

## Right to Control Consultation 2009 (Deadline 30/09/09)

Q/P	Right to Control Consultation Questions	SIA Response
Q.1 P.22	What criteria should we use to select funding streams to be included in the trailblazer sites for the Right to Control?	All the funding a service user would normally qualify for that are paid, or delivered via services on a regular basis (see SIA response to Q.2). However, there could be a case for including extra funding for equipment via Access to Work grants and Local Authority and/or NHS equipment budgets.
Q.2 P.23	Which funding streams do you think could and should be included in the trailblazers?	<ul style="list-style-type: none"> <li>• Access to Work (support worker payments) – to be paid as a Direct Payment</li> <li>• Local Authority (LA) Community Care budget</li> <li>• Continuing Healthcare NHS</li> <li>• Independent Living Funds (ILF)*</li> </ul> <p>*NB – ILF money should remain separate from LA control to ensure this funding is continued to be used to allow disabled people to get the extra support they need to participate fully in society – as there could be a danger that ILF money just gets lost in the Community Care budgets!</p>
Q.3 P.24	Only disabled people will be able to access the Right to Control. Where a funding stream is used by both disabled and non-disabled people, how should we decide which users would be entitled to exercise the Right to Control? What funding streams used by disabled and non-disabled people could be included in the Right to Control?	<p>To eliminate this possible confusion it would make sense to only include funding streams related to people needing care and support to manage an impairment or long term condition (see SIA response Q.2). These funding streams are separate from such things as housing benefits which are made available to disabled and non-disabled people alike specifically to subsidize rent and/or council tax and are means tested accordingly.</p> <p>NB- If one consideration was to separate the additional disability premiums associated to such benefits as Income Support and Housing Benefit and add these funds to a Personal Budget it is likely that this will prove to difficult to manage – as was the case found in the recent Individual Budget Pilots where many original funding streams thought to be possible to be included were dropped as they were too complicated to manage within such a budget concept.</p>
Q.4 P.25	What things would public bodies need to do to make it as easy as possible for disabled people, who are using different funding streams in the trailblazer areas, to use the Right to Control?	<p>It is important that Local Authorities and Primary Care Trusts in each trailblazer area work together to deliver the concept with one body taking a lead role in delivery so users or their representatives have one point of contact.</p> <p>Disabled people would need clear advice on how various funding streams making up their Individual Budget are sourced, how total amounts are calculated and just what their responsibilities are in the way it is managed.</p> <p>It is also vital that a proper account of a persons disability related expenditure is used in any financial assessments and proper advice and guidance is provided.</p> <p>NB - It is vital that disabled people in trailblazer areas have access to a local user-led organization (modeled on successful Centres for Independent Living CIL's) to provide</p> <ul style="list-style-type: none"> <li>• independent advice</li> <li>• advocacy &amp; brokerage</li> <li>• support to manage budgets</li> <li>• peer support</li> <li>• organize local campaigning/lobbying activity</li> </ul>

		<p>Local authorities must support such organisations to ensure that they have the capacity to deal with the increased workload that will follow the introduction of the Right to Control.</p> <p>Local authorities should also discuss the Right to Control with other advice giving bodies such as Citizens' Advice Bureaux and to ensure that each office has access to the appropriate specialists who can advise disabled people on this issue.</p>
<p>Q.5 P.27</p>	<p>What should public bodies and other service providers do when faced with a situation where some current users of services want to do new things with their Right to Control, but some want to carry on using current services?</p> <ul style="list-style-type: none"> <li>• Should public bodies and providers continue to buy and run current services for people who want them even if much smaller numbers will use them? For example, this could be more costly and would mean that less money would be available for other people</li> <li>• How could service providers work with disabled people to make sure this type of service could still be provided?</li> <li>• If a service has to close because not enough people wanted to use it, what plans should a public body make to ensure that people do not become socially isolated and still have choice and control?</li> </ul>	<p>It is likely from the outset that some people will exercise their Right to Control to still have their care and support provided in the traditional manner (e.g. provide or commissioned by their Local Authority) and this should continue to be their right.</p> <p>Should public bodies and providers continue to buy and run current services for people who want them even if much smaller numbers will use them? For example, this could be more costly and would mean that less money would be available for other people?</p> <ul style="list-style-type: none"> <li>• There is no evidence yet to suggest that people will move over in vast numbers, from the traditional methods of having their care and support delivered, until new initiatives like the Right to Control are seen as a convincing alternative – For evidence to the contrary you only need to look at the introduction of Direct Payments and Individual Budget pilots that worked for some people but failed to persuade the majority to change the way they received care and support.</li> <li>• How could service providers work with disabled people to make sure this type of service could still be provided? <ul style="list-style-type: none"> <li>• If the Right to Control initiative works then it is likely that traditional ways of providing care and support will gradually wind down as new popular methods replace them which could be near seamless. However, if a critical mass of service users wish to retain a traditional service then it is likely that the service will survive. It is therefore crucial that service providers work with service users and fully consult with them as various services adjust and adapt to new environments and markets.</li> </ul> </li> <li>• If a service has to close because not enough people wanted to use it, what plans should a public body make to ensure that people do not become socially isolated and still have choice and control? <ul style="list-style-type: none"> <li>• The service would need to be brought under the control of such a body as the Care Quality Commission overseeing a temporary service provider until the service users left are found an alternative provider/service that fully meets their needs.</li> </ul> </li> </ul>
<p>Q.6</p>	<p>What should the public body do in the situation where it costs more for one individual to use their budget to buy equipment or a service than for a public body to buy it?</p> <ul style="list-style-type: none"> <li>• Should they stop an individual from buying equipment himself if it means there is less money for other people?</li> <li>• Should they allow him to buy equipment himself only if he can show that he needs different equipment from what the public body already offers?</li> </ul>	<p>What should the public body do in the situation where it costs more for one individual to use their budget to buy equipment or a service than for a public body to buy it?</p> <ul style="list-style-type: none"> <li>• Where a Public Body or group of Public Bodies are able to obtain discounts on popular items of equipment because of bulk buying it would make financial sense to continue with such arrangements. However, such bulk purchasing could be arranged by a CIL or group of</li> </ul>

