homes and their concerns about the prospect of living in aged care facilities. Many were concerned with the lack of autonomy for nursing home residents and the lack of disability expertise among staff. The psychological impact of living in this environment was described as follows:

People who have to go into aged care because of real care needs lose their soul. They suddenly become…robots. 'Do this, go here, do that'…They say you can come and go as you please, but in reality or in practice, that can't happen…If you want to do anything they've got to try and ring a bell and get someone to take them…That's why people give up and die. Someone else rules their world.

Another interviewee emphasised the specific difficulties for people with a physical disability without specialty expertise in nursing homes in SCI and other spinal and neurological conditions.

An interviewee residing in a nursing home also highlighted the excessive costs associated with living in the facility. The interviewee reported how the initial financial burden of paying refundable accommodation deposits, without receiving benefits through ongoing investment was unjustifiable.

4.2.2.2   Private housing

Six of the interviewees or their family members remain in their own homes. This included individuals with newly acquired injuries as well as those with longer experiences of living with disability. For one interviewee with a family member with a recently acquired SCI, home modifications were required following discharge, however government support for renovations was severely lacking.

Consequently, they had to pay for bathroom renovations out of pocket, relying on superannuation funds and loans from family members.

Remaining at home by themselves or living with family members was a priority for most interviewees. One participant future-proofed their property soon after acquiring their injury through self-funding: "**I built my house [decades ago]. I designed it myself and a builder and I put it together…I understood the whole process of how it could be done…There is no way that they could handle me in a nursing home. They would not know where to begin**". Another interviewee similarly renovated their current home, widening hallways and doors. They also recounted the experience of first modifying their home following their injury. The modifications were funded through government funding, however there was an 18-month delay before the modifications were actually made. This interviewee also anticipated moving to an aged care facility at some point in the future.

4.2.3   Navigating the aged care system

Many interviewees noted the difficulties of understanding and navigating the aged care system. Computer literacy could be a potential barrier to accessing information, particularly as many felt that there was an expectation of a certain level of fluency.

For one interviewee, navigating the system with their family member, who had recently acquired SCI, was confusing: "**It's very opaque, the whole system…It's a world of initials…nothing is integrated…There's booklets and beautiful stuff, but…I think there's a real role for a care coordinator. Some person that you have that's yours, that will coordinate care for you across the trajectory**".

Due to the difficulties many encountered, interviewees highlighted the need for confidence to self-advocate and seek support: "**You have to have the confidence to ring up somebody, to fight for you**". For many, this involved seeking assistance from local, state and federal MPs.

4.2.4   Service providers

Many interviewees, including those inside and outside of aged care facilities, complained about the lack of disability expertise among aged care service providers and access to disability support workers. One interviewee with established experience of disability stated "**I found that [disability service providers in my state] were excellent when I started, but at the present time,…the administration is dreadful and the workers are so slapdash and completely without any idea of SCI**".

Another participant described the impact of the NDIS on accessing disability support services: "**We can't get carers because there's no one available. The NDIS has sucked in everything…It has sucked the carer pool dry**".

4.2.5   Discrimination against people aged over 65 with a disability

Many of the interviewees were very frustrated at the differential treatment they experienced due to a lack of supports since the introduction of the NDIS. One interviewee suggested that the underlying reason for underfunding supports for over 65s with a disability was a concern that the system could be abused. Another described it as follows:

[CoS] is not the NDIS for seniors…we're put on the scrap heap, because we have no goals, we have no aspirations…[NDIS] is the gold standard. We're getting offered a second-rate grab bag, a complete mishmash. I'm on CoS…other people are on aged care…there's no rhyme and no reason for it …With enough noise, we could change it, but we need everybody on board.

One interviewee with a family member in a nursing home agreed, and felt: "**This government of ours can do better. We don't treat our loved ones this way…They have so much ability, we don't rob people of their ability…they're just ripped off of so much potential**".

4.3   Employment
While there was only one employment focus group with three interviewees, employment and issues related to training were also mentioned in three other interviews.

4.3.1   Government schemes
Interviewees' experiences with government disability employment schemes had generally not been particularly successful. One interviewee had engaged with Disability Employment Services over an extended period, but found their communication and management very inadequate: "**They're trying to sign you up to useless training courses, but they won't divulge what the actual courses are…When they did contact my employer, [they] said, 'It's useless, I don't know what they're talking about'. They're pretty much incompetent**".

Another interviewee was registered with the Disability Management Service and has not yet successfully found long-term employment. Since registering for the service 9 months ago, the interviewee had only been shown two possible job advertisements. Further, their case manager had failed to notice that one of the requirements for one of the positions required fluency in a specific language, which made the interviewee ineligible. The other job did not pan out successfully as the company did not offer them any hours as they had overemployed during that period.

Only one interviewee had had a positive experience on returning to work, through supports through JobAccess, within 6 months of acquiring their injury.

4.3.2   Attitudes of employers and colleagues
Interviewees observed that often attitudes were quite variable as it simply depended on the approach of individual employers and also as a result of the diversity of people's experience of disability. One interviewee suggested that the difficulty may be more evident for people with acquired disability rather than congenital disability, as employers may be "**scared**" of making adjustments on employees' return to work.

One difficulty an interviewee had encountered related to disability toilets in the office.[12] They had regularly found that the disability toilet was blocked, which led them to require extra time during their bathroom break. It was only on application to their employer that the interviewee was able to ensure that policy was amended to ensure that other employees did not use the disability toilet.

An interviewee described the specific difficulties involved in certain industries. For example, recounting a past experience participating in teacher training, the interviewee said, "**I put myself at risk and a lot of teachers said, 'While we would love to have more wheelchair teachers', because I had to lean over students, that put me at risk of a complaint**".

One participant was concerned about disability awareness training as a method to improve attitudes: "**I found the disability awareness training to be condescending and a waste of time**".

4.3.3   Finding a job and the application process
Interviewees' experiences of applying for jobs was often very difficult and frustrating. Two interviewees noted how employers would be critical of the gap in time in which they had been

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[12] Note disability accessible toilets will be further discussed in Community access - Section 4.5.

unemployed during the period directly after acquiring their injury. One interviewee makes a concerted effort not to identify as a person with disability, however explaining periods of unemployment post-injury was still challenging as "**employers don't like that gap**".

Many interviewees described the difficulties of remaining at home without the stimulation of a job: "**When I was doing nothing, I was going mental, sitting at home, not leaving the house, so you're happy to do anything**". For many interviewees aged over 55, while they felt a strong desire to work, they found that they were being forced into early retirement due to the barriers in finding any employment. One characterised the process as "**[taking] everything from you, so to build the confidence up again and go, 'I am employable, I can do this. I have got a head, I have got a brain'**" requires significant effort.

One interviewee noted the challenge of getting a job in a competitive job market, particularly for those aged over 55 with a disability: "**I'm sure the will is there from employers…to do the right thing. But if they have the option of me or the other 40 highly qualified 25 or 30 year olds. It's pretty easy for them…I know what side I'd be falling on…I'd still be out of a job if I wasn't working for someone I knew**". Additionally, others described how few responses from employers they received despite sending a significant number of applications out. As such, many resorted to Disability Employment Services to assist in the job search. Though for one this was a reluctant choice as "**I don't want to live disability and work disability**".

Two interviewees with extensive employment histories described the struggles of finding a job in their field or at a level that they had experience at: "**One of my friends said to me…'You're aiming too low'…And I'm like, 'Well I can't go much higher, I've got to get in somehow'**". For one interviewee with experience in the public service, they noted that disability identified employment positions "**[are] not at the senior level…[People with disability] must be satisfied with just getting the crumbs that they are offered…No one must be experienced. No one must have qualifications. No one must be knowledgeable**".

4.3.4 Future initiatives to address employment

During the employment focus group, participants had several recommendations as to how to address chronically low rates of employment of people with disability. These recommendations included:

- Finding appropriate employment via organisations like SCIA;
- Establishing a support person or recruiter to liaise between employers and job applicants with a disability;
- Employment quotas within government and private bodies for people with disability.

One interviewee was very clear that employment quotas can only be effective if conducted with firm targets: "**Try not to guise [employment quota policies]…because that does not work. Hard figures. Hard figures at every level**". They were also critical of the process of proving disability to employers as it involved providing personal medical documentation, which could be too rigorous.

