

The Spinal Injuries Association's (SIA) response to the Care and Support Green Paper

About SIA

The Spinal Injuries Association (SIA) warmly welcomes the proposal to establish a new national care service.

SIA represents the 40,000 Spinal Cord Injured (SCI) people throughout England, Wales and Northern Ireland. SCI manifests itself as paraplegia (full or partial paralysis of the lower limbs) or tetraplegia (full or partial paralysis of all four limbs), both of which will result in full or partial loss of sensation in the affected limbs and render the individual doubly incontinent. Many of SIA's tetraplegic members have a need for very high levels of care and support throughout their lives from the moment of injury. Other members need care and support increasingly as they age but at an earlier age than their 'able-bodied' peer group due the effects of their disability over time (e.g. over-usage of upper limbs for weight-bearing transfers).

The focus of our response is to help achieve a world class care service that can achieve the best outcomes for all SCI people.

1. We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:

- prevention services**
- national assessment**
- a joined-up service**
- information and advice**
- personalised care and support**
- fair funding.**

a) Is there anything missing from this approach? b) How should this work?

SIA agrees with these broad principles. The concept of personalised care and support which will assist people to live in their own homes for as long as possible is warmly welcomed. Similarly, we fully support the principles of a national, portable assessment and breaking down the artificial barriers which currently exist in care provision, namely between health and social care, to ensure a joined up service that will best serve people with SCI.

In broad terms this should work by:

- **Prevention services** – lowering eligibility criteria's for services across the UK to a national agreed minimum level to stop people slipping into high critical need either entirely or prolonging them longer in lower levels of

need. This will be both beneficial to the health and wellbeing of the individual and cost effective to the state.

- **National assessment** – any agreed national assessment format taking into account the extra costs related to people needing specialist care and support needs. NB – assessments and packages also need to be portable enabling people to move easily from one area to another of the country
- **A joined-up service** – Requiring NHS, Local Authorities and other service providers to work closer together
- **Information and advice** - being provided by an independent body (ideally by a user-led local Centre for Independent Living, or user-led national organisation)
- **Personalised care and support** – disabled people being able to either direct and commission their care and support via direct payments or choose how their care and support is delivered via an individual/personal budget
- **Fair funding** – The concept of “fair funding” is of course open to interpretation – fair to whom? Currently, Local Authorities operate a ‘Fair Access to Care Services’ policy that is anything but fair, with some of SIA’s most severely disabled members experiencing a postcode lottery of inequitable care funding. The funding of the service must be adequate nationally and allow the needs of persons with high levels of physical disability such as tetraplegics to be supported to an adequate extent.

SIA looks forward to making further comment when more detail of these proposals becomes available.

2. We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.

a) Do you agree?

b) What would this look like in practice?

c) What are the barriers to making this happen?

For people with SCI, who in many cases become severely disabled (paraplegic or tetraplegic) at a comparatively young age but who can expect to live to something approaching a normal life expectancy, choice and joined up services are vital concepts. Our members wish to live as independently, and to have as much control over their lives, as is possible, something that they are able to achieve through a good system of care and support. Direct Payments with which our members can directly employ Personal Assistants (‘carers’) are an important component of this, and the use of care agencies which employ staff with specialist training in SCI are another. Personal budgets may prove to similarly empower our members.

To make this vision a reality, it is important that:

- care and support is funded adequately so that (i) Local Authorities can adopt an attitude of ‘what can we do to help you?’, rather than one of ‘how few hours of assistance can we get away with providing?’, which is the reality for some of our members, and (ii) remuneration for Personal Assistants is sufficient to allow recruitment and retention and allow stable care to be given.
- The frequently nonsensical partition of care provision into ‘health’ and ‘social’ care (e.g. in relation to the management of incontinence) is eradicated and that care provision for an individual is viewed holistically.
- The government recognises the impact of changes in employment law (e.g. Working Time Directives, flexible working, and extension of paid maternity/paternity leave or annual leave entitlement) on the delivery of care and the burden that is placed on our members as employers of Personal Assistants.
- Individuals with SCI need to be given choices in how their care and support is provided. For example, over-prescription as to the status of allowed ‘carers’ such as insistence on the use of CSCI -registered care staff or use of a care agency, should be avoided.
- Avoidance of overly-prescriptive Health & Safety regulations that limit choice of manual handling of disabled people in transfers (e.g. from bed to wheelchair)
- Local Authorities, PCT and other service providers STOP working in isolation
- User Led Organisations providing support services for users are adequately funded with sustainable funding streams

Additionally, SIA opposes the Government’s proposal to means test Attendance Allowance (AA) as this will further limit disabled peoples’ capacity to manage their care needs as they wish. SIA understands that even if a person passes a means test they will not receive AA as any payment will become part of their overall care package. Some people with SCI reject a care package, instead choosing to be cared for by partners or family members. For these people AA is used to offset the extra costs associated with managing their disability and the loss of earnings their partners and family incur when giving up work to provide their care and support.

