

SCIA Service Provider Survey Final Report

Policy and Advocacy Team

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1. Summary

SCIA's Service Provider Report provides valuable insight directly from people with spinal cord injury (SCI) and neurological conditions and their family members and caregivers into people's experiences with disability and aged care service providers. The data obtained from this anonymous survey will inform Spinal Cord Injuries Australia's (SCIA) advocacy work to address current barriers and challenges to accessing support.

SCIA undertook this survey because of the feedback from members about their experiences with service providers. On 10 May 2023, this topic was discussed at a Representative Advocacy Online Forum. The discussion was sparked by a member who wrote to SCIA's CEO about her own experiences with service providers and her experience working in the sector. In her correspondence, the member identified issues including limited availability of support staff, high turnover of staff, lack of flexibility, and limited choice and control in accessing timely support, as well as last-minute cancellations and leaving people with disability without care if a shift could not be covered. Other issues identified included poor communication about last-minute changes, not being consulted about changes, and service providers not following up on complaints.

The Service Provider Survey was emailed to 3,154 SCIA members, of which 2,289 are people with disability. Sixty-eight (68) people responded to the online survey.

The survey identified issues that resonated with previous findings in SCIA's Policy and Advocacy Engagement Project in 2020, the NDIS Independent Final Review Findings, and the Royal Commissions into Aged Care Quality and Safety and Violence, Abuse, Neglect and Exploitation of People with Disability.

2. Survey Objective

The objective of the survey was to actively engage with SCIA members, people with spinal cord injury and neurological conditions, their family members, and carers to better understand the barriers and challenges people with disability experience when accessing care from aged care and disability service providers.

To achieve the objective, several survey questions were asked, including basic demographics and other questions to identify the key themes, experiences, and issues that people were experiencing.

3. Methodology

The survey was designed with a combination of open-ended and closed questions. The survey included questions relating to demographics, information about support funding, types of supports, support hours utilized, and questions about respondents' experiences with service providers and support workers.

SCIA advertised the survey on its website and through various social media platforms. Members were also emailed directly and provided a link to the survey. The survey was readvertised and promoted twice in late December 2023 and early February 2024.

4. Survey Results

There were 68 responses to the survey, with a completion rate of 100%. Within the first month of the survey opening, 66% (44) responses were collected.

Of the survey respondents, 53 identified as people with disabilities, 16 as carers, guardians, or family members of people with disabilities, and some as both a person with disability and a carer for a person with disability.

4.1 Demographics

The survey recorded demographics on gender identification, age, and geographical area type, including which Australian State or Territory the respondents lived in.

The gender split across respondents included 57% identifying as female and 42% identifying as male. The age breakdown skewed toward older age brackets, with 56% of respondents aged over 55, 16% aged between 45- 54, 18% aged between 35- 44, 9% aged between 25- 34, and one person preferring not to say.

Regarding the geographical area people resided in, most responses (59%) were from people living in metropolitan areas. The responses from people living in regional and rural areas comprised 41%. In terms of which state or territory respondents lived in, the majority, 66%, identified as living in NSW, with 11% in Victoria and 23% evenly split across South Australia, ACT, Queensland, and Western Australia.

4.2 How did respondents feel about providing feedback and/or complaints to providers

Seventy Seven percent (77%) of respondents identified that they felt comfortable providing feedback to their service providers. The ones who affirmed they did not feel comfortable providing feedback generally believed that they:

- would experience negative repercussions that could impact their support needs,
- felt that service providers would not listen to them,
- did not have a trusting relationship with their support staff or the service provider's management and
- have had a negative experience when providing negative feedback in the past.

When asked if they had made an official complaint to their service provider, the response was evenly split among respondents, with 50% answering they did and 50% that they had never made a complaint to their service provider.

Only 39 respondents responded when asked if they were satisfied with the results of their complaint, with 26% identifying that they were satisfied with the outcome of their complaints. A further 31% identified that they were not happy with the outcome of their complaints. Of these, 23 respondents provided an outline of what they were dissatisfied with, with 57% stating that service providers did not act on the complaint or that after an investigation, nothing changed.

