

[Copy of text SIA fed into the Office for Disability Issues \(ODI\) Website June 2011 re: ODI's shadow report on how the UK Government is performing against its commitment to the articles laid out in the UN Convention on the Rights of People with Disabilities.](#)

## **Article 20 – Personal Mobility**

The majority of SCI people require a wheelchair to go about the daily business and the Spinal Injuries Association (SIA) is concerned that for many the wheelchair(s) they receive are not fit for purpose for some people:

***“The wheelchair services set up in Wales is inadequate, inflexible and fails to take into account the particular needs of people who require their services. Unlike the voucher scheme in England where we believe there is flexibility to chose the wheelchair that suits yourself best, in Wales we are bound by their very strict procedures. My husband is a C6/7 Tetraplegic with no hand function and limited arm function. He can self propel but only (at this stage) for short distances. He only came out of hospital 9 weeks ago so we hope with time and training his strength and ability to propel for longer distances will improve. We therefore requested (and expected) a self propel wheelchair that is as light and maneuverable as possible. We found one that was suitable that was far cheaper then the big, heavy electric chair they believed he should be in and a similar price to the one we ended up with. We eventually got a self propelled chair but it is a tank! We asked to use the funds they would have provided for this chair to add to our fundraising so that we may purchase the exact one we wanted – not allowed! So we have ended up with a tank, that as soon as we can get the fundraising etc sorted out will be replaced with the one my husband wants, and the one that suits his requirements far better. This whole wheelchair saga has been very stressful for us both, has strained my husbands already weak shoulders numerous times and is a complete waste of money for the taxpayer! All that staff time, and the purchase of the wheelchair will be wasted, as once we have our own it will sit in the garage. I had hoped to at least be able to donate it to a charity to help others, but because apparently it doesn't even belong to us we can't do that either!”***

## **Article 19 - Living independently and being included in the community**

SIA has concerns re: the closure of the Independent Living Funds (ILF) & reductions in NHS Continuing Healthcare Funding

### **ILF**

Many SCI people need a care and support package to enable them to live as independently as possible. Those with a high lesion injury may need a significant amount of care and support some 24/7.

SIA is most concerned that since 01/05/2010 the UK Government closed the ILF to all new applicants.

*The ILF is an Executive Non-Departmental Public Body of the Department for Work and Pensions. It awards payments to severely disabled people to support the cost of their personal assistance, enabling them to live fully inclusive independent lives in their communities. To get payments from the ILF you have to meet certain conditions.*

*The ILF provides financial assistance under the terms of a single publicly financed discretionary Trust Deed - The Independent Living Fund (2006), governed by a Board of nine Trustees. The ILF currently provides financial support to over 21,000 disabled people in the UK, and has supported over 46,000 disabled people during the last 21 years.*

According to the last user profile report published by the ILF (2006), that gave a breakdown of users of the Funds re: disability, 1266 users (7% of total users had a SCI). These users and those with a SCI applying before 01/05/10 will have their ILF funding protected although they can not expect any increases to cover any changes in their care-packages unless they are employment related or they have a change in income.

Newly injured people with a high SCI lesion who are/were in the process of treatment and/or rehabilitation or are/were awaiting discharge/have recently been discharged from a SCIC or other hospital, who have not applied to the ILF by 01/05/10 now face the prospect of having to live with a severely restricted care package compared with those who applied pre-01/05/10. They will now be dependent on their Local Authority making up the shortfall which ILF has traditionally provided to enable people to do more than just get up in the morning, get fed and go to bed at night.

With Local Authority Community Care budgets coming under enormous pressure since the 2010 UK Government spending review it can be assumed that many Local Authorities will only provide minimum funding and those SCI people without access to ILF will be without the extra support to enable them to start re-entering and taking a part in mainstream society. It could also be assumed that if budget pressures remain for some time and ILF is amalgamated into Individual or Personal Budgets or Direct Payments and therefore the overall Community Care budget the awards for care packages/assessments which will then be purely undertaken by Local Authorities will be driven down.

Using statistics gathered in SIA's Preserving and Developing the national SCI service report it is fair to estimate that there will be approx. 75 newly injured high lesion SCI's between 01/05/10 & 30/04/11 who would have qualified for ILF but will now be unable to apply for this extra funding for care and support.

