



Spinal
Injuries
Ireland
Support at every stage



2019
2023



SPINAL NEWS SPECIAL EDITION STRATEGIC PLAN

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Thank you to all our service users and family members for participating in the 2018 research. Your input has been invaluable in directing the strategy 2019-2023

Further thanks to our donors, sponsors, volunteers and contributors who have continued to support SII as we have grown and developed our services since our charity was founded. With your help, we look forward to seeing what we can do together as a community in the coming years.

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INTRODUCTION BY THE CHAIRMAN & CEO OF SPINAL INJURIES IRELAND

In 2018, we reached a new milestone, the celebration of 25 years of Spinal Injuries Ireland, marking this with a move to a dedicated new headquarters in Dun Laoghaire.

This offers the organisation the ideal platform from which we can tailor our services to provide the best support pathway to people with a spinal cord injury and their families. We are extremely grateful to Minister Finian McGrath and the HSE for assisting us in facilitating this move.

Since 1993 Spinal Injuries Ireland has grown from its original remit as a resource and information service with one staff member providing an outreach service to today where we provide a pathway of care for as long as our service users need us with a team of ten support workers.

This is against a back drop of no additional state funding despite increasing services which puts increasing pressure on the organisation to raise in excess of €600,000 annually. Over the next 4 years we need to build this funding capacity sustainably and this is the greatest challenge that the organisation faces.



Over the last 4-year strategic period the organisation has reached out to as many stakeholders as possible through **'This is my Life'** roadshow in 2016 and the first spinal cord injury, national conference **'My Life and Wellbeing'** sponsored by Coloplast in April 2018. These additional service elements would not be possible without the support of our corporate partners.



Spinal Injuries Ireland has also championed the cause for guaranteed medical cards for people with a SCI. To date this has not been achieved but it is a fight we will continue for the next strategic period in the hope that it will be achieved by 2023.

We operate in an ever changing and stringent regulatory environment which is very onerous on a small charity with limited administrative resources. We would like to thank our Operations Manager and two volunteers who ensured we are compliant with the Governance Code. This is a major achievement for a small charity as we are one of just over 500 charities in the country that has achieved compliance.

We work in partnership with Dr Eimear Smith and the Spinal programme in the NRH. We would like to thank Dr Smith for sharing her findings with SII, Prospective Epidemiological Update on traumatic spinal cord injury (2018). These findings in conjunction with the service user study undertaken by Dr Padraig MacNeela (NUIG 2018) informs the direction of the organisation for the next four-year period.

We, with the Board of Directors and staff, look forward to continuing to work in collaboration with the HSE, NRH & all partner service agencies that we signpost to and to all our private and corporate donors who support the work we do financially. If we continue to collaborate we can achieve the best outcomes for people with SCI in Ireland.

John Twomey
Chairman

Fiona Bolger
CEO

RESEARCH: DR EIMEAR SMITH, NRH

Until recently, there had only been one previous study on the epidemiology of spinal cord injury (SCI) in Ireland. Epidemiology describes the causes of injury (or any health condition), who it affects and the types of injury that occur. The previous study examined the number of cases of traumatic SCI admitted to the National Rehabilitation Hospital in 2000. That year, there were 46 cases or 13 per million population, half of which were due to road crashes; average age of injury was around 37 years. It has been the opinion of healthcare professionals working in SCI that the epidemiology has changed in recent years, so an extensive review of this topic was carried out during 2016 and 2017. Two studies, one retrospective and one prospective were done on traumatic SCI and one on non-traumatic SCI. SCI in children was also reviewed.

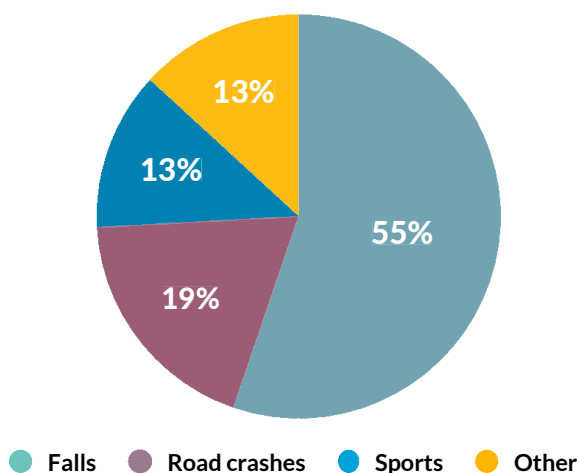
Between 2010 and 2016, the number of new cases of traumatic SCI was quite consistent, from a lowest number of 53 in 2014 to a high of 61 in 2013 and again in 2016; per million population, this equated to a range between 11.5 and 12.8, one of the lowest incidences in the developed world. Males remain in the majority, 72.1% of injured persons. There are more older people sustaining traumatic SCI and as a result, the mean age at onset is steadily rising as is evident from the table below.

The most common cause of injury is falls as can be seen in the pie chart. Coincident with this change in age profile and cause of injury, the patterns of injury are also changing. Incomplete tetraplegia is now the commonest pattern of injury – this means an injury to the spinal cord in the neck, with partial but not total paralysis of most or all muscles in the body, usually accompanied by bladder & bowel difficulties.

Average age and age ranges of traumatic spinal cord injury onset

(Years)	2010	2011	2012	2013	2014	2015	2016
Average age	44.1	49.3	48.3	47.9	52.6	51.2	52.8
Age range	18 - 87	16 - 89	19 - 81	16 - 85	17 - 89	17 - 89	17 - 98

Causes of traumatic spinal cord injury in Ireland, 2010 - 2016





Non-traumatic SCI has never been studied in Ireland previously. During 2017, there were 128 new cases, which is an incidence per million population of 26.7, more than double that of traumatic SCI in any year. The number of older people who develop non-traumatic SCI is even greater than that of traumatic SCI, resulting in a higher average age of onset - this was 56.7 years with an age range of 17 to 87 years. The gender split is fairly equal, 50.8% of cases were female. Incomplete paraplegia was the most common pattern of injury, partial but not total paralysis of the lower limbs only, sometimes accompanied by bladder & bowel difficulties. Degenerate conditions of the spine were the most common cause (almost half) – an example might be a disc prolapse or arthritic changes in the vertebrae compressing the spinal cord. Tumours were the 2nd most common cause (26%), most of which were metastatic spinal cord compression or secondaries from cancer.

Finally, spinal cord injury in children is exceedingly rare. Between 2000 and 2015, the incidence per million population was 1.4 per million per year for traumatic SCI and 1.6 per million per year for non-traumatic SCI. This means that 1 or perhaps 2 children have a traumatic SCI and the same number, a non-traumatic SCI in Ireland each year. Road crashes were the most common cause of traumatic SCI and transverse myelitis (inflammation of the spinal cord) was the most common non-traumatic cause.

Thankfully, the majority of the injuries in children did not affect the upper limbs and the children with non-traumatic SCI, in particular, had a lot of recovery in the lower limbs.