Three respondents stated that due to their circumstances, they were forced to change service providers. One respondent changed service providers because of the lack of action about their complaint. Another respondent stated that the service provider told them they were not allowed to contact the NDIS Commission to find out about NDIS rules when a participant questioned them about NDIS rules. The service provider then contacted the respondent's support coordinator, requesting a change of service provider on behalf of the client. When the client refused, the service provider stopped filling their shifts. Another respondent stated that even after contacting the NDIS Fraud Squad for overbilling, nothing changed, forcing the respondent to change service providers. This service provider is still operating and potentially still overbilling vulnerable people with disability. Respondents also identified that complaints took a long time to be finalised.

Issues with service provider management of complaints is supported by The Royal Commission into Aged Care Quality and Safety which identified that “people receiving aged care, their family members and their advocates have described the powerlessness, despair, anger and frustration that they have felt when confronted with providers’ resistance to feedback and complaints.”¹

One respondent stated ... “I really had to fight to get it to a higher level [of support] where they [My Aged Care] begrudgingly agreed. Clients should not have to fight like this for their rights.”

75-year-old female respondent living in Regional NSW

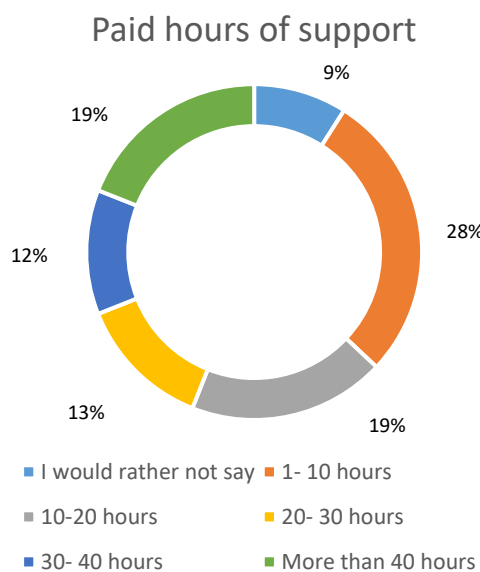
4.3 Support funding, management of support funding and access to disability supports

Respondents were asked about the type of funding they accessed. The majority of respondents (54) stated that they accessed support funding through the National Disability Insurance Scheme (NDIS). Eighteen (18) respondents stated that they received funding through the Department of Veterans Affairs (1), My Aged Care (7), iCare, or equivalent service (2) or that they funded their own supports (8). Five (5) respondents identified that they used other means of funding to pay for their supports. There was some crossover in accessing funding for disability support needs, with 77 responses provided by 68 respondents.

When asked how they managed their funds, the majority (53%) of respondents stated that they used a plan manager or an intermediary to manage their funding. Thirty five percent (35%) stated that they were self-managed, with a further 10% stating that their funds were agency managed.

Respondents were asked how they accessed their disability support services. One hundred and four (104) responses from 68 respondents were received, indicating that people with disability access more than one service provider to meet their support needs. The majority of respondents (52) stated that they accessed support through a disability service provider, 28 from sole traders, 17 from platform or intermediary providers, six (6) from other providers, and one (1) from an aged care provider.

4.4 Paid hours of support



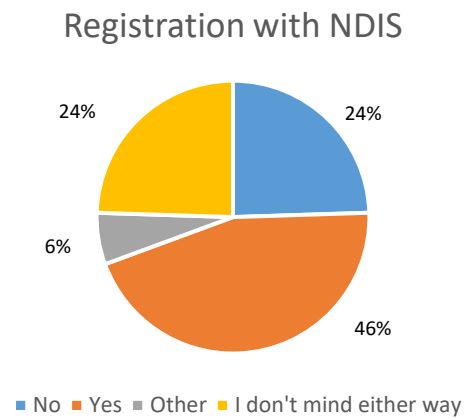
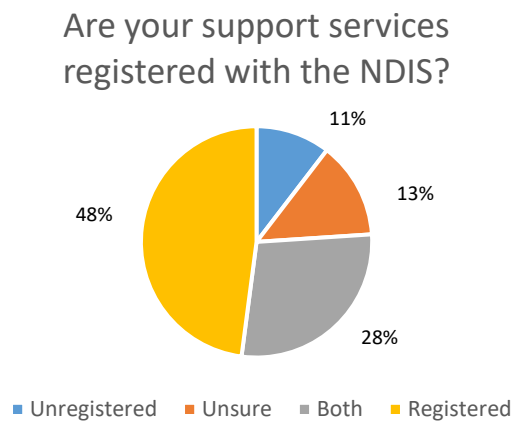
Graph 1 shows the number of paid support hours respondents accessed per week.

