

The Spinal Injuries Association's (SIA) response to the Department of Health's consultation on the Personal Care at Home consultation

About SIA

The Spinal Injuries Association (SIA) warmly welcomes the opportunity to respond to the Department of Health's consultation on Personal Care at Home. 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. Consequently, many tetraplegics have a need for very high levels of care and support throughout their lives from the moment of injury. Paraplegics 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 the provision of personal care services that can achieve the best outcomes for all SCI people, namely independence, choice and control.

[Do you agree with the substance of the proposal as set out in this document? If not, why not?](#)

SIA welcomes these proposals. The extension of non-means-tested, personal care and support to those with high needs, who are currently just outside the eligibility criteria for it, will assist people to live in their own homes for as long as possible and is warmly welcomed.

[Are there any potential positive impacts on equalities of this policy? Similarly, are there any potential negative impacts?](#)

The term 'free personal care' suggests an effective extension of the definition of health care needs to include personal care tasks such as washing, skin care and toileting. This in turn indicates that support with personal care that was previously subject to means testing, may now become available 'free' to all who qualify. If this is the case then this bill will enable more people with high needs to remain independent in their own homes and to have as much control over their lives, as is possible.

This independence, choice and control thereby achieved represents a positive impact on equality to those with the highest care needs. However, we anticipate that eligibility criteria will be drawn up so tightly that it will be difficult to qualify, and negative impacts will flow from unjustified findings of ineligibility (as already

happens with NHS Continuing Healthcare). Similarly, those on the cusp of eligibility will be negatively impacted on.

[An Impact Assessment is available to accompany this consultation document.](#)⁷
[Do you have any comments on the perceived costs and benefits outlined in the Impact Assessment?](#)

The Bill guarantees free personal care for the 280,000 people with the greatest need and with around 50,000 people receiving non-means-tested NHS Funded Continuing Healthcare, this would appear to be a significant extension of non-means-tested care support.

If it is assumed that the additional number of people who will be eligible total 230,000 (280,000 less the 50,000 currently in receipt of Continuing Healthcare funding) then the allocated funding (which has to come from efficiency savings) equates to only £56 per person per week. This is not a realistic figure to adequately manage the personal care requirements of this high needs group as it equates to only 9.6 hours of assistance at the National Minimum Wage or 3.5 hours at a typical care agency rate of £16.00/hour. Howsoever calculated, this is not sufficient for the care needs of a SCI tetraplegic person or an elderly paraplegic.

If the Bill results in a greater take up of people receiving personal care and therefore an increase in cost to the public purse:

- this must not lead to standards in personal care services being driven down because of greater cost – the delivery of personal care should always be of suitable quality and fully meet the needs of users i.e. SCI people require specialist personal care which will likely be more expensive to deliver
- it must also not lead to eligibility criteria levels being driven up i.e. only people deemed critical being eligible for care/support, or more stricter guidelines being phased in for ‘people deemed in the highest need to enable people to receive free personal care at home’
- it must not threaten:
 - direct payments & ILF
 - the intended role out of individual/personal budgets
 - NHS Continuing Healthcare funding

On the proposals in Parts 1 and 2

[Is the level of detail proposed for the regulations appropriate? If not, why not?](#)

SIA questions whether some re-ablement needs will be able to be met within a six-week period. People with spinal cord injury may require substantial personal support, as well as significant housing adaptations that may not be able to be completed within a six week period.

The definition of personal care as laid out in the proposals leaves a lot of grey areas. For example:

- It is not clear about food preparation – SCI people require a healthy diet to maintain such things as skin care and bowel care which means meals need to be prepared with fresh ingredients.
- Cleaning and house-work should be included in free personal care provision for hygiene purposes. Bathrooms and food preparation areas will require regular cleaning as part of the process of care delivery, yet it is not clear if this would be included in a personal care budget.
- Assistance with laundry should be included in free personal care provision for hygiene purposes – for instance someone with continence issues will need help in this area.

Assistance with shopping should also be included in free personal care provision as people will need to procure food and cleaning materials to maintain a healthy diet.

Although the definition of personal care lists support which is vital to a person with a SCI, many SCI people will need considerably more support than this basic provision to enable them to take an active role in society. For instance, if someone with a SCI has a social night out they will need some aspects of personal care mixed in with the so-called social care or support, such as eating and drinking, toileting and dressing.

It is not clear where the 'personal care' aspect of a persons care/support package begins and ends.

[Is the balance right between regulations and guidance? If not, why not?](#)

The proposals seem well balanced between prescriptive regulation and more adaptable guidance, which should allow for the flexibility and innovation that will be required during the first year of this scheme.

[Is there anything that you feel should be in the guidance rather than regulations, or vice versa?](#)

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. 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 believes that support should **NOT** be dependent on local eligibility criteria, postcode or Local Authority resources, and that the Department should regulate

a national eligibility criteria that establishes transparently fair rules for financial support needs.

[Has anything been omitted from this document that should be included in either the regulations or the guidance?](#)

As discussed above, the Department should prescribe guidelines for eligibility to this scheme to prevent a postcode lottery in service provision.

[Which of the 3 options do you feel would be most appropriate for allocating the amount needed for personal care needs to eligible individuals?](#)

SIA is concerned that allowing councils a flexible approach could not only exacerbate the postcode lottery which currently exists in care funding but also increase a lack of portability for care, support and healthcare. Whilst there are guidelines rather than mandatory regulations, there will always be significant variance in interpretation and application across the country.

It will be appropriate to revisit these regulations and reassess them in the light of the evidence produced in the first year. Services users and their organisations must be a part of this process of reassessment.

[Do you have any further comments on the allocation of the amount needed for personal care needs to eligible individuals?](#)

The funding of the service must be suitable nationally and allow the needs of persons with high levels of physical disability such as tetraplegics to be supported adequately.

National, transparently-fair rules for eligibility need to be established so that, for example, a C5-lesion tetraplegic living in Newcastle would be entitled to receive the same level of support as a C5 tetraplegic in Northampton.

[Do you have any comments on the aspects of implementation outlined in the document?](#)

Paragraph 16 of the document states that a council *may* wish to identify those that who may be eligible for free personal care whilst paragraph 17 states that they *may* wish to invite people not known to the council to apply prior to October 1st. Given that eligibility criteria for non-means tested personal care will be changing, many people previously ineligible for such care will now be able to apply for it.

A council should be compelled to pro-actively identify those suitable for the scheme and ensure that they are aware of their entitlements to this new form of funding.

In particular, do you have comments around any level of retrospection?

The level of retrospection seems suitable, but only if a council has actively ensured that anyone eligible for the scheme is aware of their potential entitlement prior to the October 1st opening date for applications.

Do you have any comments on the collection of new data and its relation to existing information?

As the eligibility criteria for access to free, non-means tested personal care will be changing, it is important that a council pro-actively gathers information on those who will qualify for it under the new assessment guidelines.

A council should approach such potential service-users, particularly those that would not have qualified for free healthcare provision before, to ensure that they are aware of their potential new entitlement before October 1st and thereby ensure that those with the highest needs can apply for the scheme in good time.

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