



Spinal Injuries Association (SIA) Shadow Report 2011 re: UN Convention on the Rights of People with Disabilities (UNCRPD)

SIA wishes to submit this separate shadow report directly to the Committee reporting on the UN Convention on the Rights for People with Disabilities focusing on areas covered by Articles 25 (Health) and 26 (Habilitation and rehabilitation) where we are extremely concerned that the UK Government is NOT adhering to its commitments under the UNCRPD concerning the needs of Spinal Cord Injured (SCI) people.

Sent by email to the following email address:

UN Committee on the Rights for People with Disabilities: crpd@ohchr.org

And by post to:

CRPD Secretariat, UNOG-OHCHR, CH-1211, Geneva 10, Switzerland

Copies sent to:

UKCDP: info@ukdpc.net

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On behalf of SIA

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Introduction

The Spinal Injuries Association (SIA) has done a significant amount of recent research and consultation with SCI people regarding the issues they face which are covered by the UNCRPD and will be feeding other concerns separate from articles 25 and 26 via the following channels:

- The UK Disabled Peoples Council (UKDPC)
- Disability Committee, The Office for Disability Issues (ODI) – UK Government Department

About SIA

SIA was established in 1974 and not only works to support and promote the wellbeing of the 40,000 spinal cord injured (SCI) people in the UK but also to provide assistance to their families, friends and health care professionals.

We work to support, advise and campaign on all aspects of spinal cord injury. Our vision is the full integration and participation of spinal cord injured people in society. Through our services and publications, we aim to equip spinal cord injured people with the knowledge and skills they require to successfully rebuild their lives after injury. Core activities include our Freephone Advice Line, Peer Advice Service and employment service."

As a true user-led organisation, which was founded and continues to be managed by spinal cord injured people, we fully understand the needs of the people we exist to serve.

Our aims are to:

- Provide a spinal cord injured person, and their relatives and friends, with life-long assistance that spans right from the moment of injury and throughout the remainder of their lives.
- Provide services to increase an individual's quality of life.
- Increase the knowledge and awareness of the causes and consequences of spinal cord injury.
- Campaign for the best medical and social care for spinal cord injured people.

About SCI

SCI can occur at any age and depending on the level and severity of injury to the spinal cord leaves a person with various degrees of paralysis which effects body movement (e.g. the ability to walk, use of arms and hands, reduced bowel, bladder and sexual functions and in some cases the ability to breath).

The effects of SCI are usually permanent and currently there is no cure (Harrison 2000). It is estimated that there are approximately 40,000 people with SCI living in the UK; a prevalence of 0.07% (Nicholls et al 2005) Although the lack of a national database means that precise figures are not available, the estimated incidence ranges from 800 - 1200 new patients annually (Nicholls et al 2005; Aspire 2010; MASCIP 2010).

Learning to live with a SCI can require huge personal and psychological adjustment on the part of the person with the SCI and family members. This is in addition to the enormous physical challenges that are faced in order to learn how to optimise independence in daily living. There is evidence that a period of high quality specialised inpatient treatment and rehabilitation is necessary to achieve optimum quality of life after a SCI (SIA 1997).

In a number of countries including the UK, USA, Canada and Australia recommend that transfer to a specialist SCI Centre, where high quality specialised rehabilitation and access to information and psychological and peer support is available. Transfer should be made as soon as possible after diagnosis of the spinal cord injury to optimise outcome (Aung 1997; Carvell 1989; Carvell 1994; SIA 1997). This stance is supported

by the Spinal Injuries Association (SIA), the British Association of Spinal Cord Injury Specialists (BASCIS) and the Multidisciplinary Association of Spinal Cord Injury Professions (MASCIP) .

SIA's main concerns re: where the UK Government is failing to adhere to the requirements of the UNCRPD covers the following articles (in order of perceived importance to SCI people as a whole):

Article 25 Health (paragraph b)

Article 26 Habilitation and rehabilitation (section 1)

SIA had gathered the following evidence and personal experiences (in bold italic type) re: the UK Governments failure to adhere to the requirements laid out in the above articles:

Article 25 – Health

SIA has gathered significant evidence on the state of Healthcare provision for SCI people and is concerned that the UK Government falls well short of the requirements that are set out in paragraph b of Article 25:

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

SIA estimates that 10% of newly injured SCI people in the UK never get to one of the 11 UK specialist SCI Centres which have been set up to support patients sustaining spinal cord injury through the initial period of treatment and rehabilitation and provide on-going lifelong support. The consequences for this group of SCI people is that they receive no proper rehabilitation or education re: managing a SCI and find themselves being constantly re-admitted into general hospitals with bowel, bladder and skin problems e.g. pressure sores.