Although the Government has given assurances that similar moves in Disability Living Allowance (DLA) are not being considered at the moment, recent comments from Andy Burnham, Secretary of State for Health, seem to indicate that this is only true for DLA payments to those under the age of 65. SIA is concerned that this is the beginning of a review of all such benefits, the removal of which will have dire consequences for many disabled people.

Both AA and DLA are critical for the well being of SCI disabled people. The mobility component is essential for the mobility of disabled people and the care element is meant to cover the additional costs accrued as a result of their disability rather than just being an element of funding their care provision. Indeed, many recipients of these benefits are not in receipt of care at all, but are still reliant on these payments to meet disability related costs such as cleaning, gardening, additional heating etc. In the event that these benefits become part of an overall funding pool for care, will the disability related costs of those ineligible for such care continue to be met through AA or DLA payments?

3. The Government is suggesting three ways in which the National Care Service could be funded in the future:

Partnership – People will be supported by the Government for around a quarter to a third of the cost of their care and support, or more if they have a low income.

Insurance – As well as providing a quarter to a third of the cost of people’s care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.

Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.

a) Which of these options do you prefer, and why?

The consultation document does not give great detail on how each of the proposed methods of funding would be implemented, so it is difficult to say with certainty which option would be most acceptable to SCI people. Although the models clearly refer to care in older age, the document does not give much clarity on care for working age disabled people beyond a conviction that the “majority” of these users would get their care for free. SIA would welcome an explanation of how this free care would be assessed, who would be eligible and what is proposed for the subsequent ‘minority’ who will also require care through their adult lives. The method in which care is provided for working age disabled people will have the greatest impact those with an SCI.

SIA would also like clarity on how the care provisions for working age adults will marry with the proposed models for care for the over 65s, the costs which an individual will incur during the transition from one to the other and how their care provision will be affected by this change.

Considering the needs and views of our members, SIA is vehemently opposed to the Insurance option, which we believe would not offer an equitable solution for disabled people. Under the DDA 2005 it is still possible to discriminate against a disabled person in insurance provision. As they represent an increased risk, those disabled people who are not currently in care but will almost certainly require it in later life will either face vastly increased premiums or essentially be

uninsurable to the majority of private insurers. Whilst the consultation document states that those disabled adults who do not work will have their care provided for free, those that do work or accrue savings will have to pay for a large proportion of their care without the same financial assistance available to the general population through private insurance policies. If this option is selected, it is unacceptable that a group with a greatly increased likelihood of care requirements in later life will not be able to benefit from the same protection as others.

With the Government's ambition to get disabled people back into the workforce, it is likely that the proportion of disabled people affected in this way by the insurance option will increase. In the eventuality that it is adopted it is likely that disabled people will be less inclined to take up employment so as to ensure free provision of their care in the future. This will not only have an increased cost implication for Government in terms of benefit and care costs, but will stand in the way of the social integration and social mobility that employment affords, thereby considerably setting back the disability equality agenda.

Basing our views solely on the information given in the consultation document, the Comprehensive model is SIA's preferred option. It is fairer than the insurance option as everyone has the same opportunities to cover their future care costs.

However, any such Government insurance scheme must be managed transparently, with all monies accrued being fed back into the care system. The National Insurance scheme, which seems comparable to the proposed plan, is now regarded as little more than an additional tax imposed by Government.

There may also be some merit in considering funding the new care service through general taxation, a route currently ruled out by the Government. In the consultation document the Government asserts that:

'The generation currently in their 50s and 60s, or older, has benefited in particular from massive increases in property prices, as well as free higher education and other advantages.'

However, future generations will not have these same benefits. Higher education is no longer free in England and students now leave University thousands of pounds in debt. Property prices are at record highs, but the boom experienced since the 1980's cannot continue as prices will always be limited by what first time buyers can afford. Social changes are also afoot such as higher separation rates and the end of the concepts of 'jobs for life' and 'final salary pensions', all of which will have an impact on the relative prosperity of future generations.

b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

SIA is aware of considerable disparities in the levels of care and support currently being made available in different parts of the country to members with very similar levels of disability and need, and of marked differences in the assessed financial contributions that its members have to make to their own care costs. This problem is compounded by the increasing stringency on the part of some Local Authorities in their eligibility criteria for support under the Fair Access to Care Services (FACS) assessment process, which renders some of our members unjustifiably ineligible for assistance. As such, SIA believes that support should **NOT** be dependent on local eligibility criteria, postcode or Local Authority resources, and that national guidance that establishes transparently fair rules for financial support needs to be established. Hence, for example, a C5 tetraplegic living in Newcastle should be entitled to expect the same level of support as a C5 tetraplegic in Northampton.

SIA believes that once a workable package of care is established and the necessary funding agreed, then should that disabled person at a later date relocate to a new authority, social, health or combination, the established care package and funding should automatically be accepted by the new authority(s), without the need for reassessment, suspension of service (funding) or any action on behalf of the new authority(s) that is in anyway detrimental to the continued care of the disabled person. i.e. care packages and their funding must be transportable and follow the disabled person.