Of the 68 survey respondents, the majority, 47%, received under 20 hours of paid support per week. 25% identified that they received between 20 and 40 hours of paid support per week, and a further 9% stated that they received more than 40 hours of paid support per week.

¹ The Royal Commission into Aged Care Quality and Safety, A summary of the Final Report, page 135

4.5 Registration of providers

Respondents were asked if they used registered or unregistered providers and if they minded if their providers were registered or not. The following graphs provide respondent responses:




Graph 2: Support services registered with NDIS.

Graph 3: Support services registered.

Forty-eight percent (48%) of respondents identified that they used registered providers, with a further 28% stating that they used both registered and unregistered providers. Thirteen percent (13%) of respondents answered that they were unsure if their providers were registered or not. Only 11% of respondents stated that they used unregistered providers. When asked if being registered with the NDIS was important to them, 46% of respondents said they wanted their providers to be registered with the NDIS. 24% stated that it was not important to them if their service providers were registered, with a further 24% stating that they did not mind either way.

4.6 Types of supports respondents generally accessed on a regular basis

Type of support	Number of responses
Domestic assistance (e.g. cooking, cleaning)	48
Transport	28
Community participation	39
Personal care	40
Short term accommodation	7
Medical (e.g. capacity building, nursing, therapeutic support, physiotherapy, occupational therapy, speech pathology)	32
Supported independent living	4
Support coordination and/ or plan management	9
Work-based assistance	3
Other	5



On average, the 68 respondents who participated in the survey said that on a scale of 1- 10, they rated their overall experience with accessing support through service providers at 5.6.

Table 1: Total number of responses: 215 from 68 respondents

Respondents provided 215 responses to the types of support they accessed regularly. The top service type accessed was domestic assistance, followed by personal care, community participation, medical, and transport.

4.7 Issues respondents experience with their service providers

Type of issue	Very satisfied	Somewhat satisfied	Neither	Somewhat dissatisfied	Very dissatisfied
1. Interaction with a service coordinator	16	15	16	16	5
2. Kept informed about changes	15	13	11	17	12
3. Choice and control in support workers	14	12	15	15	12
4. Flexibility to adjust service times	14	23	13	11	7
5. Quality of support workers	14	22	8	15	9
6. Interaction with support workers	18	22	12	13	3
7. Service provider cancellation policies	8	13	20	8	19
8. General rapport and understanding by a service provider	12	24	12	7	13

Table 2: Respondents about how satisfied or dissatisfied they are with their service providers.

The majority of responses (255) from respondents identified that they were generally either very satisfied (111) or somewhat satisfied (144) with service providers across the 8 issue categories outlined above. A further 182 responses from respondents identified that they were either somewhat dissatisfied (102) or very dissatisfied (80) with service providers across the same categories. Eighty (80) respondents indicated that they were neither satisfied nor dissatisfied with their service providers across the identified categories.

The areas where clients were either somewhat or very satisfied included their interaction with service coordinators (1), flexibility to adjust service times (4), quality of support workers (5), interaction with support workers (6), and general rapport and understanding by service providers (8). One area where respondents were somewhat dissatisfied or very dissatisfied was issue number 7, service provider cancellation policies. Otherwise, it was a 50/50 split across categories 2 and 3, where service providers kept information about changes and the offer of choice and control in support workers.