There are many implications of these research findings in the adult population for Spinal Injuries Ireland. Higher numbers of people with newly acquired SCI means greater demand for the service provided by SII. With an older age profile, there is a need to provide peer support for this age group and possibly less demand on vocational and sports/leisure services. Some frail older people, or those with SCI due to cancer secondaries, might not be fit for an active rehabilitation programme in the NRH or may have a shorter life expectancy and opt to return closer to their families as soon as possible after the acute phase of care. This could pose difficulties for SII, trying to bridge the gap to patients who have not had specialist rehabilitation at the NRH, and therefore might not have been educated to a high level on issues such as bowel, skin and bladder care, and have had less exposure to appropriate equipment such as wheelchairs and assistive technology. In addition, it can be more difficult for an older person to achieve home discharge after a severe injury particularly if he/she lives alone. In this case, SII may have to play a bigger role in advocating for larger home care packages for older people or alternatively, might have to provide support and advocacy for older people as they settle into a new life in a nursing home.

Purpose of the research

The Spinal Injuries Ireland research was carried out to describe the profile, impact, and consequences of spinal cord injury for SII clients. The 2018 research gives an update on the findings from the last research conducted in 2014 by Dr Katrina Collins. The main sections in the survey component of our recent research were on living situation, personal independence, access and transport, finances and employment; perceptions, suggestions, and satisfaction with SII services; Social support, resilience, distress, and challenges. The survey was supported by interviews with family members to better acknowledge the needs and suggestions of supporters of people with SCI. The survey was designed and analysed by Dr Pádraig MacNeela, Senior Lecturer at the NUI Galway School of Psychology, who also carried out interviews with family members.

Main Findings

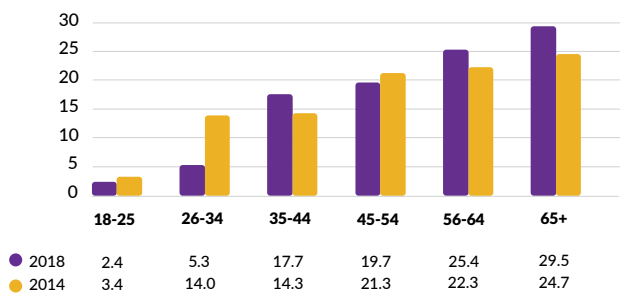
- Road traffic accidents and falls were the most commonly reported causes of spinal cord injury (24%) followed by a medical cause (23%) and sports injury (9%).
- Three-quarters have a medical card, and 38% of medical card holders say finances are a big challenge, compared with 16% of non-holders.
- Two-thirds of medical card holders said that the possibility of losing their medical card has a big impact on their outlook on employment.
- 40% of participants were concerned about employer attitudes to people with disabilities.
- Over 60% cited physical pain and 55% stated physical issues (e.g., bowel/bladder) were significant challenges.
- 50% of the participants received scores suggesting severe or moderate mental distress.
- 77% of clients with a mental health challenge also had stressful physical challenges with bladder and bowel control. People who had mental health issues as a major challenge were three times more likely to report finances or social life problems as a major challenge.
- 50% report sometimes/often experiencing social isolation from others.
- 44% say Spinal Injuries Ireland has made them a stronger person.
- Wheelchair users are less likely to report sadness some/most of the time (6% vs. 26% of unaided walkers), or that mental health was a big challenge (23% of wheelchair users vs. 38% of unaided walkers).
- Wheelchair users are less likely to be on/under poverty line (19% vs. 31% of unaided walkers), and more likely to have a medical card (80% vs. 69% of unaided walkers).
- In satisfaction ratings of SII services, information sources/resources were highly rated (e.g., magazine, website, social media, emails, conference, resource centre, community outreach officers)

Background of SII clients

There were 375 survey participants, 69% male and 31% female. This was similar to the 2014 survey, although in 2018 the research with SII clients was completed by survey (focus groups for family members), whereas face to face interviews were conducted in 2014. Over half (55%) were 55 years or older. The remaining clients were aged 35-54 (38%) or under 34 years (8%). Just over half (53%) were married, 36% were single, and the remainder were in a long-term relationship or widowed.

Over one in five (22%) were living alone, 11% with their children, 9% with parents, and 7% in a nursing home. Nearly all (92%) said they were satisfied with their current living situation, but 35% identified barriers to the current living situation, primarily in access to paid care, physical access problems, financial issues, and levels of family support. The survey participants were from across the country, with 25% living in Dublin followed by Cork with 10% of respondents. There was a nearly even split between urban (52%) and rural (48%) dwellers.

Percentage in Age Categories, 2018/2014

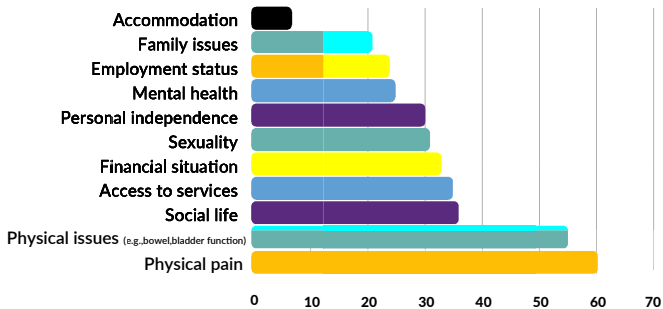


Road traffic accidents and falls were the most commonly reported causes of spinal cord injury (24% each), with 23% reporting a medical cause and 9% a sports injury. Nearly 30% reported having spinal injury for five years or less, compared with 6-10 years (19%) and 10 years+ (52%). Seven in ten of the participants were paraplegic and 30% were tetraplegic, while 37% said their injury was 'complete' and 63% described it as 'incomplete'. Nearly all participants with a complete injury were full-time wheelchair users, compared with 37% of people with an incomplete injury. More than half reported using a wheelchair full-time and 8% used a wheelchair some of the time. This compares with 18% who used a walking aid and 19% who walked independently.

Major Challenges

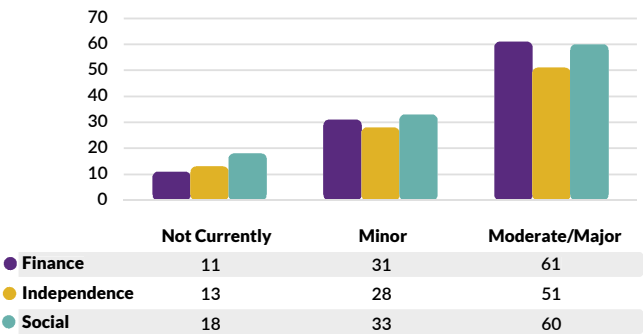
The survey asked about current challenges for SII clients. The percentage of clients who said they were experiencing 'moderate' or 'major' challenges are displayed in the table below. Physical pain was the most common significant challenge followed by physical issues such as bowel and bladder function.

% of SII Clients For Said They Were Experiencing 'Moderate' or 'Major' Challenges



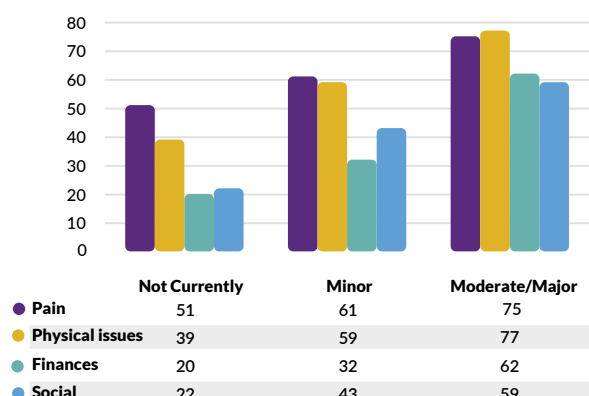
Follow up analysis of the challenges revealed some important association between some of these issues. Comparisons were made between SII clients who were experiencing a moderate/major challenge in a particular area compared with those who said that area was not a challenge or was a minor challenge. SII clients who said access to services was a moderate or major challenge were more likely to report significant challenges in their finances, social life, and personal independence. For instance, 61% of them said that finances were a big challenge for them, compared with 31% who said access to services was a minor challenge and 11% of people for whom access to services was not currently an issue.

