

## **The Spinal Injuries Association's (SIA) response to the Department of Health's consultation on Direct Payments for Healthcare**

### **About SIA**

The Spinal Injuries Association (SIA) warmly welcomes the proposal to introduce Direct Payments for Healthcare.

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 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 the provision of healthcare services that can achieve the best outcomes for all SCI people, namely independence, choice and control.

### **Question 1: Do you agree with the substance of the proposal?**

For Spinal Cord Injured (SCI) people choice and joined up services are vital concepts. SCI people 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. These Direct Payments are currently only available in social care, and SIA applauds the proposal that this freedom of choice be made available to those who receive some or all of their care payments from the NHS.

It is fully appropriate that Direct Payments for healthcare are modeled closely on those for social care as this is a method already well understood and supported by disabled people, service providers and disabled people's organisations. By bringing the two closer together SIA hopes that this will ultimately lead to a more holistic method of funding care provision in the future which breakdown the artificial divide that currently exists between health and social care provision.

The Dept of Health should note that when an individual receiving a Direct Payment employs someone directly they must meet the following requirements:

- contracts and providing details about possible terms of service;
- minimum wage legislation;
- working time directives;
- health and safety regulations;
- leave entitlements, including dependency and maternity leave;
- sick pay;
- training and development;
- pension scheme provision (where appropriate); and
- notice requirements.

It is essential that all the costs related to these requirements are fully met within the individuals Direct Payment and that the PCT clarifies its responsibility to anyone employed in such circumstances.

### **Question 2: Is the level of detail proposed for the regulations right?**

The level of detail proposed for the regulations seems right and should allow users and pilot authorities to work within these guidelines to discover what works well and what doesn't during the course of the pilot scheme.

However, the proposals do appear to give individual PCT's a lot of flexibility in the way they can deliver Direct Payments. SIA is concerned that this very flexible approach could exacerbate the postcode lottery and a lack of portability for care and 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 by the pilot process. Services users and their organisations must be a part of this process.

### **Question 3: Is the balance right between regulations and guidance? Is there anything that should be in guidance rather than regulations, or vice versa?**

The proposals seem well balanced between prescriptive regulation and more adaptable guidance, which should allow for the flexibility and innovation that will be required at the initial pilot stage.

Under section 9.1, the requirement to provide support, information and advice, SIA would like to a more prescriptive approach to how PCTs are required to provide their information and advice – namely through user lead organisations such as Centres for Independent Living. Most disabled people who choose to direct their own care will need some information and support, especially those engaging for the first time, and it is appropriate that this comes from an independent peer support service that may also be able to provide advocacy to those who require additional support throughout this process.

#### **Question 4: Is there anything else we should include?**

SIA would like more information as to how the results of the pilots will be made available to service users and their organisations. A website should be established giving progress reports and information from the pilot authorities allowing disabled people involved in the initiative to freely post their comments and suggestions so that their representative organisations can independently monitor the direct payments initiative. By keeping user lead organisations engaged in the process this will allow them to be better informed and, consequently, support and guide service users more effectively when the direct payment scheme is adopted nationwide.

Those organisations that have been involved in this initial consultation should then be further consulted on the process of adapting the pilot guidance to suit a national roll out of direct payments for healthcare, once the pilot period is complete.

To ensure that user-led organisations are properly engaged in the monitoring and evaluation of the pilot scheme, SIA proposes that a review group of user-led organisations should evaluate the progress of the pilot scheme alongside the DH evaluation team – similar to that set up when Social Care Individual Budgets were piloted.

SIA would also like to see DH giving more support to private sector provision of Individual Service Funds (ISFs). Personal Health Budget monies will need to be held somewhere, often by an independent third party organisation. Since private care providers already support many of the people who will participate in the pilot, it makes sense that they are asked to help hold the budget for the service user to draw down (This will require a commitment to clear reporting via regular statements and transparency over transactions).

PCT's should produce an 'accredited suppliers' list, to assist new comers to Direct Payments to source a suitable care provider. This way the PCT meets its duty of care and the 'patient/service user' is free to decide who they go to [either on, or off the list], but they ultimately bear the responsibility for that choice. Such a list should be for guidance only so that it is not restrictive and allows people to choose from outside 'the box' – an option which is particularly important when it comes to meeting specialist needs.

Daniel Burden  
Head of Public Affairs  
[d.burden@spinal.co.uk](mailto:d.burden@spinal.co.uk)

Spinal Injuries Association  
SIA House  
2 Trueman Place  
Oldbrook  
Milton Keynes  
MK6 2HH

0845 678 6633