



Spinal Injuries Association (SIA)

Response to: Department of Health – Caring for our future, shared ambitions for care and support Consultation

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Sent to: Department of Health

By e-mail to: caringforourfuture@dh.gsi.gov.uk

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Sent on behalf of: The Spinal Injuries Association (SIA)

The Spinal Injuries Association (SIA) is the leading national user-led organisation supporting the interests of 40,000+ people in the United Kingdom who have sustained a spinal cord injury (SCI). SIA has a membership of over 5,000 people who have sustained a SCI.

SIA welcomes the opportunity to comment on the 6 areas the Department of Health has identified to make the biggest improvements to the care and support system and the recommendations of the Commission on Funding of Care and Support:

1. What are the priorities for promoting improved quality and developing the future workforce?

SIA – Quality to a user of Social Care means having a choice of services that reflect the concept of person centered care and support, and self direction that are flexible enough to allow a person to live independently as possible. It is of up most importance that care workers fully understand a person's needs and condition/disability and are trained appropriately. It is also important that all care and support is delivered within a sensible, but not over burdening health and safety framework.

To ensure these principals are upheld at a local level there should be a robust framework for monitoring and commissioning services, which involves (to a high level) service users, their family carers and their local user-led representative organisations.

Local authorities should have a duty to develop and implement their monitoring commissioning strategy through user-involvement and customer insight. Moreover it is also important that users concerns and suggestions for improvements are acted upon. To enable this to happen there must be total transparency at all stages of any monitoring and commissioning and complaints procedures. Service users should also take part in any panels adjudicating over these areas.

People should have as much flexibility as possible in using their Personal Budgets to enable them choice and drive the market from a user/customer perspective which will raise standards and reward those providers who best suit their needs and allow them to live as independently as possible. This should also apply to NHS Continuing Health Care Funding.

However, if Social Care budgets continue to be placed under year on year pressure then it is likely that any market driven improvements will not exist as users will be forced to choose providers purely on cost. In many areas of the UK the care and support service provider market has traditionally relied on a poorly paid, motivated and trained workforce to drive down costs and/or maximize profits which has led to restricted choice between bad and worst for users. Standards and quality will only improve if front line staff are highly motivated, trained and rewarded and this will only happen if DP users are allowed to pay an appropriate rate for the services they receive.

2. What are the priorities for promoting increased personalisation and choice?

SIA – For people with a Spinal Cord Injury, 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.

It is important that all those charged with delivering Social Care services understand fully and buy into the concept of Independent Living, and Person centered, self directed care and support. This includes Social Care Managers, Providers of services and all back room and front line staff.

A person's needs should be viewed holistically. In keeping with the principle 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 and re-design of social care should recognise these points.

It is very difficult to navigate the care system as people often do not know what they are or aren't entitled to, how eligibility criteria are applied or how support plans are put together. Many disabled people do not know what services they can get as there is virtually no comprehensive information about the care market.

Furthermore, transparency of the care market will encourage innovation, as providers can develop new services that fill gaps.

There should be a standard format for local authorities to provide information about local services and access to services re: assessments eligibility, support planning, etc. Local authorities must be required to give clear and impartial information about care services which could include 'ratings' and comments given by customers. This will increase consistency across the country, and enable customers to compare authorities and services.

3. How can we take advantage of the Health and Social Care modernisation programme to ensure services are better integrated around people's needs?

SIA – There needs to be a national, portable assessment for individuals alongside the breaking down of artificial barriers which currently exist in care provision, namely between health and social care, to ensure a joined up service that will best serve disabled people. 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.

4. What are the priorities for supporting greater prevention and early intervention?

SIA – To ensure a good system of early prevention is put in place government must remove local control over eligibility criteria's for accessing services and establish a national level set at low need which is applied and enforced across the country. This will stop people slipping into the high levels of need and put a stop to the post code lottery which now applies to social care provision in the UK.

To enable disabled people to improve their health and well-being charging policies for care and support and the benefit and tax system should fully take into account the full/added costs of disability. For example people should not have to make the choice between eating and heating their home adequately.