4.4 Housing

Housing was a major issue across all demographic groups and was mentioned in all over 65s interviews as well as a further four interviews. This section explores different housing options for people with disability and the associated costs involved with each.

4.4.1 Home modifications

For people with newly acquired injuries, home modifications were often necessary on returning home from hospital. Home modifications have already been discussed in an earlier section, but it is

important to note that when disability accessible accommodation is unavailable, people will usually incur additional, significant expenses when moving to an unmodified private property: "**I know there's easy fixes to a lot of things, but if you've spent your entire money on just getting a basic place, and because I haven't got employment at the moment, I can't rely on my partner to take on a full mortgage**".

4.4.2   Social housing

Very few interviewees had personal experience living in social housing, however many knew of others in similar circumstances living in social housing accommodation.

For one interviewee living in WA, they cited the long waiting list as a major barrier to ensuring that their family member could return home to live with them from a nursing home: "**There's a really long waiting list. We tried to get on Priority Assistance. And we got turned down…because [my family member] already has a roof over [their] head where [they are] now**".

One interviewee described the difficulties of living in the only disability accessible house on their street. As they said, "**The Housing Department was only ever making houses accessible if somebody that needed it was going to be living in there**". While, they could access their own home, the barrier to other people's social housing homes still existed: "**People could visit me, but not once [during that time] could I actually get inside anybody else's house…you're isolated…and that's not good**".

Another interviewee in the over 65s group generally commented on the disconnect between government and people's housing needs: "**It's an issue in society more than just aged care…I think that the federal government…is so far removed from what normal people [experience]…How can they possibly understand how difficult it is for people?**".

4.4.3   Renting and owning

Interviewees recounted difficulties they had renting properties, while keeping their former disability inaccessible properties and searching for new private rental homes or accommodation to buy. Post-injury, one interviewee was hesitant to sell their townhouse, which was inaccessible, without having suitable accommodation to buy and out of concern that it may be difficult to obtain a mortgage. However, as a result, the interviewee is now renting and concerned about the financial burden: "**I've got no income at all and I'm just relying partly on my savings and on my partner…Our money is separate…I've never asked for anything and [they've] never asked for anything either and I don't want to start now. But my anxiety and fear about this…**".

4.4.4   Specialist Disability Accommodation (SDA)

One interviewee had direct experience accessing SDA for their family member through funding in their NDIS plan. The interviewee became aware of SDA approximately 4 years ago, however on approaching plan managers, support coordinators, NDIA staff and others, no one had any knowledge of SDA. While searching for possible options for SDA via the Housing Hub website, the interviewee found it very difficult to find suitable accommodation, within a desired location as the market was so limited. During a regular check of the site, the interviewee discovered a new build that was suitable for their family member and "**then it sort of snowballed from there**". The process was longwinded and involved finding the right support persons to put in the SDA application, OTs and a specialised support coordinator. The application was speedily approved, which according to the interviewee is highly uncommon. Describing the process overall, the interviewee outlined:

> *It's a hard slog. The house is the easy part, the building is the easy part. It's getting the supports in place and actually getting the application in, it's a lot of hard work…The key is, you have to find a support coordinator who is familiar with writing housing reports…Otherwise you're set for failure!*

Another interviewee was aware of SDA, but was concerned that "**all they're doing is building many institutions…where they've got a block of units and they're all built to the accessibility standard and they're planning to put people with disabilities in all of them. It's just an institution with a slightly different framework**".

4.4.5   Looking for housing

The overarching difficulty when searching for housing has been a lack of disability accessible housing in all housing categories (private, social housing, SDA). Discharge from hospital had been delayed for a few interviewees due to an inability to find suitable housing. Major housing websites usually do not have a filter to find wheelchair accessible properties, which complicates the search as each individual listing needs to be analysed.

One interviewee has spent almost 4 years searching for suitable housing to either buy or rent. They engaged a real estate agent, however they have been unable to find accessible housing. When the real estate agent had taken the interviewee to properties, they had failed to notice steps leading to the front door. Further, suitable properties are generally located outside of their desired area and or does not match their specific housing needs.

Another interviewee with disability argued that "**it's an absolute myth that accessible housing is that much more expensive**". They explained that based on their experience, while the additional cost of ensuring units and houses meet disability accessible standards was minimal, the difficulty remains in convincing the building industry to universally construct disability accessible accommodation.

4.5   Community access

One focus group specifically discussed community access issues, however five other interviewees also raised access concerns in their local areas. The vast majority of interviewees discussed access issues they had encountered in NSW, mostly in Sydney. Only one concern related to the ACT and one in SA.

4.5.1   Local communities and councils

Two local councils located in the Sydney region were specifically discussed during the focus group.

Interviewees were generally complimentary of their local communities in ensuring access to local beaches, shopping centres, parks, recreation areas and hospitals. However, they also cited a few specific issues. These included:

- Construction of poles in pedestrian areas (preventing motorcycles, but also wheelchair users);
- National parks typically failing to construct ramps;
- Single step shops; and
- Raised council gutters.

Many interviewees were frustrated that councils had failed to consult them before constructing inaccessible buildings and facilities. Some argued that they should be consulted during the development approval stage and others noted that generally: "**There's total disregard by many councils of enforcing [the Access to Premises regulations]…Sometimes things are approved, years and years and years ago, and they're approved under old regs. But when they're built there are new regs**".

One interviewee had been consulted on many areas and conducted an evaluation of local disability toilets and their council "**were quite proactive and interested in what I had to say**".

4.5.2 Private and public transport

4.5.2.1 Private transport and parking

Parking was a major issue faced by multiple interviewees across different Sydney regions. Disability parking is generally limited and many interviewees felt that parking permits were granted too liberally to people who may not necessarily need them. For two interviewees, when there is limited disability spots they are forced to park in the middle of two parking spaces.

In many parking stations, one interviewee noted that with a modified vehicle, when driving, it was not possible to access the ticket from the automated machine at the entrance. Some suggested that this is remedied through number plate recognition technology. One interviewee recommended that number plate recognition technology be prioritised in hospital parking. However, as one over 65 year old noted, in order to access extended periods of free parking in some stations with number plate recognition you require a mobile phone to download a specific application, which is impossible for people without a mobile.

4.5.2.2 Public transport

Many interviewees who had lived with disability for a significant period felt that public transport in Sydney had greatly improved: "**The change is massive. You can actually get on a train and it's not a big deal**". The introduction of the light rail in Sydney and the addition of elevators at stations has improved ease of travel for many interviewees. Additionally, they found transport staff "**very well organised, in fact, they're really keen for you to use their ramp...I've found them very proactive**".

However, one interviewee emphasised that the light rail would only improve service delivery in specific areas of Sydney. Additionally, they felt that several stations were still inaccessible and recommended that improvements should be made on a priority basis depending on the demographics and needs of specific suburbs.

4.5.3 Ramps and lifts

When discussing modern, newly constructed buildings, one interviewee noted how many buildings instead install wheelchair lifts. For some, these lifts are "**very unreliable and they don't give you equal access at all and it often is so poor that you just wouldn't ever go there**".

One interviewee complained that even though several buildings had ramps, many other aspects of the building, including the width of doors were inaccessible, but many people understood accessibility to simply relate to ramps and lifts.

4.5.4 Toilets

Disability accessible toilets still remain an issue in different types of buildings. Many interviewees highlighted that disability toilets are often used as storage rooms, restricting access or making it very difficult to open and close the toilet door. One recommendation to address this issue was to implement a penalty system administered by a Local Council to check disability toilets. Without checks, the onus is continually on the person who needs to use disability toilets to make a complaint. Many also mentioned how many disability toilets still have the heavy doors, which are difficult to handle: "**It's almost like there's a bank, bank vault behind. I've got to get somebody to open it**".

4.5.5 Public utilities

Most focus group interviewees agree that public utilities were generally improving, however they noted that older water fountains that had not yet been replaced were still problematic.

4.5.6   Safety procedures

In one discussion, the issue of access and safety procedures in different educational institutions was raised. According to one interviewee, the institution did not have a thorough fire safety procedure for wheelchair users. As a result, a plan was designed to introduce a tarpaulin water slide would could be used in an emergency situation. However, the interviewee was concerned that such a 'solution' could endanger their family member further.