Links Between 'Access to Services' and Other Challenges

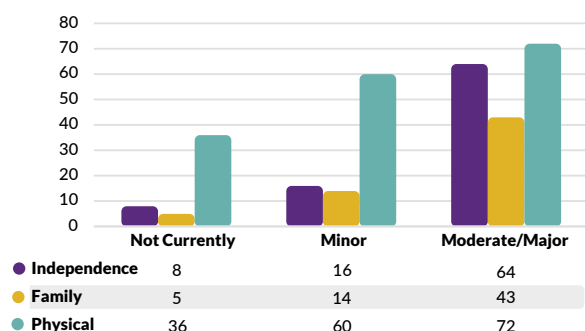


A similar pattern can be seen among people who reported moderate or major mental health challenges. 75% of these participants also experienced pain as a moderate/major challenge (51% of participants for whom mental health was not currently an issue). Seventy-seven per cent of clients with a mental health challenge also had stressful physical challenges with bladder and bowel control (39% of clients who did not have a mental health challenge). People who had mental health as a major challenge were three times more likely to report finances or social life problems as a major challenge. SII clients who reported a moderate or major challenge in their social life were much more likely to report challenges with their personal independence, family issues, and physical issues such as bladder and bowel control problems. For example, nearly two-thirds of people who felt challenged in their social life said they had a challenge in their personal independence too, compared with 8% of people who said social life was not currently a challenge.

Links Between 'Mental Health' and Other Challenges



Links Between 'Social Life' and Other Challenges



Finances

More than four in ten of SII clients (43%) said that they have some financial concerns, and 16% reported having significant or very significant financial concerns. Three quarters of the survey respondents had a medical card, and only 36% of these people reported being financially comfortable. Eight per cent of medical card holders reported being below the poverty line and 17% were on the poverty line. Those participants aged less than 45 were also at risk of poverty, with 9% of this group under the poverty line and 22% on the line. The poverty levels have decreased significantly from 40% in the 2014 survey to 25% in 2018. This reflects the national economic situation as Ireland was emerging from recession in 2014.

Nearly one-quarter of medical card holders were involved in employment-related activities and 29% were retired. This compares with 47% of other participants who reported employment-related activities and 34% retired. Over two-thirds of medical card holders said the possibility of losing the card was a big impact on their outlook on employment.

Employment

Thirty per-cent of the survey participants were retired (rising to six in ten of over 55s). Nearly half (47%) of the participants were involved in employment-related activity, including full-time work (8%), part-time work (9%), volunteering (12%), a training course or rehabilitation programme (5% each), and a formal educational module or course (8%). A further group of SII clients said they were personally ready to take part in employment but were not doing so yet. For example, 21% said they were ready to engage in part-time paid work, 20% were ready to take part in a training course, and 18% in a rehabilitation programme, but were not doing so at the moment.

The survey included items on barriers and issues in employment. Nearly one-third (31%) of the participants said they were not in employment due to their spinal injury, and for two-thirds the impact of spinal injury had a significant impact on their employment outlook. There was widespread concern that employment would involve losing their medical card, and over 40% of participants were concerned about employer attitudes to people with disabilities and lack of job opportunities.

Participation in employment-related activities rose to 55% among under 45 year olds, including 18% in full-time, 23% in part-time work, and 4% self-employed. For some other groups the participation rate was lower, with 23% of people who had a SCI for less than five years taking part in employment activities and 30% of wheelchair users.

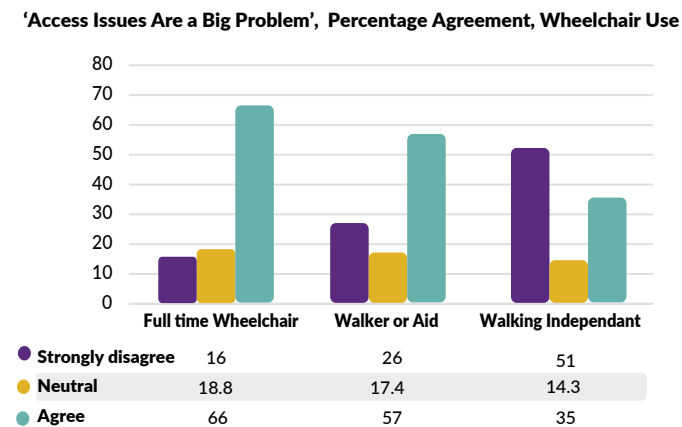
Looking at barriers to involvement, 60% of wheelchair users were concerned that employment could result in loss of the medical card, 47% reported limited job opportunities, and 37% cited transport issues.

Independence and Access

Most people (71%) reported frequently driving their own car, 38% are frequently driven by others, and 12% frequently took public transport. Almost two-thirds of participants (63%) felt independent in being able to get to the places they wanted to go. Nevertheless, over half (56%) reported that access issues were a big problem and 31% said that transport issues prevented them from doing things they needed to do.

More than six in ten (62%) of wheelchair users said they can get to places they need to, a lower percentage than that reported by people who can walk independently (77%). More than one-third of wheelchair users (36%) reported they had significant problems with transport issues (18% of unaided walkers). Access issues such as ramps, entrances, and footpaths were a significant issue

for wheelchair users, with two-thirds agreeing that these were a major issue compared with 35% of unaided walkers.



Looking at personal care and independence, 77% of full-time wheelchair users reported being independent in eating/drinking (compared with 93% of those who walk unaided). There were also differences in personal independence in bathing (44% of wheelchair users, 81% of unaided walkers), dressing (59% compared with 89%), skin management (54% compared with 86%), mobility/turning in bed (60% compared with 92%), getting in and out of bed (60% compared with 93%), and use of the bathroom (54% compared with 89%).

Perceptions of SII Services

One purpose for the survey was to ask people how they rated SII services. The answers showed that information sources and resources were rated most positively – such as the SII magazine, website, social media, emails, annual conference, resource centre, and community outreach officers.

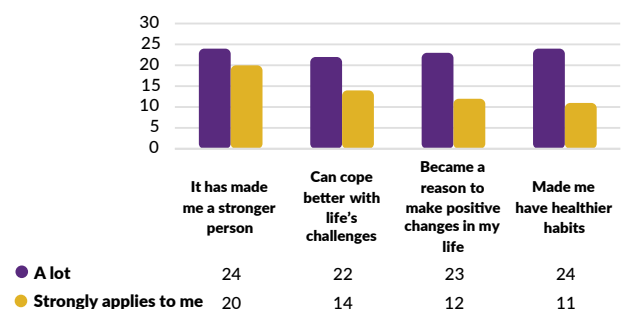
Participants were asked to indicate their top priorities for SII to focus on in the future, based on their own needs and goals. The priorities were grouped as referring to 'information' and 'services'. In this section, participants were asked to give their top future priorities for SII. Among the top priorities for information were for SII to provide information on research and new treatments (35%), financial supports such as grants and benefits (27%), and physical health (19%). The top three services priorities from survey respondents were for assistive technology (19%), counselling and mental health (17%), and peer support (14%). Four in ten of the participants (44%) said that SII had made them stronger individuals.