When asked if they experienced challenges when connecting with disability service providers, 64% stated that they did. Thirty four percent (34%) of respondents identified that they had complete choice and control over their support services, and a further 53% of respondents identified that they felt they had control over their supports.

Respondents also stated they had to go to multiple service providers because of the lack of staffing. Another respondent told us that she felt threatened, abused, and ignored by two support workers and had to ask her husband and a friend for support to manage the situation. This resulted in changing service providers and disengaging with the support workers. She added that it took her a lot of courage to change providers. Another respondent stated that their service provider did not follow up on a case of physical abuse.

One respondent told us that their service provider..." ...didn't meet my needs, stipulated what times shifts times I would have, stipulated how I can and can't use my funding, [and they] didn't have the enough qualified or suitable staff."

Female respondent living in Metropolitan Area

Many respondents stated that short-term cancellations, staff not turning up on time or at all to shifts, and the inability of service providers to replace the workers meant they had to rely heavily on informal supports. Another respondent added that when this happened to him, there was no way to directly contact the service provider to tell them that the support worker had not turned up and that a

replacement worker was required. He stated that this situation required multiple follow-up phone calls to get through to the service provider.

Another respondent stated that it is very difficult to find providers willing to work in rural areas; often, the provider would tell clients that they can provide support workers for them, only to contact them at the last minute to tell them that they cannot help them. Respondents stated that often, office staff and coordinators lacked experience, did not understand the concept of choice and control or the need for flexibility, did not answer phone calls or emails, made mistakes with rostering, and were unwilling to find reliable new staff that met participant needs.

People over 65 who are not receiving NDIS services stated that the Home Care Packages offered by Aged Care Services do not adequately meet their support needs. A person with a disability in the ACT said that the person he cared for has My Aged Care funding and when they approached ten agencies in their area for support; they all declined, stating they were trained to provide aged care, not disability care.

One respondent said that many times service providers tell her they have plenty of suitable people who are fully trained. However, invariably, they don't have staff, they cannot fill the shifts requested, and when they did send support workers, she found them inappropriate and useless at home. The theme of not being able to replace support workers or getting support workers who were not fully trained was echoed by several other respondents.

“The first question they ask is, “are you with the NDIS?” Not what support do I need, what is my disability and when do I require support.”

Male respondent from ACT

Staff shortages are a real issue in the aged care and disability sectors. This is supported and echoed by previous work by the SCIA Policy and Advocacy team in SCIA's Policy and Advocacy Engagement Project², which identified issues with staff training in the NDIS, better awareness and disability expertise amongst aged care providers and their staff as well as complaints about the lack of support workers available. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with disability identified “storages of disability workers across Australia and that recruiting and retaining a suitably skilled workforce continues to be a significant challenge for service provider organisations”³ across Australia.

The NDIS Review Findings Final Report states that 17-25% of the NDIS workforce leaves the sector each year.⁴ The Royal Commission into Aged Care Quality and Safety final report identified that in in-home care, one-third of consumers stated that staff in the sector were not adequately trained. That there was no continuity of staff and that there were high rates of staff turnover. Further, in residential aged care, there were concerns about understaffing, high rates of staff turnover, and agency staff not knowing consumer care needs. In the respite care and Commonwealth Home Support Program, about 30% of consumers were concerned about staff, including understaffing, training continuity, and communication issues.⁵

² SCIA Policy and Advocacy Engagement project Final Report, December 2020, page 8-9

³ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Executive Summary, Our Visions for an inclusive Australia and Recommendations, Final Report, page 160.

⁴ Working together to deliver the NDIS, NDIS Review Findings Final Report, page 193.

⁵ Royal Commission into Aged Care Quality and Safety, final report, page 72.

4.8 Choice and control over support services

When respondents were asked if they felt they had choice and control over their support services, 37% told us that they had complete choice and control, 52% told us that they felt they had some choice and control, and nine percent (9%) felt they had no control over their support needs. Some people added that when they started to self-manage and/ or use sole traders, they felt they could finally exercise choice and control in their service provision.