4.5.7   Hotels

Two interviewees mentioned the challenges they had had when staying at hotels due to limited availability of disability rooms. One interviewee found that the disability rooms in hotels usually did not accommodate their whole family: "**You couldn't book a room that could fit even two children, because apparently disabled people may only have a couple, if you're lucky**". Another interviewee recounted their experiences complaining to hotel administration as disability rooms were only located in undesirable locations, overlooking carparks and garbage disposal areas.

4.6   Community health

While only two interviews were conducted on the topic of community health services, community health services were mentioned by twelve other interviewees. An overwhelming theme in many of these discussions was that "**no two spinal patients are the same**", nevertheless, many people had similar observations or feedback on different community health services.

4.6.1   Local GPs, specialists and other health practitioners

Both interviewees were sceptical that their GPs could provide insight into their spinal care needs, despite having treated them for extended periods of time: "**They tend to know a little bit about a lot. But when it comes to spinal care, even though I've been with my GP for years, [they] don't fully understand**". For both, who had acquired their injuries some time ago, they relied either on their own knowledge, assistance from community nurses or referral to specialists that they had found on their own to obtain further tests, new treatments or advice. One interviewee suggested that connecting to service providers and practitioners had become more complicated since the introduction of the NDIS: "**I found after the NDIS I haven't been able to access the nurses much**".

Each interviewee highlighted that connecting with the right practitioner to best understand and listen to their needs had the greatest impact on their health. Some interviewees had had poor experiences with certain specialists and this had complicated their ongoing rehabilitation. Connecting with the right specialist was also difficult depending on where they reside, as often people were forced to travel to other cities for an initial consultation. As one interviewee described it: "**The healthcare profession needs a big shake up, a big wake up call, because at the end of day, without them, nothing will get done. But, we can't have them calling the shots either…**".

Others found the costs of obtaining OT assessments prohibitive, which in turn affected their ability to access government supports. One interviewee who had specialist knowledge of wheelchairs, but was not accredited, was astonished that the OT who attended their nursing home could not provide any assistance in conducting a wheelchair assessment. They suggested that accreditation of OTs should be revised to ensure that knowledge of wheelchair users' needs was understood better to "**help our disability industry**".

4.6.2   SCIA, Spinal Outreach Service (SOS) and other consumer organisations

Many interviewees had connected with SCIA via NeuroMoves, SCIA's exercise and therapy service. As such, some reflected on their experiences attending NeuroMoves. Most interviewees only became aware of NeuroMoves via word of mouth from friends and family and internet searches. Several

interviewees regularly attend NeuroMoves in different states and have found it to be a positive influence on their rehabilitative or exercise journey. However, three interviewees found the prices of classes "**prohibitively expensive**", or an inconvenient distance from regional centres.

Overwhelmingly, interviewees and their family members who had acquired injuries and had engaged with SOS were very positive about their experiences, particularly on returning home: "**They go out of their way to help you…when you're in hospital it's very different, but when you're at home, that's when things hit you. The things which come up you haven't even thought about**". One interviewee also appreciated the virtual meetings SOS conducted during the COVID period. Many people also appreciated that SOS acted as a useful referral service during the post-injury period.

4.6.3   EnableNSW

Multiple interviewees have had interactions with EnableNSW, which provides assistive technology and other services to NSW residents with specific short term or ongoing health needs. Many engaged with EnableNSW immediately following their injury and some interviewees still engage with them as they receive certain supports via government programs, including CoS and CHSP.[13] For two interviewees with acquired injuries they had found their interactions with EnableNSW somewhat difficult, particularly as they did not have much choice and control in accessing assistive technology and equipment. One interviewee had difficulty communicating with them to ensure they received support before their NDIS plan commenced: "**Enable was harder to deal with. That required a lot more follow-up…And it was touch and go whether we would have the Enable stuff in to get me home…Enable wanted to know if I was on the NDIS yet…**". Another interviewee was frustrated that EnableNSW refused to fund certain features, including tip-bars, or make alterations to footplates, particularly when they required immediate support at a time when they were "**a real big deer in the headlights**".

Another interviewee who had had to interact with EnableNSW before the introduction of the NDIS found "**the government didn't give them that much funding so they could only say yes to the very bare minimum**". The lack of choice and control seems to be an issue for other interviewees who still have to engage EnableNSW as they are not on the NDIS. One interviewee has found that they seem accommodating on the phone, but in reality they are very prescriptive as to how to use equipment. They described their approach as follows:

> They've just put in this new request for a wheelchair…it's quite an expensive one, I'm waiting for them to fall over laughing…It's difficult, they don't like you to actually use their wheelchairs. I'm a very heavy user…So I get a lot of wheelchair repairs because I use it. They don't like it, and they get a bit annoyed. They said, 'We're not going to pay for any more repairs. You pay for your own repairs'.

4.6.4   Psychosocial supports

Receiving ongoing psychosocial support is a critical aspect of successful rehabilitation following an injury.[14] However, for many interviewees, they agreed that psychosocial care is an ongoing support that could continue long after a person first experiences their injury. For one interviewee, addressing the psychological impact of acquiring SCI decades ago was an important development: "**It took me years to process it…I've had counselling and a lot came out of it. I've had so much suppressed anger that I was carrying around with me**". For some, peer support was proposed as one of several different informal psychosocial supports to assist people on their journey. One interviewee described the

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[13] EnableNSW will be further discussed in case studies in Section 4.7 Assistive Technology.
[14] J. Middleton, K. Nicholson Perry, A. Craig, 'A clinical perspective on the need for psychosocial care guidelines in spinal cord injury rehabilitation' *International Journal of Physical Medicine and Rehabilitation*, vol. 2, 2014, p. 26.

significance of mentoring: "**I think a good, strong character mentor is good, because they give you guidance on life in general**".

4.6.5   Searching for community health services

As with many of the various topics already discussed, finding appropriate community health services and practitioners was very difficult and usually required basic computer literacy. Additionally, some mentioned the frustration of constantly having to collect and recount medical histories to different practitioners and service providers.

Accessing the right services has been critical for many interviewees or their family members' rehabilitation: "**We're diggers, we keep on trying to find out new things that's happening all the time…If we hadn't gone and followed different leads, looked up people…I'm sure [they] wouldn't be where [they are] today**".

4.7   Assistive technology

There were no focus groups or interviews that solely focussed on assistive technology. However, assistive technology and equipment was raised by two thirds of all interviewees. This section will explore a few case studies of interviewees and their family members' experiences

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NDIS support for wheelchair and repairs

An NDIS participant sought to get funding in their NDIS plan for a wheelchair and repairs:

The major issue with my first plan was that the first sentence was, 'I'm a 30 whatever year old wheelchair user' and then I never had any funding in my plan for a wheelchair…so yeah, that was fun. 'Cause it needed mods and there was reports and everything put together. But there was no funding in there to fix like a nut on my wheelchair that fell off just after I got my plan. And then, you know, so I was plan managed and the plan manager is like, 'You don't have any funding for wheelchair repairs'. And I was like, 'Doesn't that come under low cost AT?'. 'No, it comes under wheelchair repairs in capital.' And I'm like, 'Well, why don't I have wheelchair repairs?'. I rocked up to my planning meeting in my wheelchair! So you know, those sorts of things that you would think were obvious were not.

Applying for a wheelchair through the NDIS

An NDIS participant struggled with the wait time to receive their wheelchair:

I've had a very different experience…I found equipment before, wasn't it easier? Because now you have to wait. Like, let's say my wheelchair breaks down today. Then I have to apply for it and then wait for it. And the wait is very long. Otherwise I can apply it in my new plan. But then the new plan comes after one, two months and then I have to wait for the wheelchair to come, which is three, four months as well. So I find that the waiting is very long now. One thing I did was, because I knew that the waiting was so long, I applied for my manual wheelchair at least one year before I thought this might give me some trouble. It was so scary, you know? What if I'm stuck? This is how I get to places and it's too expensive for me to afford it…The fear of what if something goes wrong? I won't be able to do anything about it. I have some funding [for repairs and maintenance], but if it's a big cost, then you have to do the urgent review. [However] the NDIS is very vast, it gives you a lot more freedom. I can even apply for some upgrades if that makes sense. For your manual wheelchair, you can get the SmartDrive.