Mental Health and Well Being

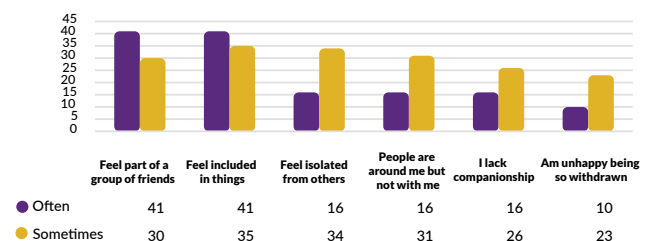
The survey included a range of items on factors related to personal well being and mental health. These showed that 50% of participants were experiencing severe or moderate mental distress. We saw in another section of the survey that people who reported a mental health challenge were more likely to experience other challenges too.

Up to 50% of the respondents to the survey reported that they felt socially isolated on a regular basis. Looking at the possibility of SII leading to enhanced personal insights and resilience, more than half saw themselves as resilient and able to bounce back from adversity.

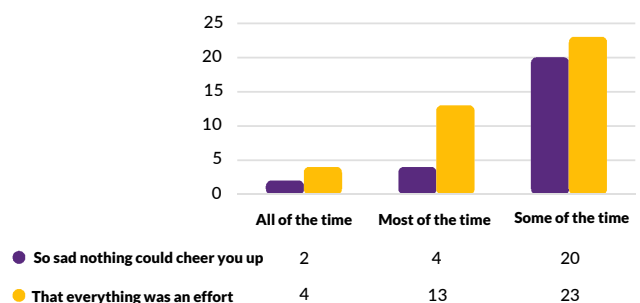
Percentage Who Identify With Strengths Arising from Spinal Cord Injury



Percentage of Participants Who Regularly Experience Feelings of Belongingness and Loneliness



Percentages of Survey Participants Who Had Regular Feelings of Distress in the Past Month



Certain groups of survey respondents were more at risk for distressing experiences, particularly under 45s, people with a complete SCI, and wheelchair users:

SII clients aged under 45 years:

- Most likely to report lacking social companionship often or sometimes (56%, compared with 36-38% of other age groups); Higher rates of social isolation (65%, compared with 38-48%); More likely to report mental distress, such as being sad most or all of the time in the past month (32%, compared with 4-8% for other age groups).

SII clients with a complete injury:

- More at risk of feeling sad some or most of the time (27%) compared with people with incomplete SCI (6%).

Wheelchair users:

- Higher rates of reporting lacking social companionship often or sometimes (48%, compared with 34% of people with SCI who can walk independently), and feeling isolated regularly (53%, compared with 39%).

Complete/Incomplete Injury:

- More active in driving/working, but more likely to report mental distress

Complete/Incomplete Spinal Cord Injury

Each group of SII clients had a distinctive profile across the survey items. Looking at different age groups, levels of injury, and other factors helps to demonstrate the diversity of needs and experiences that exist within the community. As a further example of this, the survey found that SII clients with a complete SCI were more active in areas such as driving or working but were also more likely to report mental distress.

- 80% of people with a complete injury report driving frequently, compared with 68% of incomplete SCI participants. One-quarter of complete SCI respondents were driven frequently by family members (44% of those with incomplete SCI).
- One-quarter of people with a complete injury (26%) were in full or part time work, compared with 18% of those with incomplete SCI.
- One-quarter (27%) of people with a complete spinal cord injury reported being sad some/most of the time, compared with 6% of those with incomplete injury. Similarly, 22% reported feeling hopeless some/most of the time (6% of people with incomplete SCI).
- Just over half of people with a complete injury (55%) described physical pain as a moderate/major challenge, compared with 67% of people with incomplete SCI.





Interviews with Family Members

Focus groups and interviews were held with family members of SII clients in Dublin, Galway, and Limerick. As parents, partners, and siblings, family members described their role as involving continuous workload and responsibility, planning and vigilance. Although the experience could be rewarding and meaningful, nonetheless the effect of care-giving was emotionally draining and could lead to social isolation. Family members talked extensively about supports needed by the person with SCI and tended to see their own needs as secondary. **This highlights the need for support for carers themselves.**

The family members described lacking information, signposts, and preparedness when spinal cord injury first came into their lives and at key stages thereafter, such as when their family member left the initial rehabilitation programme. The family members made practical suggestions such as:

- Tailoring information to individuals at each stage of the journey of providing care.
- Enhancing opportunities for family peer support to allow for more information exchange, empathy, and sharing.
- Greater access to mental health/coping resources for carers and the person with SCI.
- Acknowledging the family as having equal needs to the person with SCI.

Statements made by family members during the interviews reinforce the stress and strain involved in being a carer, with examples such as:

- “We climbed a steep hill because we had no one to help us, we learned the hard way”.
- “It is a frustration, it mentally destroys me, ... it’s us as parents and what it does to our lives”.
- “It’s very hard, it’s very difficult, you are on call all the time”.
- “You become socially isolated, you are not involved in activities your friends are involved in”.
- “[The children] went from having an active dad to having a cranky old dad, a guy who has gone into himself”.





This participant describes having to be very organised in maintaining links with friends, it becomes another job that must be planned and worked toward because these links are important:

“I have to work very hard to stay socially integrated myself, I pencil in, every six weeks to meet friends for lunch... you’ll get left behind, you have to work an awful lot harder with all your relationships outside of the person with disability. It’s easier to stay at home ... you can manage things easier at home, so you stay at home”.

High levels of work, planning, and organisation were reflected in many aspects of life, including spouses maintaining a relationship with the person with SCI (“going to restaurants, going out for a drink at night, going for a holiday, everything has to be pre-planned, ... that all causes stress within you, ... you have to work really hard, to retain as much a normal life as you can, ... it changes the relationship”). This participant describes the work involved in maintaining intimacy in a relationship with someone who has SCI: “the sexual side of your relationship suffers if you become a carer, where is romance between a full-time wheelchair user and a carer, he’s my husband and I’m his wife, ... you could walk into the GP forty one times but that’s one thing they would never ask about”.

Another important theme was the need for information and guidance at each stage of the caring journey. This parent describes the disorientation of the early stage of being a carer and feeling there is little direction to follow: “You walk outside that door you are walking into a maze, there’s no direction ... with cancer or the heart there’s signposts”. Following the intensive phase of early rehabilitation, families felt they were left to find their own direction and further steps to maximise the person’s potential. Families can feel neglected as a result: “There was no follow up service ... that was the hardest time, he had gone from being in this complete little bubble and then there was nothing, he was at home with me, I got no phone calls, no one asked me how I felt, ... as the carer, I was never spoken to”.

The focus groups were an opportunity in themselves to exchange information and empathise with one another, and the families felt that there should be more regular opportunities of this kind: “As family we love the person we are dealing with, but we are totally affected emotionally, so we need more and more support”. There is a bonding and connection that takes place naturally between people affected by the same issues: “If we do meet, there is no awkwardness, you can sense an understanding, that person will look at me, and say ‘he’s very bad today’, there’s no awkwardness, I’ll know what she’s talking about, it’s grand to be able to sit down and have a conversation with someone who has walked that journey”.