Respondents felt they had no or only some choice or control because service providers did not consult with them about support workers they sent to assist them; they could not manage the high staff turnover and staff cancelling shifts at the last minute. Other issues included changes to schedules and staff made without being informed. Respondents also identified that they experienced that there were not enough staff available, affecting the times they could receive support. One respondent stated that the support workers that were sent to him did not have knowledge of what their care plan entailed.

When asked if they believed that their support staff had adequate training on their specific support needs, 38% of respondents indicated that support staff were not adequately trained, with a further 41% stating that their support workers were well trained to meet their needs. When asked if they thought their support staff adhered to their support plan and preferences, most respondents, 69%, told us that their support workers adhered to their support plan most of the time (46%) or all the time (23%). A further 23% stated that only some support staff adhered to their plan and preference, and 3% stated that their support workers did not adhere to their support plan.

At hearings, The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability identifies "... failures by disability service providers to give clients choice and control over important aspects of the services they received. These included their personal care, their daily activities, and the contents of their service agreements."⁶

4.9 Instances of unprofessional behaviour from staff

Respondents were split 50/50 (49% - no and 49%- yes) when asked if they had experienced incidents where they believed support staff acted unprofessionally while supporting them.

Respondents stated that they had witnessed unprofessional behaviour, including staff arguing with each other, not following care plans, bullying participants, not understanding boundaries, not dressing appropriately for work, going through people's private papers and other confidentiality breaches, conducting their own person business whilst caring for the client, not including the person with disability in conversation, walking out on service, turning up late or not at all, being argumentative, constantly talking on mobile whilst caring for the person with disability, vaping in the car, stealing from clients, speaking about other participants in front of a client, swearing, being disrespectful, physically abusing clients and not listening to instructions causing injury.

One female respondent reported inappropriate, belittling behaviour, coercive control, sexual innuendos, and inappropriate touching. Respondents identified that support workers across the sector lacked training and experience, causing, at times, physical injuries and, in some cases, not being able to operate simple equipment safely. Support workers lacked first aid and other basic training, and generally a lack of experience in working with people with SCI.

⁶ The Royal Commission into Violence, Abuse, neglect and Exploitation of People with Disability, Executive Summary, Our Visions for an inclusive Australia and Recommendations, page 157

“[Support worker] constantly on the phone whilst supporting me. Turning up late or not at all.”

Female respondent from South Australia

A respondent stated that a support worker left her in the sun on a very hot day. The respondent said she called the support worker, but she could not hear her because she had fallen asleep. On another occasion, a support worker told the client that the service provider was so short-staffed that in the middle of the shift, she had to leave her to put another client into bed and then come back to her to finish her shift. This continued for weeks until the client found out that the support worker was being paid for both shifts and was doing the same thing to the other client.

A person over 75 years with a disability told us that she was being treated like “[her] brain does not work” and that she expected too much from the service.

A female respondent from Regional NSW

Another respondent stated that an Occupational Therapist suggested unsafe practices in her home and ordered expensive and useless assistive technology that the respondent was not able to use and that they had to wait for an Occupational Therapist report for several weeks to enable access to important/ urgent support. In one incident, the participant told us that the therapist did not supervise her adequately, resulting in an injury, and subsequently, she could not get out of bed for days to clean or feed herself. Therapists are charging as much as \$200 per hour, and in one case, the Physiotherapist was always late and often finished ahead of time. Another respondent stated that her plan manager took eight weeks to process payments on several instances.

A respondent stated that support planners were also untrained in supporting people with disability.

4.10 Feeling unsafe whilst being supported by support workers

Respondents were asked if they felt unsafe whilst being supported by support workers. Sixty percent (60%) stated that they felt safe, and a further 38% said they did not feel safe.

Respondents identified that, at times, they felt uncomfortable with some support workers. One respondent said she felt uncomfortable in a car with a support worker who could not drive well. Examples given included not having experience in using equipment, hoists, electronic and manual wheelchairs and breaks being left off wheelchairs, doing transfers resulting in fall risks, not knowing what to do in a medical emergency, lack of understanding of geriatric SCI, not being in attendance when taking people out into the community resulting in one case a serious injury.

