

## **The Spinal Injuries Association's (SIA) response to the Law Commission's consultation paper on Adult Social Care**

### **About SIA**

The Spinal Injuries Association (SIA) warmly welcomes the opportunity to respond to the Law Commission's consultation on Adult Social Care.

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 to 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 legal statute that will achieve the best outcomes for all SCI people.

[Question 2-1: Is our proposed three-level structure for the regulation of adult social care law \(consisting of primary legislation, statutory instruments and guidance\) appropriate?](#)

This approach seems to give a suitable degree of legislation coupled with the flexibility for care to be provided in a way suitable to local circumstances. 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. 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.

[Question 2-2: Should there be a duty on the Secretary of State and Welsh Ministers to prepare a code of practice to bring together statutory guidance?](#)

A unified code would simplify the current legislation for users who may be daunted or confused by the number of guidance documents which currently exist. Additionally, by bringing the guidance closer together, this may ultimately lead to a more holistic view of funding care provision in the future, breaking down the artificial divide that currently exists between health and social care provision.

[Question 2-3: Is our process-driven approach to adult social care \(a prescribed assessment and eligibility process, with support from prohibitions, a broad list of services, care plans and statutory principles\) sufficient to determine the scope of adult social care, or is further definition required?](#)

Whilst SIA broadly agrees with this approach, any such definition should also include areas such as advice, signposting and following up cases for those who fall just outside eligibility criteria to try and ensure that they receive any additional support that they may be available or that they are entitled to.

**Question 3-1: Should there be a principle in our proposed adult social care statute which provides that decision-makers must maximise the choice and control of service users?**

The concept of choice and control is absolutely vital to the successful provision of care services to users and should be the corner stone of any future legislation.

**Question 3-2: Should there be a principle in our proposed adult social care statute based on person-centred planning – or should this be incorporated into other provisions of the legislation?**

Person centred planning should be central to any new statute. Whilst the concept should be incorporated into other provisions of the legislation, it should also be a principle in its own right in order that its importance is recognised implicitly.

**Question 3-3: Should there be a principle in our future adult social care statute which provides that a person's needs should be viewed broadly?**

A person's needs should be viewed holistically. In keeping with the principal of personalisation, users will have very different needs that they may consider should be met by their care provision, and differing methods of meeting these needs. A broad view of a person's needs would also assist a service user to take full control of their care provision. Any future legislation should recognise these points.

**Question 3-5: Should there be a principle in our proposed adult social care statute based on the concept of independent living?**

Such a principal should be included in any forthcoming statute. 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.

**Question 3-6: Should there be a principle in our proposed adult social care statute based on an assumption of home-based living?**

Whilst home based living is certainly the preferred method of care provision for the majority of our members, some people may wish to have their care and support provided in an alternative method, and this should continue to be their right. If the statute is weighted sufficiently in favour of choice and control, as SIA advocates, then this should ensure that all of those who wish to receive their care at home have that right.

**Question 3-7: Should there be a principle in our proposed adult social care statute based on dignity in care?**

Every human has a right to be treated with dignity and respect. This must be recognised in any future statute.

Question 3-8: Should there be a principle in our proposed adult social care statute based on the need to safeguard adults at risk from abuse and neglect?

An adult requiring care of any type is vulnerable and open to abuse. The need to protect them must be recognised in any future legal statute.

Question 3-9: Should any one principle in adult social care be given primacy over all other principles?

As mentioned above, the concept of choice and control should be the corner stone of any future legislation. 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 control 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.

Question 4-1: Should our proposed adult social care statute include a right to have an assessment on request?

Yes, the new statute should include this right.

Question 4-2: Should our proposed adult social care statute recognise co-produced self-assessments as a lawful form of assessment?

Providing that the assessment has been conducted with an independently recognised advocate, co-produced assessments should be deemed a lawful form of assessment.

Question 4-3: Should our proposed adult social care statute allow for a pure self assessment for certain people or groups of people?

Such self assessment is wholly appropriate for SCI people who have experience of their care provision and care needs, and who have the confidence to self assess. However, for those who are new to receiving care, it may not be suitable for them to assess their own need without advice.

Question 5-1: Should our proposed adult social care statute encourage a more unified assessment process for carers and cared-for people?

Yes, the assessment of carer and the people they care for should be viewed holistically as sometimes care needs may add up to more than the sum of its parts. A collective need may be identified which is not immediately apparent in the assessment of two individuals.

Question 5-2: Do you think the carers' assessment duty should be merged with the community care assessment duty in our proposed adult social care statute?

As the needs of carer and cared for person – or their opinions on needs – may differ considerably, the duties should remain separate to ensure that everyone's views and needs are heard during assessment, particularly those who may have trouble speaking for themselves.

Question 9-1: Do you think that community care services should be undefined in our future adult social care statute?

Given the broad ways in which a user may receive care to meet their needs, a definitive list may allow for certain, unconventional services to slip outside of the regulations. By leaving the term undefined, an individual is free to argue that such services form a legitimate part of their care provision.

Question 11-2: We welcome comments about whether prisons should be included or excluded from adult social care.

Whilst it can be argued that a disabled person in prison has relinquished certain rights by committing a crime, those with care needs will be reliant on the provision of care services to conduct their daily lives on a par with other prisoners. By excluding such prisoners from social care they would be additionally punished as they would no longer be able to function on the same level as their peers.

However, whilst prisoners with high needs should be supported, in such cases it may be appropriate that care is provided without the same degree of choice and control afforded to people in the community. That said, this care provision must still meet the needs of the individual.

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