Gaps in access to equipment for over 65s through aged care

A person aged over 65 is still waiting to receive funding from their HCP and relies on accessing assistive technology and equipment through EnableNSW:

I'm sort of in the middle of that at the moment. My commode chair died. Actually, I did get a new one, but it was no good. I've got to go through the process again. And now Enable are saying, but you've been approved for my aged care package. So you're sort of in exceptional circumstances now…There will be people that couldn't find their way around it…But now we're sort of discussing around a new cushion…and so which if it comes to it, I can afford to buy a new cushion for $400, you know…but that comes out of the money that I've got stashed away in case I need it for top up personal care…that's sort of how I'm planning. The aged care package won't be enough and I'll probably have to pay for, I don't know, one shift a week or two shifts a week out of my own, or die or something.

Advocating for those who cannot access equipment through aged care

A person living in a nursing home is advocating on behalf of a fellow resident to obtain a new wheelchair from their HCP:

I'm working with a lady here, she's got MS [multiple sclerosis], trying to get funding for her power wheelchair. There's nothing. And I've got to call up shortly and find out what the quote is for an electronic chair. It looks like it'll be close to $30,000…And we can't seem to get anything out of the government. I'm even…writing direct to the Prime Minister and getting really savage about it. Probably go to the press. This is what the government doesn't do for you.

For this lady I've done 33 requests for funding from different organisations. MyAgedCare, nope, not interested. I went to [a disability organisation], they have a $5000 grant, but that was already used so we can't help you. We've had…these philanthropists, can't get a thing. And [another disability organisation], you give them all the gear, all they have to do is read it and write, you know advocacy. I went to Canberra and they said, 'Oh, that's all done by our central office'. 'Well, will you send it to your central office'. 'We have'. 'Well have you done any follow up?'. 'No'…I don't know whether they don't think they're gonna get success or if it's also downright rude that you don't follow up. How can I continue planning if I don't get feedback? We've only had one letter back from the Minister…[and they] said, your last resort may be a grant in aid. And if the Treasurer says No, it's all over bar the shouting.

I've been working with this lady for…probably about February…The first chance she had some surplus out of her Commonwealth Home Care Package, she asked for it to be used…but then there was such a rush between her getting in from home into this nursing home that the OT designed a chair that's about 2 inches short underneath her legs. The seat finishes a good four inches back from behind her knee. Gives her no stability…her feet are constantly falling off the footplates and nothing about putting on a foot strap or anything like that. It's a hell of a mess…and these people, these OTs, to do this lady's assessment, $193 an hour…The alternative is, she's already suffering bad fatigue and there's already situations where she has to go back to bed…flat out, they just took a folding frame chair and put an add on motor on it…It doesn't help the lady.

5 Other issues

There were several general trends that emerged from interviews, which will be discussed below.

5.1 Community attitudes

Interviewees were asked whether they thought community attitudes and behaviours toward people with disability had improved in recent years and what initiatives could further knowledge and awareness in the future. A lot of interviewees found that community awareness and real understanding of disability was still lacking:

[They]'ve all said it, 'people with disabilities should be seen, but rather not heard'. And that mantra really needs to disappear…I just can't believe we're in the year 2020 and yet people with disabilities are still fighting to be accepted into mainstream society…For ordinary people they just seem to be an unknown.

Another common observation was that the diversity of experiences of disability needs to be better understood as disability can affect every demographic of society. For several interviewees with SCI who are, or have been able, to walk in public, they found that those around them failed to understand their situation: "**They will think you're normal and that you're going to get 'better'…It's quite frustrating to explain and explain again. It's annoying people just don't get spinal cord injuries unless you're in a wheelchair.**". As another interviewee described, "**There's so many different types. And it's just a different normal**". One interviewee noted that even though people with disability are a minority, "**It's not, it shouldn't be a separate thing. We're not special, we're just not like everyone else…[We're] just part of the community**".

For several interviewees they felt that their experience as a person with disability, or their family member's experience, varied as on an individual basis they had encountered respect and assistance from people, but it depended on the "**outlook of the person themselves**". Instead, they felt the issue remained at a wider systemic level: "**Individually people are kind. But as a community we kind of don't, we kind of ignore it**".

Many interviewees acknowledged the challenge of universally changing attitudes and behaviours, but the majority supported different strategies and programs that could improve community awareness and inclusivity to foster respect and understanding. These included:

- Education and staff training (particularly in schools);
- Promoting positive and inclusive language around disability;
- Media representation;
- Integration in schools and other institutions;
- Visibility in local communities by promoting accessibility;
- Public awareness campaigns; and
- Staff quotas for people with disability.

The majority of interviewees specifically supported increased media representation of people with disability: "**If there was more on TV, so we saw more commentators with disabilities, more actors with disabilities, more normalisation of people living their lives**". Some cited the example of the Paralympics as promoting awareness of disability. Two interviewees specifically identified the benefit of having actors with disability appearing on Australian soap operas.

One interviewee felt that the impact on young people of understanding disability could be a powerful strategy to normalise disability:

When a child is confronted with something from a very young age, it's normal to them, they don't find it weird. My niece, she's seen me in a wheelchair, so she doesn't find being in a wheelchair any different, she doesn't treat me any different. In her school, they had to bring something that [represented] one change that they want to embrace. So she brought a Barbie doll in a wheelchair because she thought that's the change she wants to see…That little girl…recognises that disability is not accepted, and she wants that to be accepted. Because she has seen me…I found that so deep.

5.2   Engaging with people with disability

The majority of interviewees were keen to engage further in the development of policies and programs that affect people with disability.

The consensus among interviewees was that engagement is best conducted face to face and through active listening to people with disability and their carers to better understand their specific needs: "**I think the more you talk to people in that situation, like myself and families, and the less bureaucracy you have involved the better. Because otherwise you've got people looking at, 'What can we afford, how are we going to do this?'. Things tend to just roll over and not get done**". Consultation must be conducted with people who are "**dealing with disability on a day-to-day basis**".

Numerous interviewees believed that disabled peoples' organisations, like SCIA, best serve their advocacy interests, particularly when they engage their members regularly. Some interviewees suggested that these organisations allow them to provide input, but without the demands of being on a reference group or making individual submissions to government consultations. Others were a little concerned that disability organisations could be stuck in their own "**echo chamber**", or that representation within organisations was decreasing. Additionally, some felt that it was important to ensure the 'disability voice' was positive: "**It tends to be competitive misery while trying to compete to show that our misery is worse than every other disability. And it would be good to show positiveness than just negativeness, saying 'Look at what we've achieved'**".

As to method of engagement, some interviewees preferred surveys and online engagement forums (which must be accessible for all people with disability through Easy Read English and spoken word documents), in person public consultations, and active outreach via stakeholders in the disability sector. One interviewee from a rural area noted the importance of engaging with people with disability in rural and regional areas and suggested that this could be facilitated through video conferencing.

An interviewee also emphasised the importance of ensuring that any government programs or policies need to involve accountability to people with disability:

There needs to be targets that are monitored…and there needs to be sanctions when those targets are not met. So they need to be policed. There needs to be consequences for those targets not being met, regardless of what the targets are…[As an example:] They had to get a report, so they paid someone to do it. And then it sat on someone's shelf and no one probably even looked at. And yet it had all sorts of actions and targets and target dates and all that sort of stuff in there, but nothing. Because no one is going to say, 'Well, here are the things you said you'd do, why haven't you done them?'.

5.3   Impact of the COVID-19 pandemic

The COVID-19 pandemic influenced many interviewees and their family members as well as others in their wider network in many ways. For interviewees with newly acquired injuries, border closures often presented barriers to family members visiting them following urgent hospital admissions.

For NDIS participants, of the 12 individuals with a plan or with a family member with a plan, only one was contacted by the NDIA to "ensure they [had] the essential support they [required]". In their June 2020 Quarterly Report the NDIA stated that by the end of July they had contacted 17% of Scheme participants.[15] Everyone with a plan was contacted by their care agency to provide updates on COVID protocols, provide PPE and notify participants of any changes to their plans (i.e. increases in hourly rates).

One interviewee compared how the lockdown experience was similar to their experience post-injury, however they emphasised that people with disability not only experience the psychological pressures associated with lockdowns and quarantining, but they also face physical barriers due to their disability, accessibility and housing problems. This interviewee also noted that other people failed to recognise the increased vulnerability of people with disability in different environments, including the workplace: "**My immune system is compromised…they were supposed to be wiping everything down. I watched them and there was no social distancing**".

