

CARE & SUPPORT TEAM
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SIA RESPONSE TO THE GOVERNMENT'S DEBATE ON THE FUTURE OF CARE AND SUPPORT

Section 1. 'Achieving our vision'

SIA supports the Government's vision for the new care and support system and especially in terms of its stated objectives

"that people are supported to

- Live independently
- Stay healthy and recover quickly from illness
- Have as much control over their own lives as possible
- Live with or look after their family
- Participate as active and equal citizens
- Have the best possible quality of life".

For people with spinal cord injury (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, these 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.
- Cognisance is taken of the impact of changes in employment law (e.g. Working Time Directives, flexible working, and extension of paid maternity leave) 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.

What needs to be strengthened?

Section 2. 'Sharing the responsibility for care and support'

People with SCI, especially tetraplegics, can require significant specialist care from highly trained and dedicated care teams. Often, this may involve parents, spouses and other family members who assume this role in the aftermath of traumatic SCI, as well as 'carers' that are employed in this role.

Because SCI occurs suddenly/unpredictably, often at early age, our members are rarely afforded the possibility of planning for it financially [unlike dementia and other late-onset conditions which are a corollary of normal ageing process and for which prudent planning for care fees is possible). SIA therefore supports the Government's notion of protecting financial support for people who have become disabled at a younger age.

Moreover, individuals with SCI tend to have high disability-related costs, e.g. for adapted vehicles, wheelchairs, housing adaptations, and may need to accumulate assets to budget for this expenditure. It is important, therefore, that this be recognised in any means tests of eligibility for care and support.

Section 3.' Setting fair rules for financial support in the future'

National or local?

SIA represents paraplegic and tetraplegic members with SCI throughout England, Wales and Northern Ireland. Many of its tetraplegic members have a need for very high levels of care and support throughout their lives from the moment of injury, and 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-use of upper limbs for weight-bearing transfers). However, 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. Furthermore, 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. SIA thus 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 at a later date that disabled person 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.

Same help for all or prioritise people with particular types of needs?

Currently, financial support for care and support for SIA's members comes from diverse sources, including Local Authority Social Services departments (either as agency homecare services or as Direct Payments), the Independent Living Fund, and NHS Continuing Healthcare. Relatively few members are fortunate enough to receive significant compensation awards for their future care. SCI can occur at any age, but a large proportion of SIA's members are injured whilst they are young adults and, as such, are rarely in a position to have accrued significant financial assets. In this respect, SCI typically differs from many other conditions (e.g. dementia, Parkinson's disease) which tend to arise in later life by which time an asset base can be established and for which it may be argued prudent planning for care costs can occur. Moreover, the extra costs incurred by SCI members due to their disabilities (e.g. specially modified vehicles, housing adaptation, wheelchairs, extra heating costs) can be substantial. Accordingly, SIA believes that SCI people are, along with others, a specialised group, and that some prioritization of help should be accorded to them. SIA believes that to provide the same help for all irrespective of need to be wasteful of resource.

Same help/support for all or more for people with low incomes and assets?

SIA supports the notion of providing greater levels of support for people with low incomes and assets. Untargeted support, as for example occurs with winter heating allowance for all people over 60 years of age whether they work or are retired is not the way forward.

Daniel Burden
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