Moreover, later in life many SCI people who were able to access a SCI Centre initially find themselves being admitted to a general hospital if they have other health complications either related or unrelated to their SCI. Staff at general hospitals in the main have received no training regarding the specialist issues related to SCI or the day to day care needs of SCI people and so these basic requirements of managing a SCI are often neglected when a person is placed in such an environment. This commonly leads to complications unrelated to the reason for admission and an extended time in hospital.

Bowel Care Management

Spinal Cord Injury usually results in double incontinence. Although this has a major debilitating effect on an individual's confidence it can be successfully managed with the right treatment. This successful management usually involves the digital removal of faeces to clear the bowel, prevent accidents or constipation and avoid Autonomic Dysreflexia*, a potentially fatal condition, unique to SCI.

When in a general hospital environment those who normally have their bowels managed at home by a community nurse or carer, or those that can no longer manage themselves

– for instance as a result of a broken arm – must rely on hospital staff to conduct the procedure for them. Despite Royal College of Nursing guidelines and a Patient Safety Agency Advice Directive compelling all hospitals to produce a policy on Bowel Management from 2005, SCI people are still refused this procedure with great regularity when in non-specialist hospitals. Instead they can be forced to go through various inappropriate, often humiliating and inadequate procedures re: evacuating their bowel. Or simply, Healthcare Professionals refuse to do anything!

“I was told to lie on the bed until I messed myself, then they’d come and clear it up.”

“They filled me with laxatives then, whilst I was still on the ward, they hung me in a hoist over a bucket.”

Case Study 1- (Not named):

“I was 18 years old when my spinal cord was almost completely severed in a road traffic accident in 1975. I’ve some movement in my arms and can breathe by myself, but can’t move my hands or legs. A district nurse visits me once a day and carries out a manual evacuation. Normally this works fine. However, in 2009, due to a reduction in the amount of time the nurse was allowed to support me I developed compacted bowels.

I was admitted to hospital and given a phosphate enema, which treated the problem. However, after a few days in hospital, where I was eating a normal diet, the problem started to build up again. I asked the nurses: “What are you going to do about my bowels?” and they said they were not allowed to do manual evacuations - even though the doctor thought they should – because it was an invasive procedure and they could be sued if anything went wrong.

My mother offered to do the evacuation, but was told she couldn’t for health and safety reasons. Staff knew I would only develop a compacted bowel again if I didn’t have an evacuation, and yet they weren’t prepared to do it. So they discharged me.

Last year, I was admitted to hospital with pneumonia, and again developed compacted bowels because I had no bowel care. I was given the same excuses, just from different people. Being in this situation saps your confidence. To keep your bowels moving you’re loaded up with laxatives. This makes you frightened to breathe or cough. On one occasion I was put in a hoist and left hanging in a sling with a bedpan on the bed beneath me.

I spent that time in hospital hoping I’d get through the experience without making too much mess. Nurses no longer seem to be doing manual evacuations, but you can’t just abolish a procedure and replace it with nothing. Each hospital department needs at least one person trained in manual bowel care. Some healthcare professionals don’t seem to understand the importance of bowel care for people with spinal injuries.

You’re not just treating someone who needs a bit of help because they’re feeling weak after an operation – you’re dealing with people who do not have full

sensations and need special support. Not having the right sort of bowel care is a demeaning experience. I don't like to think about the incontinence side of my injuries as a manual evacuation is a degrading procedure. But it is one that has to be done.

Some of the people SIA consulted on this issue said that they had suggested alternative methods by which their needs could be met – for instance by bringing in the carer who would normally do it for them in the community – but these requests are nearly always refused on bureaucratic grounds.

“I asked if my District Nurse could come in to do it, or even my Mum, and they refused.”

Skin Care

Severe pressure sores will become ongoing health conditions of their own, requiring further hospital admissions, possibly for life. Such conditions are therefore acquired not only to the detriment of the individual but also at a considerable cost to the tax payer. It is, however, the affect on the patient which is most important and it is unacceptable that such a debilitating condition should be acquired through inadequate care during stays in general hospitals.

“My husband received inadequate care whilst in hospital, gaining a grade 4 pressure sore which was totally avoidable. As a result he was on bed rest for 8 months after his accident and required plastic surgery to heal the sore as it did not respond to time or the minimal treatment they provided.”

“A lack of local specialist knowledge in all aspects of the care required in SCI leads me to believe that people with a spinal injury are more in danger of health related problems than ever before in recent history.”