WHAT THE WORLD HEALTH ORGANISATION SAYS

The term 'spinal cord injury' refers to damage to the spinal cord resulting from trauma (e.g. a car crash) or from disease or degeneration (e.g. cancer). There is no reliable estimate of global prevalence, but estimated annual global incidence is 40 to 80 cases per million population. The majority of cases are due to traumatic causes, though the proportion of non-traumatic spinal cord injury appears to be growing.

Symptoms of spinal cord injury depend on the severity of injury and its location on the spinal cord. Symptoms may include partial or complete loss of sensory function or motor control of arms, legs and/or body. The most severe spinal cord injury affects the systems that regulate bowel or bladder control, breathing, heart rate and blood pressure. Most people with spinal cord injury experience chronic pain.

Spinal cord injury is associated with a risk of developing secondary conditions that can be debilitating and even life-threatening e.g. deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis, pressure ulcers, chronic pain, and respiratory complications. Acute care, rehabilitation services and ongoing health maintenance are essential for prevention and management of these conditions.

Spinal cord injury may render a person dependent on caregivers. Assistive technology is often required to facilitate mobility, communication, self-care or domestic activities. An estimated 20-30% of people with spinal cord injury show clinically significant signs of depression, which in turn has a negative impact on improvements in functioning and overall health.

Existing data does not allow for global cost estimates of spinal cord injury, but it does offer a general picture.

- The level and severity of the injury have an important influence on costs - injuries higher up on the spinal cord (e.g. tetraplegia vs. paraplegia) incur higher costs.
- Direct costs are highest in the first year after spinal cord injury onset and then decrease significantly over time.
- Indirect costs, in particular lost earnings, often exceed direct costs.
- Much of the cost is borne by people with spinal cord injury.
- Costs of spinal cord injury are higher than those of comparable conditions such as dementia, multiple sclerosis and cerebral palsy.



IMPROVING CARE AND OVERCOMING BARRIERS

Many of the consequences associated with spinal cord injury do not result from the condition itself, but from inadequate medical care and rehabilitation services, and from barriers in the physical, social and policy environments.

Implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires action to address these gaps and barriers.

Essential measures for improving the survival, health and participation of people with spinal cord injury include the following:

- Timely, appropriate pre-hospital management: quick recognition of suspected spinal cord injury, rapid evaluation and initiation of injury management, including immobilization of the spine.
- Acute care (including surgical intervention) appropriate to the type and severity of injury, degree of instability, presence of neural compression, and in accordance with the wishes of the patient and their family.
- Access to on-going health care, health education and products (e.g. catheters) to reduce risk of secondary conditions and improve quality of life.
- Access to skilled rehabilitation and mental health services to maximize functioning, independence, overall wellbeing and community integration. Management of bladder and bowel function is of primary importance.
- Access to appropriate assistive devices that can enable people to perform everyday activities they would not otherwise be able to undertake, reducing functional limitations and dependency. Only 5-15% of people in low- and middle-income countries have access to the assistive devices they need.
- Specialised knowledge and skills among providers of medical care and rehabilitation services



**World Health
Organization**

BACKGROUND TO STRATEGY

In 2013 - 2014 Spinal Injuries Ireland completed the first major research project to understand the needs of people with a SCI in Ireland (Collins 2014). This research was qualitative and involved face to face interviews with 325 people nationwide. In order to assist us in developing this strategic plan, we commissioned Dr Pdraig MacNeela, School of Psychology, NUIG who designed a survey to follow up on trends over the last four years.

We would like to thank all our service users who took the time to respond to this survey. Without your co-operation we would have been unable to collate the information and evidence we require in order to assist SII make a positive improvement in the lives of people with a SCI in Ireland.

In addition, Dr MacNeela held focus group discussions with family members – their experiences and suggestions are detailed below.

KEY FINDINGS (MACNEELA 2018)

People with a SCI

Physical pain and personal care issues (bowel and bladder) are top challenges

50% received scores suggesting severe or moderate mental distress

50% report feeling isolated from others sometimes/often

44% say that SII has made them stronger

The vast majority (92.4%) considered that they are living in their preferred living situation

75% have medical cards, 38% of those on a medical card state that finances are a big challenge

Under 45s are more involved in employment however there is more evidence of financial and mental health stress

Wheelchair users have more disability but less financial and mental challenges than unaided walkers

Wheelchair users are more likely to have a medical card 80%/69%

Bowel and bladder issues bigger challenge for wheelchair users 58%/36%

Wheelchair users are less likely to report sadness some/most of the time 6%/26%

Mental health is a big challenge 23%/38%

Family members

Family needs are secondary to the person with the disability

Parents/partners and siblings described their role as one of: continuous workload and responsibility; emotionally draining; social isolation; planning and vigilance; lacking information/signposts and preparedness although also rewarding and meaningful

Practical suggestions included – information tailored to individuals at each stage of the journey; opportunities for family peer support (information exchange, empathy, sharing)

More access to mental/coping resources

'You walk outside the door and you are walking into a maze. There's no direction... ..with cancer or the heart there are signposts'



STRATEGIC OBJECTIVES 2019 -2023

- To provide quality and relevant support, information and advice meeting the needs of people with a SCI, their families and carers, professionals and the wider community
- To communicate effectively with stakeholders, to raise awareness and to improve public awareness of SCI and to advocate for the rights of those with a SCI, their families and carers
- To present relevant training and education services to people with a SCI, their families, carers and healthcare professionals
- To support people with a SCI by raising the funds necessary to ensure the funding requirements and long-term sustainability of SII
- To operate an innovative progressive organisation which meets with all regulatory requirements in the areas of financial management, human resources and governance



STRATEGY 2019 -2023

Vision

Provide on-going personalised support services for people with a spinal cord injury and their families - empowering them to live an independent and fulfilling life at home – for as long as they need us

Mission

SII's mission is to engage with people with a spinal cord injury and their family members, to address barriers to full participation in society and to empower members to work towards achieving personal, social and vocational goals

Values

- Informed - We know how to help
- Compassionate - We deliver this with empathy and understanding
- Reliable - We follow through – every time
- Empowering-- We give hope and inspiration



OPERATIONAL GOALS

The following 18 new operational goals support the 5 strategic objectives

To provide quality and relevant support to people with a SCI, carers and families

- 1.0 Roll out peer support programme nationally
- 1.1 Provide one to one case management to families
- 1.2 To present two annual conferences in 2020 and 2022
- 1.3 To present two public awareness campaigns 2019 and 2021

To communicate effectively with stakeholders

- 2.0 To continue to advocate for medical cards for people with a SCI
- 2.1 Introduce a public forum for people with a SCI
- 2.2 Introduce a public forum for families of people with a SCI
- 2.3 Work in partnership with the Spinal Team in the NRH & the acute and regional hospitals

To present relevant training and education

- 3.0 Ensure provision of relevant education materials both hard copy and digital to people with a SCI
- 3.1 Provide family specific information both in hard copy and digitally
- 3.2 Present webinar education programme to healthcare professionals

To support people with a SCI by raising the funds necessary to ensure the funding requirements and long-term sustainability of SII

- 4.0 Diversify income and develop new income streams
- 4.1 Identify new sources through grants, fundraising activities, corporate partnerships and philanthropy
- 4.2 Maintain the highest standards of transparency and governance