Disabled people, especially those who are unable to work, are amongst some of our poorest citizens, a group which is widely recognized as having health problems directly related to poverty. This group of people are likely to have poor nutrition, housing etc and in the case of disabled people greater social isolation leading to such things as mental health problems and loss of personal control of their lives.

It is important that disabled people are able to access a healthy diet which may mean a) they are able to afford to purchase wholesome food; b) they have adequate support to prepare it and eat it. It is also important that disabled people have fit for purpose homes, equipment and support, are able to access health services and fitness centers and take part fully in family and community life for their mental wellbeing.

5. What are the priorities for creating a more diverse and responsive care market?

SIA – Because of differing needs of disabled people the care market can be made of many components:

- In house local authority services – a seemingly decreasing player in service provision
- Private Domiciliary care providers either commissioned directly by Local Authorities, PCT's (Continuing Healthcare Funding) or through Personal Budgets or by private means – a seemingly increasing part of care provision
- Private Agencies providing specialist services e.g. live in Personal Assistants (PA's) trained in Spinal Cord Injury care funded via PB's, LA Direct Payments, the Independent Living Fund, Compensation awards and/or private means
- PA's and other areas of support employed directly by disabled people funded via PB's, LA Direct Payments, the Independent Living Fund, Compensation awards and/or private means
- Day care services
- Residential and Care homes

It is vital to maintain this diversity of service provision to ensure choice and differing requirements of disabled people related to the requirements of various impairments, age and an individual's social situation.

To enable the care market to flourish and remain diverse, people need flexibility in their choices and have enough money to purchase the care and support to best meet their needs. A good model of providing this is the Independent Living Fund (ILF) which allows users to take total control of the way the care and support is delivered and applies a light touch re: administration (ILF admin costs are only 2.5% of its overall annual budget). ILF also encourages Local Authorities to maintain high levels of care

awards because of match funding and also ensures high costs of large care packages are spread more evenly across the country because it is centrally funded.

SIA strongly recommends that the ILF is re-instated to pre 01/05/10 levels and is expanded to meet increased need.

6. What role could the financial services market play in supporting users, carers and their families?

SIA – Considering the needs and views of our members, SIA is vehemently opposed to an 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. Even if 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.

7. Do you have any other comments on social care reform, including the recommendations of the Commission on Funding of Care and Support?



Spinal Injuries Association (SIA) Response to Dilnot Commission’s Report on the Funding of Care and Support 2011

Dilnot Report	SIA
<p>To protect people from extreme care costs we recommend capping the lifetime contribution to adult social care costs that any individual needs to make at between £25,000 and £50,000. We think that £35,000 is an appropriate and fair figure</p>	<p>Ideally people should receive their care and support needs without cost to them paid for either by an extra universal state national insurance scheme or general taxation.</p> <p>We believe that the Dilnot commission has shaped its cap recommendation on an estimate of the population's current and predicted future wealth. As such predictions are likely to be very inexact – particularly in this era of economic uncertainty - we believe any cap should ere on the side of caution and be set at the lowest end of the recommended range i.e. £25,000.</p>

<p>Not everyone will be able to afford to make their personal contribution, and those currently just outside the eligibility for means-tested help are not adequately protected. To address this, means-tested support should continue for those of lower means, and the asset threshold for those in residential care beyond which no means-tested help is given should increase from £23,250 to £100,000.</p>	<p>SIA welcomes the fact that a person's home is not taken into account when they are financially assessed for social care and support in the community. However, it is nonsensical to continue with the £23,250 threshold when the Government is encouraging disabled people to aspire to paid work as it does not give them the opportunity to amass wealth in the same way as non-disabled people and lift themselves out of poverty.</p> <p>Advances in technology and greater educational opportunities mean that it is now possible for individuals who require a high care and support package to hold down a well paid job or set up their own business. However, for such people there is no incentive to save and invest their earnings for the future if they are required to pay for their care and support in full once they have amassed over £23,250.</p> <p>Having such a disparity between the thresholds for home support and residential care could provide a perverse incentive for people to choose to go into residential care rather than of remaining in their own home.</p>
<p>People who enter adulthood already having a care and support need should immediately be eligible for free state support to meet their care needs, rather than being subjected to a means test.</p>	<p>SIA Supports this proposal</p>
<p>Universal disability benefits for people of all ages should continue as now. We recommend that the Government consider how better to align benefits with the reformed social care funding system and that Attendance Allowance should be re-branded to clarify its purpose.</p>	<p>SIA welcomes the opportunity to clarify the purpose for which disability benefits are awarded which we hope will enable individuals to be better informed, enabling them to secure the support they need.</p>
<p>People should contribute a standard amount</p>	<p>Before commenting we would require</p>