Lack of knowledge of SCI by Health Care Professionals

Often SCI people find themselves in an environment where the health care professionals have little or no knowledge of the issues related to SCI. It is important that SCI people are able to have their day-to-day care routine continued while in a non-specialist health environment e.g. general hospital or they will suffer other complications not related to those they have been admitted for and/or are discharged in a worse state:

“Hospitals are getting worse not better. Having been an active paraplegic for 30 years my shoulders started to wear out. Despite repeated request to be operated on I was passed from one Junior Doctor to another who didn't have the experience to realise the seriousness of my condition. By the time they operated on my shoulders 18 months later they were irreparable. I am now in continuous excruciating pain with very limited arm functionality and have lost my independence completely – I now have to be looked after by carers. Had I been treated correctly and quickly by someone who knew what they were doing I could have been 'saved'. This personal tragedy has also cost society a fortune due to the care that now has to be provided for me which could have been avoided.”

SCI people and their relatives/carers, who can become lay experts (or expert patients) in the day to day management of SCI, are often ignored by healthcare professionals in the general hospital environment and feel disempowered, looking on exasperated and helpless at ongoing wrong treatment.

“I am the expert in my condition”

“My wife showed them SIA’s Factsheet on Autonomic Dysreflexia and they dismissed it saying it was just something she’d downloaded off the internet.”

**Autonomic Dysreflexia is a potentially fatal rise in blood pressure unique to SCI people with an injury above the T6 vertebrae. This condition is virtually unknown outside of specialist Spinal Cord Injury healthcare and, if they are in a state to do so, an SCI person will take great pains to explain it and its risks to a non-specialist health professional. Unfortunately, requests to receive treatment to cure or prevent issues specifically related to their condition are often dismissed out of hand by staff who do not themselves have specialist knowledge.*

The importance of SCI Centers

It is no surprise that many SCI people dread the idea of being admitted to a non-specialist hospital and would rather attend a Spinal Cord Injury Centre.

It would therefore be preferable if SCI people who require treatment either related or not related to their SCI had the choice to receive treatment at one the UK SCI Centers, which at mostly situated on large general and/or university hospital sites, to receive treatment but many can not gain access to them because of limited bed capacity.

The national lack of specialist SCI bed capacity is severe for acute, rehabilitation and re-admissions. SCI patients can be left in District General Hospitals for several months whilst they await transfer and some, particularly non-traumatic injuries, may never be referred.

When considering the issues faced by SCI people in non-specialist healthcare this leaves SCI people particularly susceptible to complications as they lack enough knowledge of their own condition to inform non-specialist staff about their care needs.

Those who experienced ‘correct’ treatment and rehabilitation in an SCI Centre at least know how they should be treated in a general hospital. Those unskilled in how to manage their SCI may experience numerous setbacks as result of further ‘wrong’ treatment in general hospitals with little chance of gainful employment or a fulfilled life.

Complications caused in non-specialist hospitals for well rehabilitated SCI people can be trauma to recover from but for those who lack knowledge or assertiveness to inform non-specialist staff of their ‘correct’ SCI care needs the prospects do not bare thinking over.

“They couldn’t provide manual bowel evacuation for the four months whilst I waited to be transferred to the Spinal Cord Injury Centre.”

Case study 2 – (Jim):

Jim a 55 yr old engineer sustained a traumatic c3/c4 level complete Spinal Cord Injury (SCI) as a result of an explosion. Admitted to Intensive Care Unit (ICU) for critical care of SCI head injury and thoracic poly trauma.

Upon stabilisation of poly trauma and no significant lasting effects of brain injury at 8 weeks he was ready for transfer to a Spinal Cord Injury Centre (SCIC), but due to still being ventilator dependent, lack of available beds in the SCIC meeting the clinical need, delayed transfer ensued.

SCIC Outreach were involved once ICU had referred Jim to the SCIC, which was shortly after admission to ICU They advised on care plan re respiratory system, skin, bladder and bowels. Upon Jim being weaned the possibility of his transfer increased, as he longer remained in the sub group criteria of ventilator dependent.