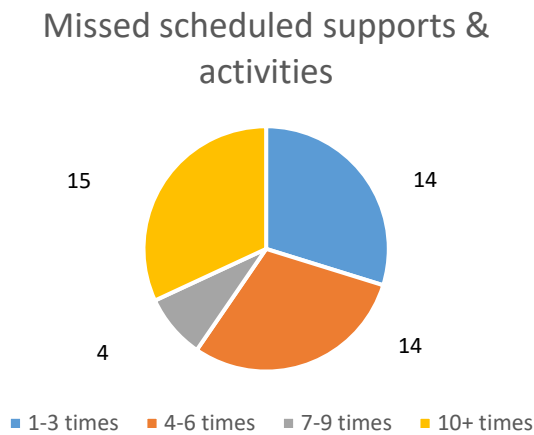
One respondent shared that her support worker stumbled over her flip-flop while pushing her in a manual wheelchair. This caused her to fall out of her chair, rendering her unconscious with a broken shoulder. Adding to the distress, the support worker, who hadn't been in Australia for long, didn't know how to call an ambulance for her. When the respondent regained consciousness, it was due to her daughter's call, that her daughter ended up calling an ambulance. These incidents highlight the challenges posed when support workers lack proficiency in English. Another respondent recounted breaking their jaw after being left unattended on top of a driveway. His support worker forgot to activate the brakes on his wheelchair.

“I was left by a support worker at a local park to walk home on my own. I have a brain tumor and walk on a stick. I was very scared.”

Female respondent from Western Australia

Missing medication and not having a general understanding of medical and disability specific issues are two other safety issues that respondents identified.

4.11 Missed scheduled supports and activities



Graph 4: Missed scheduled supports and activities.

Sixty nine percent (69%) of respondents identified that they missed out on scheduled supports due to staff cancelling their shift with little or no notice.

Graph 4: Shows a breakdown of the number of times respondents missed out on scheduled supports or activities in a 12-month period. These figures correspond with findings in the Aged Care Royal Commission and the NDIS Review findings regarding staff shortages and issues with service providers being able to replace staff.

4.11 Additional information provided by respondents

Forty-five (45) people provided additional information on various other topics or concerns.

A respondent stated that advocates were very important in advocating for the rights of people with disabilities and that advocacy needs secure funding to continue to support people with disability. This is further supported by the findings in the NDIS Review states that “individual disability advocacy plays a critical role in promoting, protecting and defending the human rights of people with disability” and that “there is approximately twice as much demand for advocacy in comparison to supply.”⁷

A carer stated that her experience with service providers was that support workers often canceled shifts and were often unsuitable to work with her son. Now that she has support workers that she employs herself, they rarely cancel shifts. Many respondents stated that since they started using sole traders, they only missed a few shifts per year and would never return to using a service provider again. One gentleman said that when he was with a service provider, they missed shifts at least once a fortnight. He wished he had moved to hiring his staff years ago. Many respondents stated that they prefer to either utilise sole traders through platforms or employ their own staff. One respondent said that she generally has a great team; she manages 11 staff she employed herself and manages her roster.

Another issue included service providers not having processes in place to manage late notifications when support workers are not able to attend a shift and then not being able to replace support workers to provide essential care. Respondents reported instances when they had to inform service providers that their staff did not turn up to a shift, and that service provider were not aware that their staff member was not coming into work that day. Respondents also identified high staff turnover and that service providers are informing them that they were having difficulties sourcing new support

⁷ Working together to deliver the NDIS, NDIS Review Findings Final Report, page 24.

workers. One person with a disability who lives in a metropolitan area in NSW said that he is finding it challenging to source support workers regularly.

Several respondents identified that support workers needed more training and a better understanding of spinal cord injuries and complex disability to deliver more consistent support for people with disability. This lack of disability training is even more evident in the aged care sector, and in other providers including support planners, physiotherapists and occupational therapists.

Respondents reported that service providers' fees were inconsistent. One NDIS participant told us that he changed providers and is now being charged \$700 instead of \$1,350 for the same service type.