<p>to cover their general living costs, such as food and accommodation, in residential care. We believe a figure in the range of £7,000 to £10,000 a year is appropriate.</p>	<p>more information on this proposal, such as how benefits will be taken into consideration.</p> <p>SIA does NOT support the proposal to include people receiving NHS Continuing Healthcare Funding.</p>
<p>We recommend that eligibility criteria for service entitlement should be set on a standardised national basis to improve consistency and fairness across England, and that there should be portability of assessments. In the short term, we think it is reasonable for a minimum eligibility threshold to be set nationally at 'substantial' under the current system. The Government should also urgently develop a more objective eligibility and assessment framework.</p>	<p>SIA supports the proposal to standardise eligibility criteria for service entitlement across England. However, any review and reform in this area should not be prejudiced by the interim recommendation to set the national level of required Local Authority funding at 'substantial'. The criteria required for a substantial level of need should not be regarded as the accepted norm simply because this short term measure has been adopted by the Government. Any review must fully inquire into the needs of those with a lower level of need who will be disenfranchised by such strict measures.</p>
<p>The Government should develop a major new information and advice strategy to help when care needs arise.</p>	<p>SIA Supports this proposal</p>
<p>Carers should be supported by improved assessments which take place alongside the assessment of the person being cared for and which aim to ensure that the impact on the carer is manageable and sustainable. We support the proposals set out by the Law Commission to give carers new legal rights to services and improve carers' assessments.</p>	<p>SIA Supports this proposal</p>
<p>In reforming the funding of social care, the Government should review the scope for improving the integration of adult social care with other services in the wider care and support system</p>	<p>SIA Supports this proposal</p>
<p><i>There are currently 152 different adult social care systems – one for each local authority in England. Entitlement to services differs across the country and people complain of a 'postcode</i></p>	<p>The Care and Support charging criteria should be the same for every Local Authority. The criteria, assessment process and formulae used to make a</p>

<p><i>lottery' of care. Different people, with similar care needs, can receive very different levels of support from their local authorities. Each local authority carries out a financial assessment of what the person can afford to pay. For residential care there are national regulations on charging, but for domiciliary care local authorities can design their own charging policies within the overall national guidance – this leads to variation.'</i></p>	<p>financial assessment should be made transparent and easy to understand, especially in the area of off-setting 'disability related expenditure'.</p>
<p><i>'As in the current system, no one will be expected to contribute their entire income to their residential care costs; everyone will be left with a certain amount of money for personal expenses each week. Under the current system, this amount is £22.60 a week (the Personal Expenses Allowance (PEA)). We think that the PEA should continue, but would encourage the Government to consider the case for increasing it in the future.'</i></p>	<p>SIA challenges the fact that the government calculates a person in residential care can live on a personal allowance of £3.23 a day. We call on the Government to review and raise this figure as a matter of urgency.</p>
<p><i>'Once the cap is in place, we think the Government could also consider whether it wishes to introduce a taper into the means test to encourage people to save. For example, under the current system, those receiving home care see every extra pound above the minimum threshold (around £170 a week for older people) taken away in social care charges. Introducing a taper into the system would mean that people saw the benefits of having some savings. We think the taper could be set at 65% so it is in line with Universal Credit. This would mean that 65p for each pound of income above a minimum is chargeable income, rather than a pound in each pound, as is the case in the current system.'</i></p>	<p>SIA Supports this proposal but would like to see the threshold increased in line with the raising of the £23,250 savings threshold</p> <p>If this proposal was adopted SIA shares the Coalition on Charging view:</p> <p>"Potentially taper for a means-test at 65% of income as with Universal Credit (rather than 100% above income support level) – would mean every income group would be better off"</p>