Jim sustained a grade 1-2 pressure ulcer on his sacrum, and for the 4 ½ months stay received no structured bowel management to meet his acute clinical need as advised by SCIC outreach. For the duration of his stay Jim remained only in ICU, and HDU where patient to staff ratio's are at there highest. There was significant pressure from the hospital to transfer Jim to alternative venues, much resisted by the family due to concerns over possible care levels

Impacted bowels and constipation complicate the respiratory system in someone with SCI. Further, the psychological impact in coming to terms with a traumatic life event and newly acquired severe disability being amplified by an unmet and unmanaged incontinence need outside of a specialist SCIC do not contribute towards the process of coming terms with SCI. Compounded by the isolation, and acquisition of a pressure ulcer, that once healed will be scar tissue requiring incredible vigilance to ensure repetitious skin breakdowns are avoided, as are hospital readmission.

Jim's rehabilitation is only just commencing 18 weeks post injury.

Case study 3 – (David):

David a 50-year-old man was admitted for elective knee surgery to alleviate chronic symptoms. Due to surgical complications he was paralysed at an incomplete mid-thoracic level. The surgical complications have resulted in litigation and an end to David's career as an engineer. He is now on benefits.

After an initial stay post op on an acute surgical ward David was transferred to a Neurological Rehabilitation Unit (NRU). He was referred to an SCIC, but due to the waiting list and clinical assessment David was categorised with a low priority for admission. As result of this David underwent rehabilitation at the NRU.

David did not receive a visit from SCIC Outreach. He did receive significant and regular involvement from the Spinal Injuries Association's Community Peer Support service.

This was the only involvement with peers David received, and to undergo this whole experience in isolation of potentially beneficial experienced patient peers from which to gain tools and coping mechanisms, combined with others experiencing the acute phase of SCI with which to share fears compound the impact of the SCI to the point where positive outcomes are virtually impossible.

David seriously struggled to adjust to the devastating impact of his paralysis. He walked into hospital for elective surgery with a view to be able to better mobilise for work, and life generally. His outcome was to be paralysed, lose his job, discharge home to completely inaccessible housing for his needs as a wheelchair user, and place incredible strain on his marriage and family. His daughter also has a disability from birth and attends a specific school for her needs within the locality of their existing home.

As a result of non-admission to an SCIC to rehabilitate David's care has been compromised. The education, equipment provision, discharge planning (which incorporates housing issues), and practical instruction to living with SCI are far superior in an SCIC compared to an NRU.

If David is not referred to an SCIC as an outpatient he will have no coordinated venue to deal with the ongoing issues associated with SCI for the whole of his life.

This puts David at risk of extended readmission to a non-specialist hospital (DGH), and associated risks such as bowel care in a DGH. NICE guidelines, RCN guidelines, and the MASCIP guide all instruct regarding the needs of bowel care in SCI. They are rarely achieved.

Physiotherapy in isolation can be sufficient, but to rebuild your life after SCI you require a holistic approach to all aspects of SCI. Care, education, mobility, transport, housing, work/study, relationships.

The risk for individuals such as David is that by missing out on SCIC rehabilitation, or having massive delays in admission to an SCIC is that significant irreversible damage can occur. The nuanced care, resources, staff experience, concentration of SCI community, raised aspirations and the centres of excellence for bladder, bowel, and skin care is either never accessed, or accessed sufficiently late enough to require a much longer stay in hospital

Article 26 - Habilitation and rehabilitation

SIA also is concerned that the 10% newly injured SCI people who never get to a specialist SCI Centre are being denied their rights under the UN Convention to receive **Peer Support** as when they are in a non-specialist hospital they are more and likely to be the only SCI person in that environment (see concerns relating to Article 25 Health).

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these

services and programmes: a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths.

Summary of SIA Concerns:

- 10% of newly injured SCI people in the UK never get to one of the 11 UK specialist SCI Centres which have been set up to support patients sustaining spinal cord injury through the initial period of treatment and rehabilitation and provide on-going lifelong support.
- Non Specialist healthcare environments e.g. district general hospitals often are not able to carry out SCI people's day-to-day care needs, and/or professionals within these environments do not understand fully SCI resulting in people being discharged with other complications or having an unnecessary longer stay
- SCI people and their relatives often feel disempowered when being admitted to non Specialist healthcare environments
- There is a chronic lack of bed capacity in the UK's 11 specialist SCI Centers resulting in SCI people experiencing admission delays and severe restrictions on re-admissions

SIA believes that many SCI people in the UK are being put at unnecessary risk because of failings we have highlighted to the UK's health care system. In some cases these failings could lead to a shortened life expectancy or be fatal.

SIA therefore calls on the Committee re: UN Convention on the Rights for People with Disability to bring these concerns to the attention of the UK Government and bring pressure to bear to insure that the UK Government's relevant health departments work closely and meaningfully with SIA, BASCIP and MASCIP to resolve these issues before the next UN Shadow Report on the UNCRPD.