***“My husband is now home and the care package is yet to be sorted, apparently all he should be doing (at the age of 35 and after a lifetime of exercise, adventure sports and outdoor living) is be washed and put into his chair in the morning, and left for the day until the evening when he is put to bed – that is no life! Instead I care for him 24/7 to ensure he can continue to live his life properly. We are being told that we will only receive 8.75 hours a week of direct payments to employ someone as a PA to help us out and that I don’t need respite! There is also no long term commitment to meet his physio and therapy needs. There always seems to be some human rights case on the TV were prisoners or convicted paedophiles are gaining because their human rights have been violated – what about my husband’s human right to live an independent, fulfilling and healthy life?”***

### **Continuing Healthcare**

Continuing Healthcare (CH) is increasingly becoming a concern as local health budgets are squeezed, resulting in reduced care packages for those who receive it. Despite the fact that Spinal Cord Injury is a stable condition which neither improves nor has a medical cure, there are numerous examples of care packages being dramatically reduced after reassessments. The case of Pamela Coughlan established that a tetraplegic who has an injury of the C5 vertebrae or higher has needs which “far exceed” the threshold for CH provision. However, even Spinal Cord Injured people with considerably greater healthcare needs than this are seeing their care packages severely reduced.

This pressure on budgets leads to an ad-hoc, post code lottery service as different trusts limit their budgets to different extents and the National Service Framework is interpreted differently to meet the needs of budgets.

***“It’s only going to get worse if they don’t put more money into the pot. We’re in year one of serious cuts and presumably they’re only going to get worse”***

### **Article 28 - Adequate standard of living and social protection**

In a recent online survey for SCI people, conducted by SIA over the winter months of 2009-2010, 58% of people responding calculated they were in Fuel Poverty.

A UK household is said to be in fuel poverty if it needs to spend more than 10% of its income on fuel to maintain a satisfactory heating regime (usually 21 degrees for the main living area, and 18 degrees for other occupied rooms).

50% of people responding to the survey said they had difficulty paying their bills. Of these:

- 10% were in arrears with fuel bills

- 3% were in significant arrears with fuel bills
- 87% often switched off or turned down their heating to keep fuel bill down
- 52% said they or their family often went without other things so they could pay their fuel bills – the most affected areas were family and social activities, and travel. 12% of those answering this question said that they often went without food and hot meals. Other responders missed out on; clothes; items for disability (incl. medication); Christmas presents; home decorating or they had parents who did not live with them helping to pay their bills.

If someone with a long term condition needs extra heating to prevent such things as hypothermia, limited blood circulation and cannot heat their home environment sufficiently then it is likely that they will develop various complications requiring costly medical and hospital treatment, and in some cases this lack of heating could prove fatal.

Many people with a SCI have no or limited body temperature control and are therefore very susceptible to temperature fluctuations (it is generally recommended that SCI people maintain their home environment to around 22 degrees Centigrade).

Although the UK Government has taken some steps to address this issue SIA believes that these steps did not go far enough and were ill thought out. As a consequence of these inadequate actions many SCI people in the UK in 2010 struggle to pay their fuel bills, are in arrears, and/or suffer health problems associated with not being able to heat the homes properly purely because they cannot afford to.

Under Article 28 of the UN Convention on the Rights of Persons with Disabilities the UK Government has a duty to ensure that people with disabilities and their families have an adequate standard of living and continuous improvement of living conditions.

'States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.'

The Government is clearly failing to uphold this duty by letting many slip into or remain in Fuel Poverty which in turn is leading to increased health problems for SCI people who can not afford to heat their homes adequately:

In the afore mentioned survey for SCI people conducted by SIA over the winter of 2009-10, the following statistics were recorded:

- 97% of people responding said they needed extra heating to help manage their SCI and ensure they remain healthy

- 26% said they had suffered health problems in the last 5 years because they could not afford to heat their home adequately – these problems included:
  - Frostbite
  - Pneumonia
  - Increase in spasticity
  - Raynaud's Syndrome
  - Bowel problems
  - Aggravated arthritis
  - Colds & Flu
  - Circulation problems
  - Cardiovascular problems
  - Brittle bones
  - Leg swelling

## **Article 9 - Accessibility**

Phase 3 of the Disability Discrimination Act (DDA) was introduced by the UK Government in 2004 which set out how businesses and services had to make physical alterations to their premises to overcome access barriers or make 'a reasonable adjustment' (E.G. installing ramps for wheelchair users) the legislation prove weak in the respect that all the onus was on the disabled person to prove they had been discriminated against re: access.