	<ul style="list-style-type: none"> <li>• Is there anything else that an individual or the public body could do? For example: <ul style="list-style-type: none"> <li>• Could the public body agree discounts with providers which cover purchases by local disabled people buying equipment for themselves?</li> <li>• Could disabled people with similar needs get together and negotiate a discount with the supplier themselves?</li> </ul> </li> </ul>	<p>CIL's.</p> <ul style="list-style-type: none"> <li>• Should they stop an individual from buying equipment himself if it means there is less money for other people? <ul style="list-style-type: none"> <li>• Not if it is deemed a 'specialist item' which an individual needs to retain/obtain his/her independence or to enable them to work, or seek education and/or training</li> </ul> </li> <li>• Should they allow him to buy equipment himself only if he can show that he needs different equipment from what the public body already offers? <ul style="list-style-type: none"> <li>• See above</li> </ul> </li> <li>• Is there anything else that an individual or the public body could do? For example: <ul style="list-style-type: none"> <li>• Could the public body agree discounts with providers which cover purchases by local disabled people buying equipment for themselves?</li> <li>• Could disabled people with similar needs get together and negotiate a discount with the supplier themselves?</li> </ul> </li> </ul> <p>This could be done via a CIL (see above)</p>
<p>Q.7 P.30</p>	<p>When might service providers and public authorities decide that commissioning the Right to Control is unaffordable, for example taking into account costs such as set up, advocacy, and other running costs?</p> <ul style="list-style-type: none"> <li>• How should they consult on this with service users?</li> </ul>	<p>In such cases the Care Quality Commission should oversee any consultation and inquiry to ensure fairness and transparency</p>
<p>Q.8 P.32</p>	<p>Is there any legislation or are there any rules about how support is provided which might get in the way of the Right to Control, and how can we overcome such barriers?</p>	<ol style="list-style-type: none"> <li>1. Some Care Providers insist that where lifting equipment is in use (e.g. hoists) then 'double-ups' or two care attendants are required because of health and safety. This is not always the case and has cost implications as well as disempowering some service users as they are often 'talked over'. This area of Health &amp; Safety is a grey area and clarity is needed</li> <li>2. Many Care Providers will not provide any cover after a certain time at night which means service users are denied access to evening activities – this needs to be dealt with via LA service procurement</li> <li>3. On occasions those people who direct their own support via direct payments need to make cash payments to a casual support worker – the rules governing these payments needs clarifying</li> <li>4. For those employing support staff directly training opportunities for these staff need to be made available e.g. lifting and handling, hygiene. This could be done in line with training for LA in-house care staff or approved care agency staff</li> <li>5. Many people are left with footing the cost of equipment maintenance and servicing to comply with Lolar rules after grant funding has run out. In cases where people have to choose between eating or heating their homes and servicing equipment, this servicing requirement is not taken on putting themselves, carers and PA's at risk from equipment failure. It is vital therefore that in the future grant funding for equipment has ongoing maintenance contract costs built into them.</li> <li>6. If/when the European Working Time directive is enforced in the UK it is almost certain to have an effect on 'live in' Personal Assistants who may not be allowed to work on a 24 hour day/stand-by basis.</li> <li>7. The transition for Children moving into Adult care and support provision is not always a smooth pathway. This is an area that requires further</li> </ol>