To operate an innovative progressive organisation which meets with all regulatory requirements

- 5.0 Remain governance code compliant
- 5.1 Report key outcomes annually to all stakeholders
- 5.2 Acknowledge and publicise funders and partners for collaborating with SII
- 5.3 Seek Carf accreditation by 2023

SERVICES STRATEGY

As demonstrated by the results of the research from Dr Eimear Smith, the demographics of the SCI population in Ireland is changing. At SII, we need to adapt and meet these needs so that we continue to remain relevant and accessible to all our service users and lead the way in terms of progressive supports for every person touched by the challenges that an SCI provokes. The responses to our service user survey, carried out with Dr Padraig Mac Neela in NUIG, was instrumental for us in shaping the future direction of the services we deliver. Not only did our service users answer the survey in great detail, they gave us so many insightful comments and invaluable food for thought. We also held focus group with family members to get their perspective on their information and support needs. We further sought the opinion of our peer supporters and volunteers, and we are extremely grateful for every individual's input. As a result, we now have a robust strategy for the next 4 years which gives us a clear direction of where we need to invest and develop our service based on solid evidence.

Our operational goals cover the full breath of our services and centre around the development of information and support for people in the SCI community, including health care professionals and the general public. We will increase public awareness and advocacy issues with well informed campaigns. We will deliver relevant education and information by collaborating with our key stakeholder and experts' in the area of SCI. Our services team will work closely with our fundraising and communication team, alongside our financial and human resource team to ensure we openly share information across the organisation and have the appropriate structures and policies in place to deliver the essential services to our service users.

Our first priority is to our current service users and potential new service users with SCI. We have over 2000 current service users and a projected 156 new cases of SCI each year. We want to start supporting people who have sustained a spinal cord injury and their family members from the moment the SCI occurs. We want to link with those affected as soon as possible, regardless of which hospital and medical facility you are attending. We will develop a clear pathway for all health care professionals to refer those who may benefit from our services to us to engage with our Community Outreach Officers and our Early Days programme.

'We are seriously neglected, it is all about the person with the disability, partly it should be, but when you think about it, there is very little support for families, you're there, you're the one who picks up the pieces'

We will develop specific and concise printed and online information resources as well as trained peer-to-peer volunteers to address the vast array of emotional and practical questions from a first-hand perspective. We will address the information needs depending on the type of injury, traumatic or non-traumatic, and tailor the relevant supports.



'Alone we can do so little, Together



Online communication is expected in the digital age and we will develop and deliver online resources to connect and engage remotely with everyone in the community. This will include moderated, online peer-support for families as well as support for service users by phone and face-to-face and group meetings. We will recruit, select, train and support each of our volunteers to ensure they have the up-to-date information and to be a valuable support, playing a crucial role for the organisation.

'If we do meet, there is no awkwardness, you can sense an understanding, I'll know what she's talking about, it's grand to be able to sit down and have a conversation with someone who has walked that journey.'

We will increase public awareness of the different types of SCI starting with national, public campaigns to highlight the causes of non-traumatic SCI such as Cauda Equina Syndrome. We know, from Dr Smith's research, that there is now a significant increase in non-traumatic cases per year and these injuries are occurring in the older population. Degenerative conditions and cancer of the spine are also rising issues. We must highlight these facts and create a greater awareness of, and greater supports amongst, the healthcare professionals and general public.

We will partner with our colleagues in the specialised area of SCI both nationally and internationally including relevant commercial companies to highlight the needs of those with SCI.

Our service user feedback on the type of information required is broad ranging and distinct to each type of injury. This includes the side effects of SCI lived with on a daily basis as well as the challenges faced living with the injury. Information about the latest research and treatments, assistive technology, and support with the emotional effects along with sexual health, social and recreational activities are just a few topics to emerge as needing greater attention. With this in mind, we are dedicated to ensuring that all of our information will be accurate and up-to-date and available in print and digital formats. We will target our educational sessions to cover relevant topics and deliver them with expert speakers via webinar and in group settings around the country.

'They need to supply different information to you, spinal injury is a big topic, and all of our circumstances are different, everyone requires different information'

All of our work will meet the requirements of the regulatory bodies we work with. Policies and procedures are essential to ensure we deliver a consistent service while measuring the impact of our work to maintain the highest standards. We will continue to value, invest and support our staff and volunteers as we move to implement our strategic objectives over the next 4 years. We are excited to see SII flourish, grow and support each service user, their families and our wider SCI community no matter what stage people are experiencing.

'I would not have got through the last number of years without the support of my community outreach officer, I encourage people to link in with SII and access their services'

We offer a unique national service through our Community Outreach Officers (COO), Peer Support Programme and Activities Programme. Contact with Spinal Injuries Ireland during hospitalisation and after discharge is a crucial factor in helping people to envisage a life with spinal cord injury (SCI) and to come to terms with the reality of injury and disability. We know those who sustain a SCI have many difficulties following discharge from hospital such as housing adaptations, interpersonal relationships, employment/vocational challenges, transport and having their personal care needs met.

Transition to community for those with a spinal cord injury can be extremely daunting when the new reality of their injury becomes apparent. We know it is not uncommon for people to experience depression and feelings of isolation at this time. The psychological consequences of SCI can become more apparent over time when the initial shock of the injury has subsided. Without the services of SII some service users have told us they feel as if they are left in 'limbo' and at a total loss as to where to turn post discharge from hospital.

Our established outreach service provides supportive, educative and practical services at this crucial time. We empower our service users to set goals using the principle of active support. Following an initial meeting with a new service user, our COOs explore goals that are influenced by personality factors, age, family dynamics, gender, material circumstances, community resources and the physical effects of their injury. All goals are set with the service users specific, individual needs at the core. Goals are short, medium and long-term depending on the need and ambition of the service user. Goals are wide ranging and are reviewed on a regular basis at face-to-face meetings as well as through telephone and email support.

Examples of short-term goals are different for everyone but can range from accessing hydrotherapy sessions in a local gym, connecting with a volunteer in our Peer to Peer Programme or securing a disability parking permit essential for service users.

Medium-Term goals are a more involved process over a longer period which often require interaction and collaboration with external agencies such as local HSE staff. As medium-term goals, we have supported service users to secure home care packages and personal assistant hours essential for returning to independent living. Long Term Goals can take many years to achieve and have varied from successful medical card applications, to attending 3rd level education for the first time.

As a result of our regular contact with people with SCI over a 25-year period, we are in a unique position to fully empathise with, and understand, the broad range of challenges that people with SCI face. Our range of services also includes Peer Support and Activities Programmes which involve support from many of our trained volunteers.

Our Services are geared toward support at every stage of the journey.

Vocational Support

The Discovering the Power in Me Programme (DPM) is delivered by SII to assist in developing and progressing service user's vocational goals for work or education, by providing guidance and support in the transition to mainstream settings. We are the only organisation delivering this programme in Europe. This course is delivered online via webinar and face-to-face, and has been very successful for many service users aiding them in the completion of their goals. DPM guides the individual to make positive changes in life to help shape the future they want. Through the course we explore techniques and tools to use which are simple yet effective in practically reaching the individuals goals and thus empowering our service users to be the authors of their own vocational path.