5.4   Specific issues

5.4.1   Support workers

In the course of discussion with 4 interviewees, they raised their concerns about the current quality of available support workers and paid carers. The pressure on the carer pool among people with disability not receiving support through the NDIS has already been discussed. However, even for interviewees or their family members receiving supports through the NDIS, they encountered several difficulties engaging assistance from support workers.

A common comment among interviewees was that the role of support worker or carer involves not just completing specific tasks, but also providing friendship to people with disability and their families: "**You need to have that drive behind you that you really enjoy being there and being a friend as well as a carer…to make things in life a little bit nicer**". One interviewee distinguishes between the role of informal carers and support workers as being paid gives them a degree of independence to choose and switch clients as they wish. Another agreed that the field is too transient and staff turnover is high, which prevents workers and clients from building meaningful relationships: "**half of them, their heart's not in the job**". Additionally, the interviewee found finding support workers for early morning shifts was very difficult. Due to this, the interviewee still has to participate in the care of their family member.

Further, interviewees were concerned that most support workers had very little knowledge or understanding of the needs of people with disability, or they failed to listen to them. For some interviewees they could recount several instances in which support workers failed to turn up to shifts or inform clients that they were unavailable: "**'Cause it's casual and they work with [multiple] agencies…there's no accountability**".

5.4.2   Access to information

Across all topics of discussion, one of the primary barriers to successfully accessing supports was a lack of information or difficulty finding appropriate, relevant information to the person. As one interviewee put it, "**No one knocks at the door and says, 'Do you need this?'**". As such, many people have had to rely on their own initiative or their family members and carers to find further support.

For some interviewees with long established conditions, they found that the internet, social media groups and contact with peak disability organisations provided them with their main source of

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[15] National Disability Insurance Agency (NDIA), *NDIS Quarterly Report to disability ministers*, 30 June 2020, p. 5.

information. Though as one interviewee argued "**There's lots of information out there, whether that's relevant to one person or another…one size doesn't fit all…Sometimes it can be information overload**".

Generally, the onus is on the individual to be proactive to discover new supports. For some during their index hospitalisation, they received a lot of material, however on their return home they usually had to rely on their own skills to find assistance: "**The file [with information on living with disability] was this thick…I was so overwhelmed**". For carers too a lack of information early on can have a major impact on the transition home: "**Even small things, I've been caring for [a family member]…and someone said to me, 'Oh, are you getting the carer allowance?'. I was just like, 'I don't know what you're talking about'. You don't know what you don't know**".

The most widely used platform to gain information was online via Google, forums, social media, subscriptions to disability organisations' news feeds. Obviously, this requires a degree of computer literacy, which may create a barrier for many people. Additionally, some were critical of the ability to obtain accurate, relevant information online as a lot of material does not relate to Australia.

One interviewee was concerned that for some people who acquired their injury a long time ago may have lost contact with the 'network' and suggested that when people visit their spinal specialist "**every couple of years, that's a really good opportunity for them to be socially as well as physically reassessed**".

Ultimately, a lack of information can be very demoralising, particularly when a person with disability is struggling: "**We're still not sure, we're learning as we go, but we're running out of time. Because there's so much that can be done for [them]. But we have to figure it out as we go, it's like a…treasure hunt with no map**".

5.4.3   Acute care

In recounting their history of acquiring injuries and ongoing care at hospital, many interviewees provided feedback on the services they had received there. Four interviewees described experiences they had had with hospitals in NSW, including specialist hospitals, Prince of Wales and Royal North Shore. For one interviewee their index hospitalisation experience had been very efficient as they were directly transferred from a regional non-specialist hospital to a specialist hospital in Sydney, before undergoing decompression surgery, all within 24 hours of acquiring the injury.

Many interviewees had had similarly positive experiences at Royal North Shore hospital: receiving surgery early; getting early, useful advice on how to adjust using technology; and the use of more modern facilities at the hospital. Others felt that Prince of Wales Hospital was impacted by underfunding and older infrastructure: "**PoW is very old…I got moved rooms three times…The room I got put in v, it was hideous. They had a big hole in the roof, they were doing some renovations. Guys would come in at 8 o'clock in the morning…They shouldn't have put anybody in the room**". Many also complained that communication between hospitals and specialists was very poor as their medical records were stored in different locations. They suggested that this issue could be improved through the introduction of the federal government's My Health Record.

One interviewee reflected on the experience of their family member as they were not admitted to a specialist spinal unit following their injury, as they were under the age of 18 at the time. As the interviewee highlighted: "**[They were] the first [child]…with a spinal cord injury in [many] years. So therefore [they] were a bit of a dummy…because they didn't know a few bits and pieces on what to do**".

For one interviewee they were very disappointed to find the lack of knowledge of spinal care in hospital when attending for a non-spinal related operation. One staff member asked them to "**just lift yourself**".

6   Conclusion

The empirical evidence from this engagement project provides significant insight into the current experience of people with spinal and neurological conditions and their family members and carers across various demographic groups. It remains clear that the role of advocacy is vital to advance the interests of this group and ensure the removal of major barriers that exist within our communities. This concluding section will address the project's initial research questions and provide further insight into the need for advocacy by SCIA. It will also briefly identify possible gaps in this research and opportunities for future engagement with this group.

6.1   What are the basic demographics of individuals with spinal cord injury and other conditions, and their families and carers?

Based on the findings from this project, it is clear that the population of people with spinal and neurological conditions is very diverse. While those with SCI tend to be older, the range of other neurological conditions people experience spans across many other age brackets. Additionally, the geographic spread of people with spinal and neurological conditions is very wide, both across different states and territories and in different types of areas. Also, while the majority of respondents were SCIA members (which may be skewed simply due to the methods of dissemination to the organisation's existing contact list), almost 20% were either unsure of their membership status or were not members. This suggests that there may be further opportunities to conduct outreach to non-members to encourage their input in future advocacy work.

The comments from interviewees highlight that any advocacy project needs to consider and reflect the diversity of experiences of disability, whether the disability was acquired or congenital, different levels of functionality or mobility, whether an acquired disability is recent or historical, in addition to the specific demographics of the individual person.

6.2   What are the key themes or issues individuals in the study population raise in relation to advocacy and their other needs?

In light of the diversity of people's experiences it is unsurprising that there are also multiple issues that have been raised in the course of this study. All the proposed topics in the survey had at least some respondents ranking them within their top three and several respondents provided insight into other issues. Nevertheless, there is consensus that there should be more focus on: the NDIS; supports for over 65s; universal access to assistive technology and housing. Additionally, removing barriers for people with disability and promoting inclusivity can also be achieved through better community access, public transport, and employment opportunities. Generally, access to information and gaining adequate support to access the right services are major issues that cut across multiple areas. Also, improving community awareness and understanding about disability will further remove barriers and achieve better outcomes for people with disability in their day-to-day lives.

6.3   What are the expectations and measurable outcomes individuals in the study population wish SCIA to achieve and focus on in their advocacy and other work?

People provided multiple recommendations for outcomes that SCIA could work towards to improve outcomes for people with spinal and neurological conditions and their families and carers. Section 3.2.3 provides the most detailed outcomes framework as it relates to different topics, and most of

these outcomes were affirmed by interviewees. Some of these outcomes relate to the work of SCIA's Policy and Advocacy Team, but others relate to the work of other SCIA teams, including Peer and Family Support, Employment Services, NDIS Support and NeuroMoves. Most respondents and interviewees felt that SCIA's Policy and Advocacy Team serve an important function in providing people with spinal and neurological conditions the opportunity to engage with policy-makers and government generally. This expectation also involves not only effecting changes in policy, but also in holding government to account in their delivery, design and monitoring of disability support programs and strategies.

Beyond the specific outcomes identified in Section 3.2.3, the major expectation arising from the study is that SCIA continue to meaningfully engage with the group to better understand their ongoing and new needs as they arise.

6.4 Gaps and future research

While we did not seek information regarding other minority statuses in the survey, the opportunity still exists to obtain data on other priority groups among people with spinal and neurological conditions. These groups include, among others, Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, the LGBTQIA+ community and children and young people. The findings from the survey and interviews underrepresent this last group. Further research projects or partnership development could focus on engaging with these groups in order to better understand their specific needs and how SCIA can advocate for these. Additionally, while it was valuable to gain insights from some family members and carers, there was not a significant number and it would be beneficial to engage further with this group.

