

The Joint Committee on Human Rights
House of Commons
7 Millbank
London
SW1P 3JA

Dear Sirs,

The Spinal Injuries Association (SIA) warmly welcomes the opportunity to submit evidence to the Joint Committee on Human Rights on the subject of Independent Living. SIA is the leading national user-led organisation supporting the interests of approximately 40,000 people in the UK who have sustained Spinal Cord Injury (SCI) and their families. SIA has a membership of over 5,000 SCI people.

We believe that the JCHR now has an opportunity to address the increasingly detrimental affect that current Government policies are having on the ability of disabled people to live independently.

Our response therefore concentrates on '**The impact of funding on the right to independent living**' and seeks to highlight the concerns that are affecting Spinal Cord Injured in the light of recent Government policies and budget cuts.

Yours faithfully,

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Executive summary and recommendations

- SIA expresses our complete rejection of the Government's intention to remove the Mobility component of DLA and PIPs from disabled people in residential care.
- SIA feels that the Government's commitment to Independent Living will be jeopardized by limiting access for those who rely on the mobility component of Disability Living Allowance
- SIA believes that without the Independent Living Fund it is likely that a disabled person could not afford to do anything more than manage their condition.
- SIA calls on the Government to reopen the ILF with immediate effect to all those who meet the eligibility criteria for accessing funding.
- SIA believes that pressure on budgets leads to an ad-hoc, post code lottery service for Continuing Healthcare, leading to severely disabled people receiving wholly unsuitable care packages for their level of need.
- SIA believes that the notion of 'The Big Society' will do little to negate the impact of budget cuts on disabled peoples' ability to live independently, and that the inflexibility of volunteers will severely impact the ability for disabled people to live independently.
- SIA believes that if the UK Government continues to cut funding on the benefits and services which support disabled people it will not be able to fulfil its obligations under the UNCRPD.

About us

- 1) The Spinal Injuries Association (SIA) is the leading national user-led organisation supporting the interests of approximately 40,000 people in the UK who have sustained Spinal Cord Injury and their families. SIA has a membership of over 5,000 SCI people.
- 2) As a user led organisation the following memorandum has been based on the experiences of our members, who are increasingly contacting us regarding the effects that Government policies and budget cuts are having on their ability to live independently.

The impact of funding on the right to Independent Living

DLA Mobility component in residential care

- 3) SIA would like to express their complete rejection of Government's intention to remove the Mobility component of DLA and PIPs from disabled people in residential care. Mobility is absolutely crucial to a disabled person's independence. Those who live in care homes will be even less able to exercise this basic human right.

- 4) Newly injured Spinal Cord Injured people are increasingly being discharged straight from hospital into a Care or Nursing home as an interim arrangement while they wait for suitable care packages, housing or property adaptations to be arranged. These can be drawn out processes and may leave such people in care homes for extended periods.
- 5) It is of vital importance that newly injured Spinal Cord Injured people start to reintegrate into mainstream society as soon as possible to avoid becoming hospital dependent and institutionalised. Removal of the mobility component, or indeed any of DLA or PIP, could severely restrict their ability to leave their institution, adapt and become independent.
- 6) With the considerable cuts being faced by Local Authorities across the country SIA anticipates that many more disabled people will be housed in Nursing and Care homes in the foreseeable future as savings are plundered from social services budgets. Removing such an individual's means for mobility will dramatically reverse the independence agenda for those disabled people most in need, in many cases irreparably.
- 7) The Government states that it is committed to supporting disabled people to exercise choice and control over their lives. This is a commendable intention, but one that will be jeopardized by limiting access for those who rely on the mobility component of Disability Living Allowance for the independence they currently enjoy and is their right.

The Independent Living Fund (ILF)

- 8) The ILF is a vital source of funding which supplements the care packages of disabled people and allows them to live an independent life with support which extends beyond activities such as bathing or having a meal cooked for them. Without ILF it is likely that a disabled person could not afford to do anything more than manage their condition.
- 9) With the closure of the ILF to new claimants and, in all probability, existing claimants from 2015, Local Authorities will be required to make up the shortfall in funds which the ILF has traditionally provided. This money will have to come from stretched budgets that are already under enormous pressure. If the ILF is amalgamated into the overall Community Care budget SIA believes that the awards for care packages will inevitably be driven down considerably.
- 10) With severe cuts to Local Authority budgets, SIA fears that many will only be able to provide minimal funding to those with high care needs. Spinal Cord Injured people without access to ILF will be without the extra support to enable them to take an active part in mainstream society. This situation will be more acute for the newly injured who require more support to reacclimatise themselves to life with a disability.

11) SIA calls on the Government to reopen the ILF with immediate effect to all those who meet the eligibility criteria for accessing funding and to work with users of ILF and their representative organisations to ensure ILF works at maximum efficiency for its users, it is accountable and it delivers value for money for UK tax payers.

Continuing Healthcare

12) 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.

13) 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 rather than people.

The Big Society

14) SIA believes that the notion of ‘The Big Society’ will do little to negate the impact of budget cuts on disabled peoples’ ability to live independently.

15) Services which are run by volunteers are inherently inflexible as they are dictated by the times the staff are available – for instance a shopping trip may occur at a particular time each week. Flexibility is absolutely essential to the idea of Independent Living – the power to do whatever you want whenever you wish.

16) There is no indication where this army of volunteers will come from, but it is likely that the majority will be those of retirement age. It is questionable as to whether these volunteers will be willing to give up late evening and early morning time to support disabled individuals, yet such support is vital if disabled people are to truly live independently.

17) An individual has more control over a service that they pay for as they are paying customers. It is considerably harder to complain to a volunteer who is giving up their time of their own free will, and this will impact the

suitability of services that disabled people reliant on volunteers will receive.

Conclusion

- 18) SIA believes that if the UK Government continues to cut funding on the benefits and services which support disabled people it will not be able to fulfil its obligations under the UNCRPD.
- 19) SIA also does not believe that the Government has looked at their reforms holistically and by reducing the support costs to disabled people across the board they will severely disenfranchise disabled people and prevent them from living the independent lives which should be their right.
- 20) Indeed, such cost cutting reforms may actually burden the tax payer with additional costs elsewhere. For instance, inadequate care packages, which result from a drive to cut budgets across numerous different areas, are likely to result in increased hospitalisation episodes due to poorer standards of care management, with conditions such as pressure ulcers and urinary tract infections becoming more prevalent. As a result of seeking savings from a social service budget, the cost will inevitably transfer to an NHS budget, but at a higher rate as the treatment of such conditions is considerable. Not only will the cost to the tax payer increase by hundreds of millions of pounds, the cost to the individual will be even greater, resulting in poorer health, loss of independence and reduced capabilities, in many cases for life.
- 21) SIA calls on the UK Government to continually assess the implications of any current and future budget cuts which may impact upon disabled people's rights as they are laid out in the UN convention.