5. Conclusion

The survey results show that respondents rated their experience with accessing support through service providers at an average of 5.6 out of 10, with significant issues relating to staffing across both aged care and the disability services sectors.

Respondents identified that the quality and availability of staffing was a major concern. This issue also resonates with previous findings in SCIA's Policy and Advocacy Engagement Project in 2021. One major concern identified by the survey included staff not turning up to shifts, with 22% of respondents reporting that they have missed scheduled supports more than 10 plus times in a 12-month period, placing responsibility onto their informal supports to fill these support gaps. These statistics are very concerning considering the complex support needs of this cohort. Staff shortages and service providers not being able to replace staff when shifts were canceled, leaving people with disability without care if a shift could not be covered, is a debilitating problem faced by people with complex physical disability. Service provider shift cancellation policies is another where many respondents were either somewhat dissatisfied or very dissatisfied about.

Staff turnover across the disability sector has been confirmed by the Royal Commission into Aged Care. The report identified in 2016 that staff shortages in both residential aged care facilities and across community care, with almost half of the home care providers reporting skilled staff shortages. The report predicts that by 2050 an additional 113,000 personal care workers will be needed, an 83% increase from 2020.⁸ The NDIS Review findings indicate that an additional 105,000 support workers will be needed by June 2025 to cover the support needs of people with a disability. The issue of staffing in the disability sector is further exasperated because 17-25% of the disability workforce leaves the sector annually.⁹

The quality of available support workers is an issue that is also very worrying, with many respondents identifying that support workers have very little knowledge or understanding of the support needs of people with SCI and other complex disabilities. This finding was confirmed by The Royal Commission into Aged Care Quality and Safety's final report, which identified that 33% of consumers identified that staff in the sector were not adequately trained to work with the elderly, (let alone with people with complex needs) and that staff turnover [in the sector] was very high.¹⁰

It is also concerning that 50% of respondents identified that they experienced incidents where they believed that support staff acted unprofessionally whilst supporting them.

⁸ Royal Commission into Aged Care Quality and Safety, final report, pages 374, 375.

⁹ Working together to deliver the NDIS, NDIS Review Findings Final Report, page 193.

¹⁰ Royal Commission into Aged Care Quality and Safety, final report, page 72.

The majority of SCIA Survey respondents (88%) either self-managed (35%) or used a plan manager or an intermediary to manage their funding (53%). Respondents on self-managed supports told us that since they employed their own staff, many of their previous staffing issues had ceased, and they would never go back to using a service provider again. Having the ability to self-manage or use an intermediary could also explain why respondents felt they had choice and control over their support services, with 89% stating that they (37%) had complete or some (52%) choice and control over their supports.

It's encouraging to note that 77% of respondents expressed feeling comfortable providing feedback to their service providers. However, only 50% indicated having lodged an official complaint with their service provider, while an additional 50% stated they had never filed a complaint. Thirty-one percent (31%) of the 39 respondents who provided feedback in this section of the survey identified that they were not happy with the outcome of their complaints, stating that providers did not act on their complaints and when they did nothing changed.

Respondents said that they did not want to make complaints because they worried about negative repercussions that could impact on their service provision. Other respondents stated that they had negative experiences when complaining in the past, and others felt that they did not have a trusting relationship with their service provider's staff. When respondents were asked if they experienced challenges when connecting with disability service providers, 64% stated that they did.

When asked if registration was important to them, 46% of respondents identified that it was, however a further 48% stated that it was not important to them (24%) or that they (24%) did not mind either way.

The other issue identified was inconsistency in the fees that service providers charged for the same service type with respondents having to "shop around" to get best value for money.

The Policy and Advocacy team values the contribution of members and the SCI and Neuro community in this survey and intends to use the information provided to address the barriers and challenges identified. SCIA will utilise the information provided to write an advocacy briefing on how the aged care and disability sectors can improve the care being provided to people with spinal cord injury and neurological conditions. This report will be shared with respondents, posted on the SCIA website, used in submissions for NDIS and Aged Care reform responses and shared with other agencies as appropriate.