6.5 The significance of advocacy and partnerships

Many of the 136 respondents in this project emphasised the continuing difficulties for people with disability as they encounter barriers in receiving supports or fulfilling their needs and hopes. As some characterised it, removing barriers for people with disability is simply a matter of respecting and practically realising their dignity. This involves listening to people to better understand their specific needs, actively lobbying policy-makers and change-makers to ensure they achieve the outcomes people with disability set. Also, many emphasised the significance of advocacy and fostering partnerships between disabled people's organisations, people with disability and their family members and carers, disability and civil society stakeholders and others, to create meaningful change.

This engagement project also provided dozens of examples of people advocating for themselves and creating individual and systemic change: "**You have to be strong or you go under…if you don't fight for everything, you don't get it**". SCIA's role should be to support all people with spinal and neurological conditions and reach out to those who may not be able to advocate for themselves.

What about for those people who can't do it for themselves? Those that need help straight away and they need people to check on them.
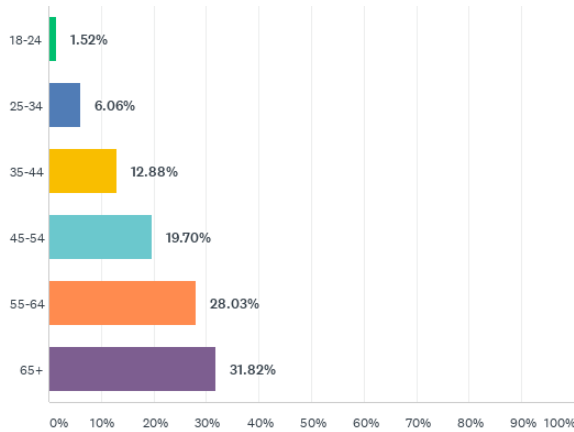
Appendices
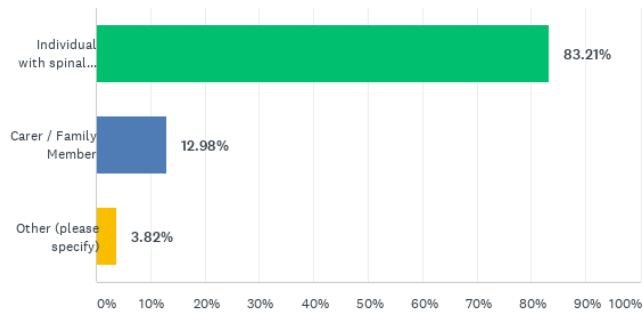
Appendix A: Demographics Summary

Gender distribution
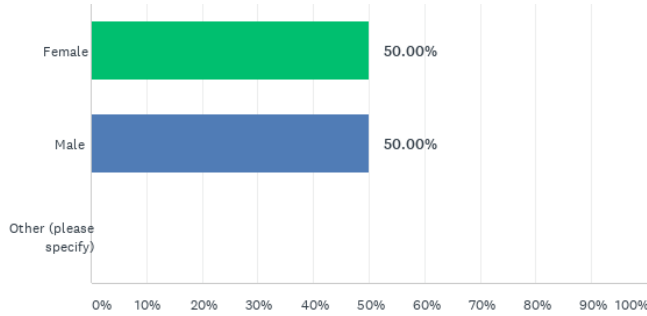
ANSWER CHOICES	RESPONSES	
Female	50.00%	67
Male	50.00%	67
Other (please specify)	0.00%	0
TOTAL		134

Age distribution

ANSWER CHOICES	RESPONSES	
18-24	1.52%	2
25-34	6.06%	8
35-44	12.88%	17
45-54	19.70%	26
55-64	28.03%	37
65+	31.82%	42
TOTAL		132

Circumstances of respondent
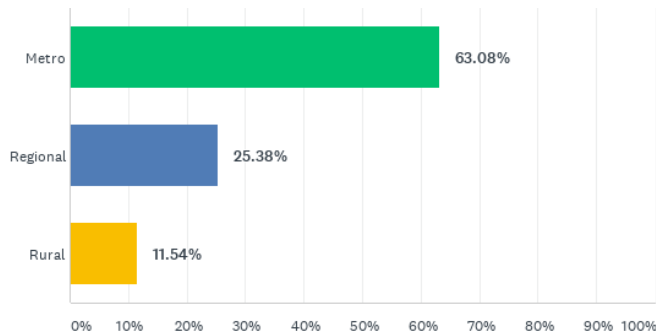

ANSWER CHOICES	RESPONSES	
Individual with spinal cord and/or neuro condition	83.21%	109
Carer / Family Member	12.98%	17
Other (please specify)	3.82%	5
TOTAL		131

Residence of respondents (state or territory)
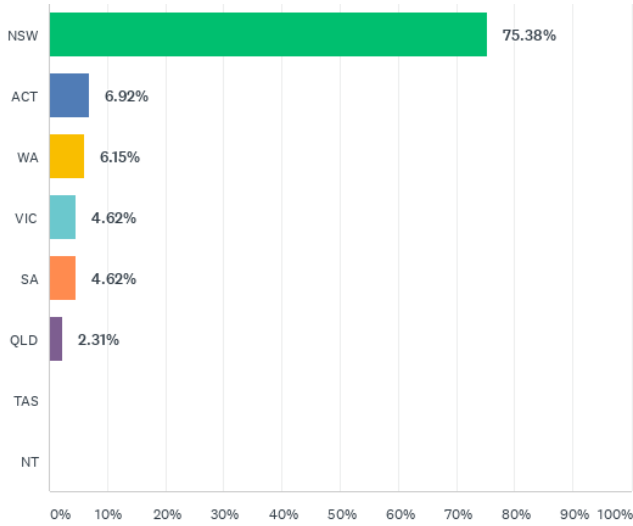
ANSWER CHOICES	RESPONSES	
NSW	75.38%	98
ACT	6.92%	9
WA	6.15%	8
VIC	4.62%	6
SA	4.62%	6
QLD	2.31%	3
TAS	0.00%	0
NT	0.00%	0
TOTAL		130

Residence (type of area)

ANSWER CHOICES	RESPONSES	
Metro	63.08%	82
Regional	25.38%	33
Rural	11.54%	15
TOTAL		130

SCIA membership
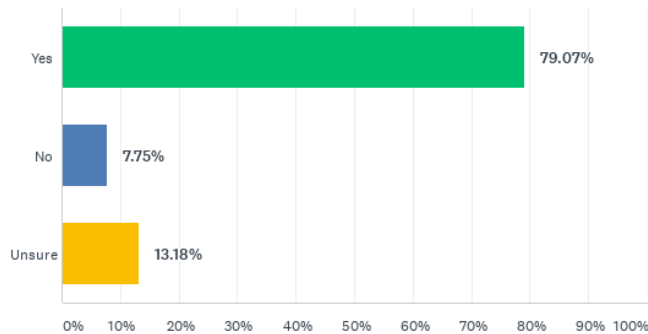
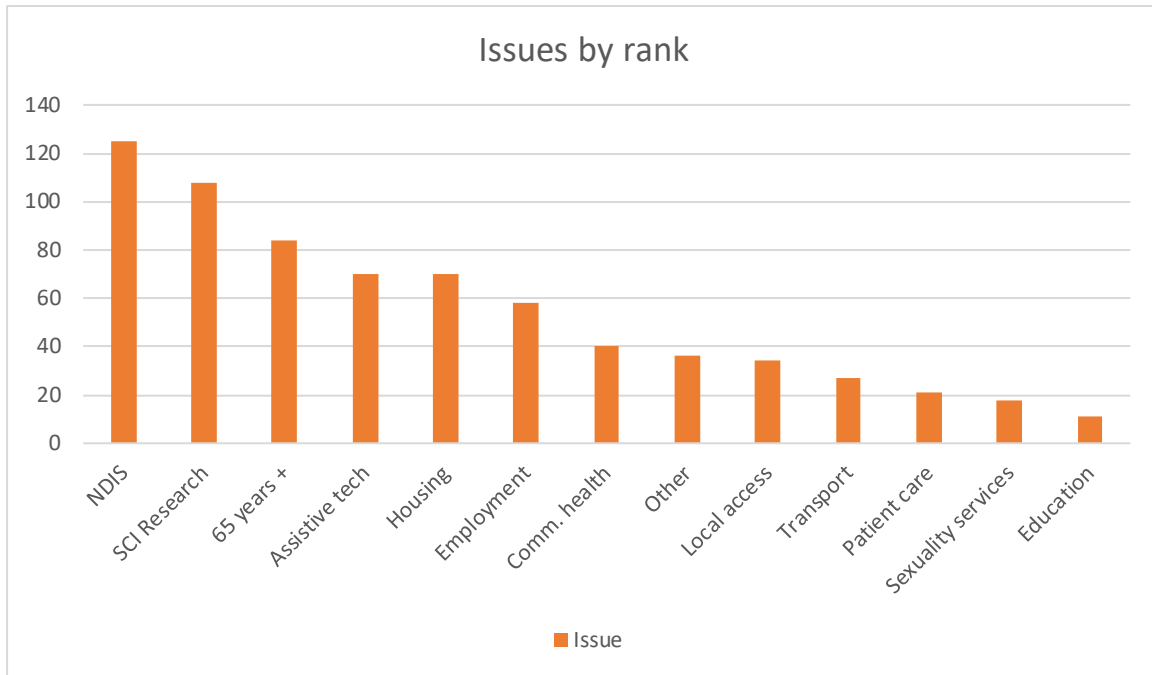| ANSWER CHOICES	RESPONSES	
Yes	79.07%	102
No	7.75%	10
Unsure	13.18%	17
TOTAL		129

