



Spinal Injuries Association (SIA)

Response to: Consultation on the Right to Control Trailblazer Regulations

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Sent to: Office for Disability Issues

By Email: right.control@dwp.gsi.gov.uk

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Sent on behalf of: 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 this consultation and offers the following response:

Question 1 (Page 15)

Do regulations 1 to 6 provide sufficient detail about where the Trailblazers will take place, and who and what will be included?

SIA is happy that regulations 1 to 6 provide sufficient detail about where the Trailblazers will take place, and who and what will be included.

Question 2 (Page 19)

Do regulations 7 to 13 provide an adequate basis for the Trailblazers to deliver information, support planning and choice to the disabled person?

The ideal starting point re: delivering information, support planning and choice to the disabled person should be for the person to first produce a support plan independently (or with help from family, friends or appropriate independent advocate) without any local authority input/influence. This would outline their day-to-day support needs, family commitments, social and community requirements, personal goals and ambitions, etc and would then form the basis for negotiation re: setting out a formal support plan with relevant agencies. This principal should be built into the regulations.

Question 3 (Page 24)

Do regulations 14 to 17 provide a sufficient framework for making direct payments?

In the example of Louisa (Community Support Worker paid by Supporting People funding) it is not clear if this service is provided 'in house' by a local authority or is a service provided by a private or other sector provider.

The Right to Control must recognise that there are still many services provided in house by local authorities with a long history of proven good service delivery the quality of which cannot be delivered by private or other providers because of viability, complexity or other sound reasons. For such services the client base may wish to continue having their support provided this way and should therefore be able to exercise their Right to Control in this way.

However, SIA recognises that user choice via market forces provided through personal/individual budgets, direct payments, etc should be a driver to shape services.

In the example given (Louisa) the critical mass for deeming a service viable was eight out of ten. In the event of a service becoming unviable in such circumstances, SIA would like to see a subsidy from central or local funds provided that would enable the service to carry on for a set time (e.g. 12 months) to allow the service users that remained enough time to find alternative arrangement/services.

NB - When the critical mass, decided by user choice alone, deemed a service provided by a local authority unviable, that authority must carry out any review of the service in line with its responsibilities laid out in the Disability Equality Duty legislation for public bodies.

For private and other service providers SIA believes that market forces driven by user choice should have no such restrictions to drive through change – unless a service is deemed specialist i.e. commissioned directly, or subsidised because it is specialist by a local authority or PCT.

Question 4 (Page 25)

Does regulation 18 provide a sufficient framework for reviewing decisions?

SIA is happy that regulation 18 provides a sufficient framework for reviewing decisions.

Question 5 (Page 27)

Are regulations 19 and 20 sufficient to allow relevant authorities to work together to provide a more streamlined service for the disabled person?

There appears to be nothing in regulations 19 & 20 regarding a person moving from one local authority area to another. Once a person has a care/support package put in place that should be honoured by any local authority to which they wish to move to without any requirement for any re-negotiation or assessments, just the normal review requirements.

**More work needs to be done in this area to design regulations and guidelines that enable people to move freely from one area of the country to another as per Article 18 of the UN Convention on the Rights of Persons with disabilities:
*'Which states Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others.'***

**And - Article 19a of the UN Convention on the Rights of Persons with disabilities:
*'Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement'***

Question 6 (Page 34)

Are there any further areas where statutory guidance is essential to support delivery of Right to Control?

SIA cannot see why it is deemed necessary to seek the landlord's permission for the Right to Control when seeking a DFG if the landlord is a local authority or housing association. This should be amended so the Right to Control for Social Housing provided by these bodies is the same for their tenants as it for home owners.

Question 7 (Page 37)

Do you think there are any further steps that should be included in the Adult Community Care directions?

In reference to the bullet point:

- *Working with the disabled person to agree the outcomes to be achieved from the resources allocated, underpinned where possible by a single agreed care/support plan.*

SIA would like to see the words 'where possible' removed to ensure there is clear movement towards a single care/support plan.

Question 8 (Page 40)

Do the suggested changes provide a sufficient framework to enable the Independent Living Fund to participate fully in the Right to Control Trailblazers?

SIA is happy that the suggested changes provide a sufficient framework to enable the Independent Living Fund (ILF) to participate fully in the Right to Control Trailblazers

SIA would like to take this opportunity to reiterate our view stated in the 2009 Right to Control Consultation that ILF money should remain separate from Local Authority control to ensure this funding continues to be used to allow disabled people to get the extra support they need to participate fully in society, otherwise ILF money could become lost in the Community Care budgets and any potential Government cutbacks.

As also stated in the 2009 response, SIA would like to see the inclusion of healthcare monies in the funding streams which contribute towards the Right to Control.

SIA would like to put on record our utter disbelief and anger that from 1st May 2010 new applicants who apply to the ILF will only have their applications considered if they work at least 16 hours a week.

For new applicants with high lesion SCI who are not employed for 16hrs or more, because they cannot continue in their previous employment due to the severity of their disability, being denied access to ILF will have a detrimental affect on their quality of life. It will also greatly hinder their ability/chance to retrain and return to the workplace in a different capacity. This change in policy was done without proper & robust consultation with disabled people and disabled people's organisations and goes against all the principals that the Right to Control initiative has been set up to achieve.