Even though this part of the DDA legislation has been in force for approx. 7 years SIA continues to be inundated by SCI people who have access issues:

***“6th form college students' performances - held in the "good" theatre with quality lighting and sound systems and such-like. But there's no wheelchair access to this theatre, so as a parent I cannot support my daughter. She was given the option of using a lower-quality theatre, but for various reasons, and this being assessed work, she would not get as high a grade there! Clear mobility discrimination! Hate to think what would happen if one of their students had mobility problems - would they automatically get a lower grade at A level?”***

***“Within 200 yards of pedestrian shopping are there are 7 pubs. As far as I know none of these have toilets that is accessible to wheelchairs. Let alone purpose build one. I wrote to McMullans the owner of the pub about it but I have not received any answers. People running the pub must have been told that, Next time I went to that pub to watch football, I received such dirty looks that it put me off going to any one of the pubs. Because I could not get to the toilets I used to leave when I needed one anyway. I thought even if I forced the issue, going there was not going to be good experience anyway. So I gave up.”***

***“One local Indian restaurant has special offers on Monday nights. I tried to go there, the door was so awkward I couldn't get in. So I asked to take away the 'special offer', but I was told that is only for diners in the restaurant.”***

***“At my local public swimming pool in Teddington my 4 year old daughter was attending a swimming lesson and I went to watch. The viewing gallery is accessible only via stairs, so I asked if I could remain at poolside. The member of staff at the entrance desk agreed and escorted me. I parked against the wall near the learning pool as she instructed, a few meters from the actual pool, leaving plenty of space for unobstructed movement of others. As the class was about to begin, 4 members of staff approached me en masse and told me I could not remain where I was. I said I wanted to watch the class - extremely important for both me and my daughter, but they were adamant that I re-position myself in the alcove where the main access to the pool is. This, apart from being out of view for the learners' pool from a wheelchair, was also a nonsense as I would be obstructing the entry/exit point! They were insistent and I became quite upset, angry even (something very rare for me) and insisted I remain to watch the class. Given my attitude they allowed me to stay, after having reprimanded me like a child for 'raising my voice'. I followed up on this upsetting event with a letter and did in due course receive a reply and assurance that in future I would be allowed to park where I had.”***

***“At the Cavendish Square Masterpark car park in central London W1 (between Oxford Street and Harley Street ) recently I was to attend an appointment with a pain consultant in Harley Street . The consultant recommended I use the above car park, which I did. I do not drive myself and so had a friend drive me. Once inside the underground parking and out of the car, we looked for the lift but could find only stairs. I pressed the assistance button and asked how I could get out, only to be told there were no lifts and therefore no provision for disabled persons and please could I leave! Apparently there is a sign at the entrance but it was not one that we had noticed.... I had naively assumed that such a car park, being entirely underground, must have a lift. Clearly they have found a way around the legislation but I was appalled. Needless to say I was late for an expensive appointment and very upset by this exclusion. I had intended to write a complaint letter but must admit I have not yet found the time or energy to do so. Perhaps I will do now.”***

***“I am still amazed at the daily discrimination that a wheelchair user faces. The pavements are obstacle courses, indeed on my own road there are kerbs without inclines/declines where a road needs to be crossed, numerous large bumps and out of place paving that often send me lurching forward in my chair etc.”***

***“Went to visit my friend at her university , partly my friends fault for taking me there , but there was no access at all for disabled people at her union club thing, there was literally about 25 steps up to main door, then when you got in abut 10 steps down, then another three, and as I smoke I had to go back up some to have cigarette, because I can hold onto things or people and walk a little bit we managed it. I just thought that for a student union bar it would have been accessible.”***