Access to Financial Assistance

Vocational goals are imperative for many service users. Many of which have an associated cost which can inhibit the goals being achieved. SII research and partner with many charitable organisations and foundations to support service users move towards their goals. Regular success is achieved whether for further education, mobility appliances or exercise programmes; these grants are invaluable in enabling service users to realise their goals.



Peer Support Services

“Being a Peer Volunteer, we offer a different perspective to the service user as we have the lived experience of SCI and using the services.”

Through our Peer Support programme, people who have experienced SCI and are in recovery themselves offer support to service users across the country. This recognised approach to support can bring benefits to service users through improved social functioning, enhanced goal setting skills, and incorporation of key recovery principles into their experience of services. Our trained Peer Volunteers connect with others and help them through appropriate sharing of their own recovery journey and perhaps, most importantly, through engendering hope.

Our Peer Coordinator engages with new patients in the NRH on a regular basis providing face-to-face support while in the hospital and connecting them with SII and their Community Outreach Officer. Our peer-to-peer programme coordinator, has first hand experience of living with a spinal cord injury giving him unique insight into the effect a SCI can have on someone. He liaises with our group of peer mentors and our peer volunteers who also provide support around the country for all levels of SCI.

Activities and Volunteering

SII deliver a range of activities for service users to participate in while in the NRH and post discharge from hospital. Activities such as the unforgettable boat experience in Dublin bay or a trip to the cinema are arranged every week and are in high demand. Many times, the service user and their family all avail of this service together fully supported by SII. Our volunteers are key to the work of SII. Our volunteers are handpicked for their positive outlook and willingness to be part of our team. These highly-trained volunteers enhance our service in such ways as driving the SII power boat each week in summer months and driving our SII van enabling service users to go on excursions. Other activities such as Watersports Inclusion day or Farmers day would not happen without our team of dedicated social volunteers.

These are a few of the vast range of supports we offer to our service users and the wider SCI community. Over the past 4 years we have developed our services to meet every changing need of those who avail of our services. We have now reviewed our strategic goals 2014 – 2018 by listening to our service users, their families and our key stakeholders. In these next four years, we look forward to further enhancing our current services and complimenting them with more information and support for those living with a SCI and those who support them, as well as the general public and health care community.

Last year we appointed our first Family Outreach Officer. The purpose of this exciting new role is to provide a comprehensive support service to people with spinal cord injury with special emphasis on providing practical and ongoing support to family members. We will engage with family members at the onset of the SCI regardless of geographical location. This new, impactful role will serve to enhance the range of services we offer to our service users and the wider SCI community.

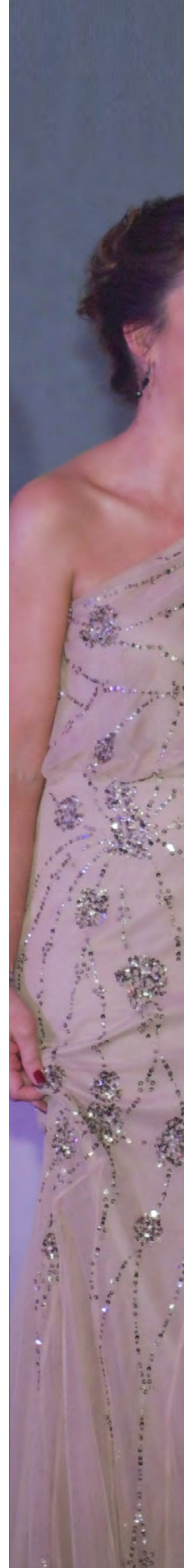
We know that there are significant informational and support needs for family members from the moment a SCI occurs, during the hospital stay, rehabilitation phase and after discharge home. From our experience of supporting service users, family life is disrupted, and new and unfamiliar responsibilities combined with emotional distress is the new reality. From our research with NUIG and anecdotal evidence, family members have their own specific concerns and information needs distinct from the service user. As part of our strategic review we held focus groups with family members to fully assess their needs from SII. Information and support needs for family members are among the top 5 needs for those living with a SCI. Research also identifies the need for a community support network, professional support and assistance with navigating the health system.

To meet these needs we are currently collaborating with the Spinal Team in the Mater Hospital where we aim to meet with new SCI patients and their families from the start of their journey. We will complement the spinal team providing non-medical support and information including access to peer support and emotional support as well as practical support for each step in the recovery phase. Our Family Outreach Officer has first-hand experience of what to expect as her son sustained his injury 5 years ago and he has just returned to college in the University of Limerick. This service will be rolled out nationally in line with our strategic objectives over the next 4 years.

We are keen to develop our service for family members. In order to do this, we need robust evidence for developing our service. To this end, we have collaborated with UCD Public Patients Involvement (PPI) Ignite. PPI in health and social care relates to research in education and training, professional practice and administration. UCD are working with people who are seldom heard to develop research, education and support at UCD to include them from the start. SII are a key stakeholder with PPI and have received core funding to conduct a joint project with Dr Sarah Donnelly, School of Social Policy, Social Work and Social Justice, UCD. Our Head of Services, Naomi Fitzgibbon, is working with Sarah to conduct two research focus groups. These will be for family caregivers to inform our strategic process and ensure SII are innovators in supporting family members with tailored programmes specific to their needs, informed by them.

Project Name: An exploration and identification of research priorities utilising a co-design approach between family caregivers of spinal cord injury (SCI) patients.

Background: Caregivers of people with a spinal cord injury (SCI) bear an important and often substantial burden both emotionally and physically post-discharge from hospital. We have much anecdotal evidence of the lack of knowledge and support on how to care for family members leading to much distress. In fact, depending on the level of SCI, it is often the family caregivers who need significant help. Lynch and Cahalan (2017) highlight that family caregivers of SCI survivors endure a broad range of physical and mental health issues, and there is a need for greater family involvement in SCI from the outset. Research suggests that education interventions and support groups may be of particular benefit (Lynch and Cahalan, 2017). This project with UCD PPI Ignite is a partnership study which sets out to capture the research priorities of family caregivers of SCI patients in the NRH through the convening of a 'Research Outreach' event.





What Will the Requested Funding be Used For?

We will create a forum where the voice and opinions of family caregivers can be captured in relation to what they feel should be the research priorities. We will invite family members to participate in a focus group. We will explore and gauge interest in the future development of an education programme designed by family caregivers for family caregivers which we would anticipate will underpin a future joint funding application. In addition, it will facilitate engagement and discussion of how future collaborative projects can be co-designed utilising a PPI approach with SCI patients and their family caregivers.

What are the Expected Outcomes?

This Project will underpin and inform the future research direction of unfunded research already being carried out as well as helping to identify future research projects which are viewed as priority by SCI family caregivers. In addition, it will create a forum whereby the hard to reach voice of SCI family caregivers can be heard through focus groups to explore and gauge interest in the development of an education programme designed by family caregivers for family caregivers. We hope this will be an empowering exercise for SCI family caregivers which we hope will lead to a co-designed SCI family caregiver education and support programme.



UCD PPI Ignite



References

National Rehabilitation Hospital (2017). Spinal Cord System of Care Inpatient Scope of Service, NRH, 2017.

Lynch,J and Cahalan,R (2017). 'The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review'. Spinal Cord Journal, June 2017.