Appendix B: Advocacy Issues Summary

Prevalence of issues respondents chose in their top 3
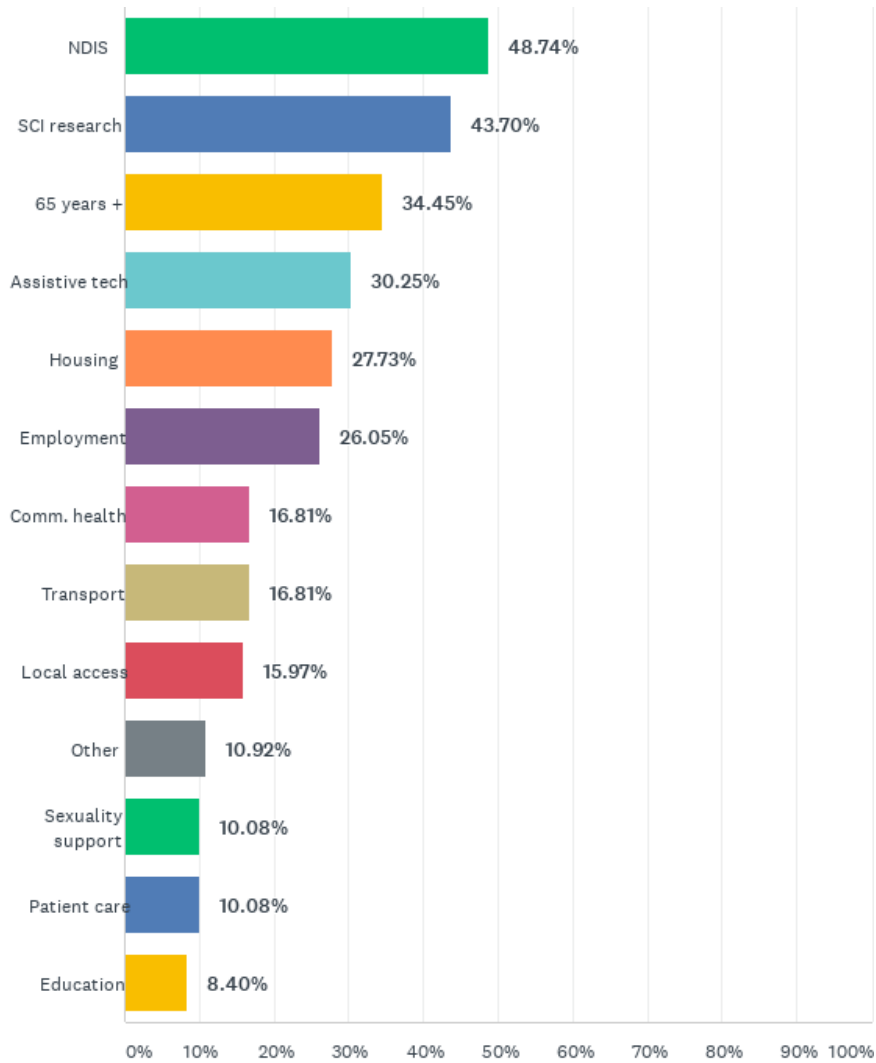
ANSWER CHOICES	RESPONSES	
NDIS	48.74%	58
SCI research	43.70%	52
65 years +	34.45%	41
Assistive tech	30.25%	36
Housing	27.73%	33
Employment	26.05%	31
Comm. health	16.81%	20
Transport	16.81%	20
Local access	15.97%	19
Other	10.92%	13
Sexuality support	10.08%	12
Patient care	10.08%	12
Education	8.40%	10
Total Respondents: 119		

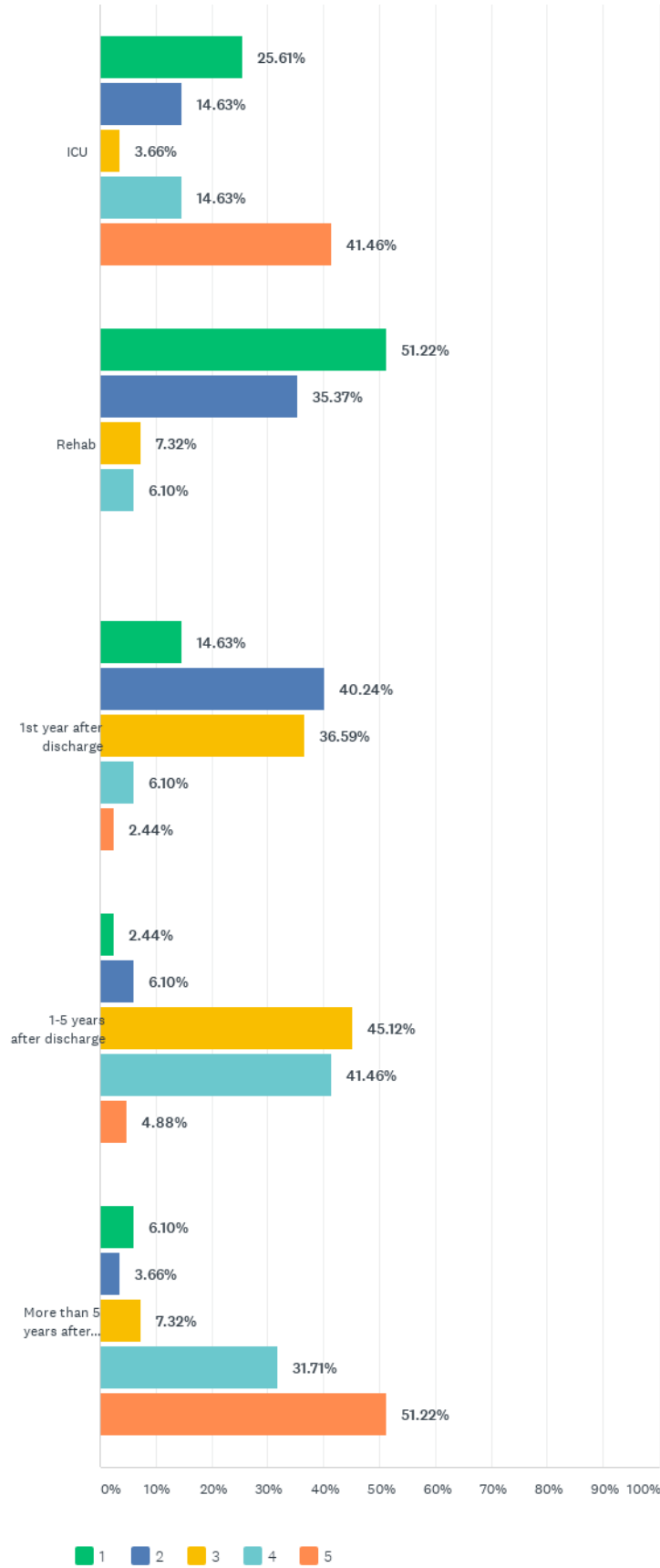*Scores for each issue after adjusting for ranking*