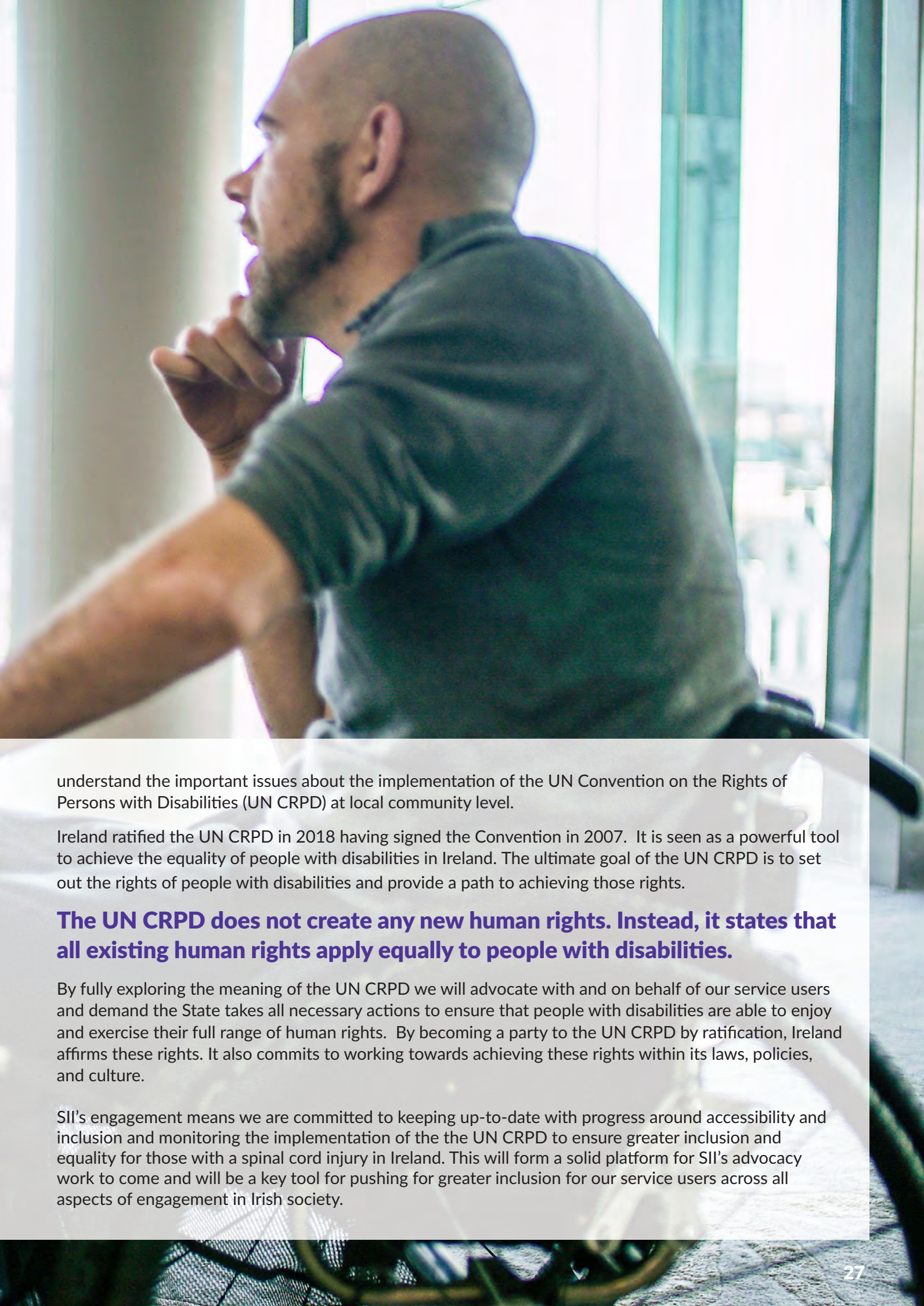
UN Convention on the Rights of Persons with Disabilities

We understand that many of the issues that result from a spinal cord injury are related to lack of medical care and access to physical, social and policy environments. With this in mind and with our strategic goal to increase our advocacy work in this area we will host advocacy training for our service users.

SII has a history of advocating on behalf of our service users. Issues regarding care packages, housing and accessing medical cards are regular issues affecting the SCI community. SII are consistently requested to support service users on how to engage with the HSE and access to essential services such as bowel and bladder care.

We want to develop the capacity of service users to understand how to advocate for themselves and others with spinal cord injury. We are developing suitable advocacy training delivered by appropriately qualified individuals. Included in this training will be the key skills required to engage with stakeholders to influence and meaningfully shape local and ultimately national services for those living with a SCI.

In order to understand and keep abreast of the vital advocacy issues, one of our Community Outreach Officers is representing SII on CISCOS 'Connecting Inclusive Social Planning, Community development and Service provision for Persons with Disabilities', 2018-2020. Hilary is taking part in this course to fully



understand the important issues about the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) at local community level.

Ireland ratified the UN CRPD in 2018 having signed the Convention in 2007. It is seen as a powerful tool to achieve the equality of people with disabilities in Ireland. The ultimate goal of the UN CRPD is to set out the rights of people with disabilities and provide a path to achieving those rights.

The UN CRPD does not create any new human rights. Instead, it states that all existing human rights apply equally to people with disabilities.

By fully exploring the meaning of the UN CRPD we will advocate with and on behalf of our service users and demand the State takes all necessary actions to ensure that people with disabilities are able to enjoy and exercise their full range of human rights. By becoming a party to the UN CRPD by ratification, Ireland affirms these rights. It also commits to working towards achieving these rights within its laws, policies, and culture.

SII's engagement means we are committed to keeping up-to-date with progress around accessibility and inclusion and monitoring the implementation of the the UN CRPD to ensure greater inclusion and equality for those with a spinal cord injury in Ireland. This will form a solid platform for SII's advocacy work to come and will be a key tool for pushing for greater inclusion for our service users across all aspects of engagement in Irish society.

MEET YOUR SPINAL INJ



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CEO



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Resource Centre Manager



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OUR COMMUNITY OUTREACH TEAM



David Fitzgerald



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Philip Quinlan
Major Events Manager



Emer Hanley
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Robert Kenny
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Finbarr Dorgan
Services Support

You can contact any of our
Spinal Injuries Ireland
team on 01 653 2180, on
info@spinalinjuries.ie
or by dropping in to our
Resource Centre.



Alison Byrne
Fundraising and
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Together We Can Do More

How can you get involved?

There are many ways you can get involved and support Spinal Injuries Ireland services.

Donate

Becoming a monthly donor or making a one-off donation means you can make a meaningful difference in supporting our national services for those with a spinal cord injury in Ireland.

Become a Corporate Partner

Your company or business can help contribute and engage with the work that SII do through fundraising events, SII talks and employee engagement in SII activities. Whether it's sponsoring an event, engaging with our SII talks or organising a staff sky-dive, there are many ways we can work together to do more.

Fundraise for SII:

Marathons or Challenges
Women's Mini-Marathon
SII Tall Ships Challenge
Paris2Nice Cycle Challenge
Host a Coffee Morning, Table Quiz or Bake Sale

Attend our annual events:

SII Spring Lunch
The Q Ball
The Cork Jazz Ball
Bag It: Preloved designer handbag auction
September Barbecue

Volunteer

You can support our work by volunteering for fundraising events, in the office, or for our activities programme

For further information on how to get involved contact our team on info@spinalinjuries.ie

WWW.SPINALINJURIES.IE
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