Issues by rank

Appendix C: Peer Support Summary

Who would be more useful to talk to when adjusting to life with an injury?
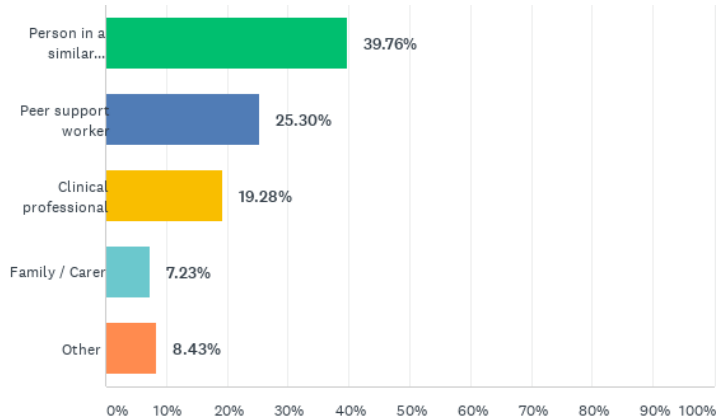
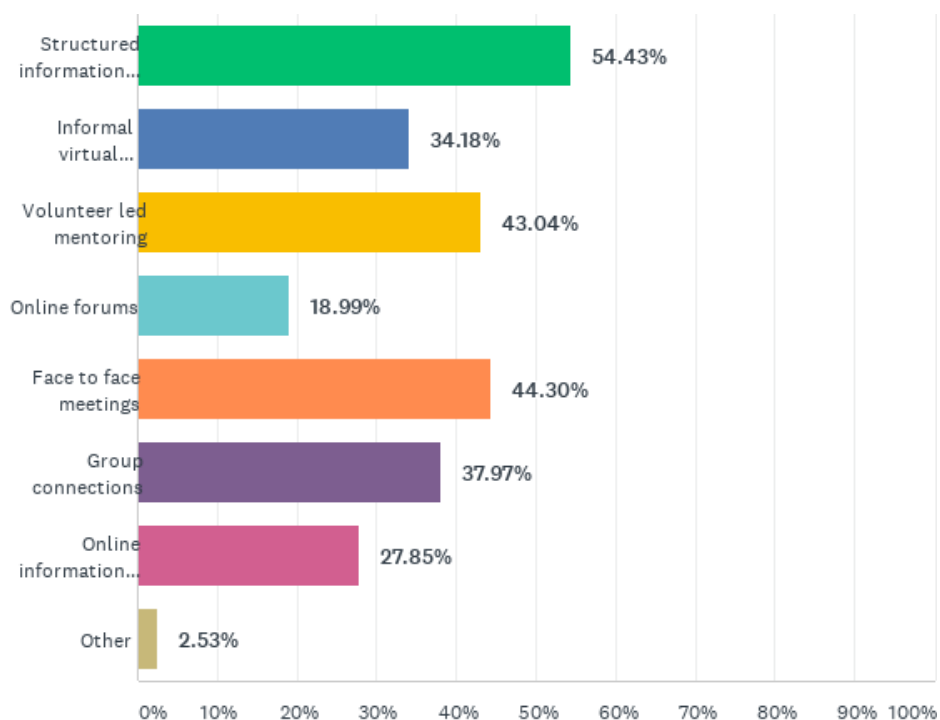| ANSWER CHOICES	RESPONSES	
Person in a similar circumstance (volunteer)	39.76%	33
Peer support worker	25.30%	21
Clinical professional	19.28%	16
Family / Carer	7.23%	6
Other	8.43%	7
TOTAL		83

At what stage do you think assistance and advice is most relevant? Rank preferences from 1-5.

Chart legend: 1, 2, 3, 4, 5

ICU
- 25.61% (1)
- 14.63% (2)
- 3.66% (3)
- 14.63% (4)
- 41.46% (5)

Rehab
- 51.22% (1)
- 35.37% (2)
- 7.32% (3)
- 6.10% (4)

1st year after discharge
- 14.63% (1)
- 40.24% (2)
- 36.59% (3)
- 6.10% (4)
- 2.44% (5)

1-5 years after discharge
- 2.44% (1)
- 6.10% (2)
- 45.12% (3)
- 41.46% (4)
- 4.88% (5)

More than 5 years after…
- 6.10% (1)
- 3.66% (2)
- 7.32% (3)
- 31.71% (4)
- 51.22% (5)

	1	2	3	4	5	TOTAL	SCORE
ICU	25.61% 21	14.63% 12	3.66% 3	14.63% 12	41.46% 34	82	2.68
Rehab	51.22% 42	35.37% 29	7.32% 6	6.10% 5	0.00% 0	82	4.32
1st year after discharge	14.63% 12	40.24% 33	36.59% 30	6.10% 5	2.44% 2	82	3.59
1-5 years after discharge	2.44% 2	6.10% 5	45.12% 37	41.46% 34	4.88% 4	82	2.60
More than 5 years after discharge	6.10% 5	3.66% 3	7.32% 6	31.71% 26	51.22% 42	82	1.82

How would you like to receive information and advice?

ANSWER CHOICES	RESPONSES	
Structured information sessions	54.43%	43
Informal virtual conversations	34.18%	27
Volunteer led mentoring	43.04%	34
Online forums	18.99%	15
Face to face meetings	44.30%	35
Group connections	37.97%	30
Online information search	27.85%	22
Other	2.53%	2
Total Respondents: 79		

Interest in participating in future SCIA advocacy work
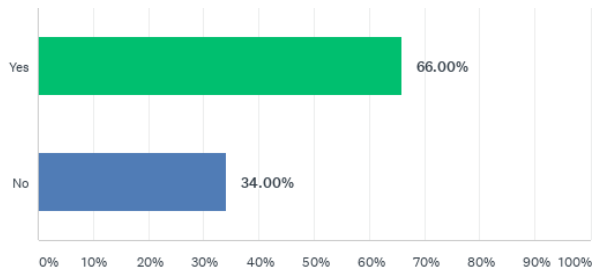
ANSWER CHOICES	RESPONSES	
Yes	66.00%	66
No	34.00%	34
TOTAL		100

Forms of future participation with SCIA
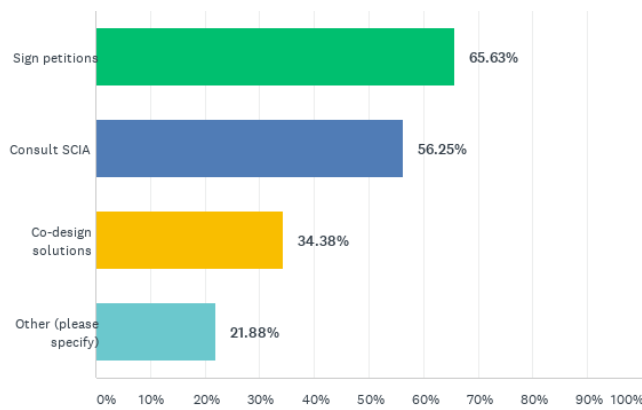
ANSWER CHOICES	RESPONSES	
Sign petitions	65.63%	42
Consult SCIA	56.25%	36
Co-design solutions	34.38%	22
Other (please specify)	21.88%	14
Total Respondents: 64		

Interest in participating in an interview
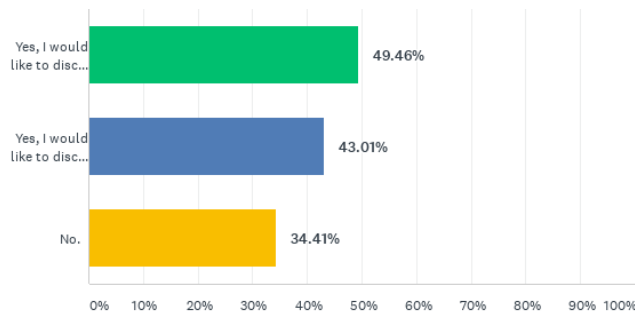
ANSWER CHOICES	RESPONSES	
Yes, I would like to discuss advocacy topics further.	49.46%	46
Yes, I would like to discuss community support further.	43.01%	40
No.	34.41%	32
Total Respondents: 93		

Note: The first option relates to discussion of advocacy issues and the second option relates to discussion of community support.