		<p>work and consultation with parents and service users who have been/or are going through this transition.</p> <p>8. There are new guidelines for the National Framework for CHC 2009 – the Decision Support Tool has been amended and has reduced risk indicators for care that will affect Spinal Cord Injured people (and similar impairment groups). Examples of changes are:</p> <ul style="list-style-type: none"> <li>o Skin – checking skin several times a day is now rated moderate, it was previously scored high</li> <li>o Chronic Urinary Tract Infections are now scored moderate (previously scored high)</li> <li>o Continuous Positive Airway Pressure now scored moderate (previously scored high)</li> </ul>
<p>Q.9 P.33</p>	<p>What information and support will disabled people need in order to enable them to exercise their Right to Control?</p> <p><u>Support needs</u></p> <ul style="list-style-type: none"> <li>• Who is likely to need this support, and how can they be supported to make the right choice for them?</li> <li>• What types of support do you think will be needed?</li> <li>• How do we ensure the inclusion of those disabled people who have, or are seen to have, limited capacity to take decisions?</li> </ul> <p><u>Support provision</u></p> <ul style="list-style-type: none"> <li>• What is the best way of providing this support?</li> <li>• What agencies are best placed to provide that support?</li> </ul> <p><u>Cost of support</u></p> <ul style="list-style-type: none"> <li>• Should the costs of supporting people to use their budget be met from within a person's individual budget or be paid for by public bodies centrally from their overall funds available?</li> </ul> <p><u>Information, advice and support</u></p> <ul style="list-style-type: none"> <li>• How important is information about the range of services/equipment and support in ensuring the Right to Control?</li> <li>• How important is information about the cost of services/equipment and support in ensuring the Right to Control?</li> <li>• How important is advice and support to disabled people in choosing and setting up support?</li> <li>• What are the best ways to make sure that people know this support is available?</li> </ul>	<p><u>Support needs</u></p> <ul style="list-style-type: none"> <li>• Who is likely to need this support, and how can they be supported to make the right choice for them? <ul style="list-style-type: none"> <li>• Most disabled people who choose to direct their own care and support will need some information and support, especially those engaging for the first time. Some people will quickly grasp the system and where to look for information and will be able to direct their own care and support themselves. It therefore makes sense to provide the right amount of support for this group at the outset, so they become independent freeing up resources for those who will require ongoing and/or higher levels of support such as advocacy.</li> </ul> </li> <li>• What types of support do you think will be needed? <ul style="list-style-type: none"> <li>• Some people will require a complete advocacy service. Others may require some training and/or advice such as employer responsibility, interviewing techniques, etc</li> </ul> </li> <li>• How do we ensure the inclusion of those disabled people who have, or are seen to have, limited capacity to take decisions? <ul style="list-style-type: none"> <li>• Via a strong localized and/or appropriate advice, advocacy and brokerage service</li> </ul> </li> </ul> <p><u>Support provision</u></p> <ul style="list-style-type: none"> <li>• What is the best way of providing this support?</li> <li>• What agencies are best placed to provide that support? <ul style="list-style-type: none"> <li>• Via local CILs and national user-led organizations</li> </ul> </li> </ul> <p><u>Cost of support</u></p> <ul style="list-style-type: none"> <li>• Should the costs of supporting people to use their budget be met from within a person's individual budget or be paid for by public bodies centrally from their overall funds available? <ul style="list-style-type: none"> <li>• Such support provision as described above should be centrally funded via Local Service Agreements and Government grants</li> </ul> </li> </ul> <p><u>Information, advice and support</u></p> <ul style="list-style-type: none"> <li>• How important is information about the range of services/equipment and support in ensuring the Right to Control? <ul style="list-style-type: none"> <li>• Very important</li> </ul> </li> <li>• How important is information about the cost of services/equipment and support in ensuring the Right to Control? <ul style="list-style-type: none"> <li>• Very important</li> </ul> </li> <li>• How important is advice and support to disabled people in choosing and setting</li> </ul>

		<p>up support?</p> <ul style="list-style-type: none"> <li>• Very important</li> <li>• What are the best ways to make sure that people know this support is available? <ul style="list-style-type: none"> <li>• Via a CIL and/or national user-led organisations</li> </ul> </li> </ul>
Q.10 P.35	What additional support will existing information and advice, independent advocacy, support brokerage and other support services need in order to meet the needs of disabled people using the Right to Control in the trailblazers?	As these services will be fulfilling a critical function in ensuring the success of the Right to Control, they will require core funding to meet day-to-day running costs
Q.11 P.36	Thinking about the current processes in place that enable someone to complain now, what kinds of help and information do you think people might need to: <ul style="list-style-type: none"> <li>• Challenge a decision that they are not happy about?</li> <li>• Request and take part in a review of a decision?</li> </ul>	To ensure these Trail Blazer initiatives are not bogged down in red-tape and long procedures re: challenges and reviews, and to ensure fairness and transparency, the Care Quality Commission should oversee any inquiries from the outset.
Q.12 P.37	What do we need to do to ensure that disabled people and their organisations play a full part in the trailblazers?	A website needs to be set up giving progress reports and information from the trail blazer sites allowing disabled people involved in the initiative to freely post their comments and suggestions and their representative organisations to independently monitor the overall Right to Control initiative.
Q.13 P.38	What are the implications for service providers and how can they be assisted to play their part in promoting choice and control in the Right to Control trailblazers?	Service providers need to provide a true and transparent picture to those users considering taking up the Right to Control initiative in the trail blazer areas. E.G. <ul style="list-style-type: none"> <li>• What the ALL the implications are for the user</li> <li>• How the initiative is working for others in their area</li> <li>• Provide regular updates of the initiatives progress to local User-led organisations who can then independently monitor progress and are then able to provide up to date independent advice to the user.</li> </ul>
Q.14 P.39	How can public authorities and service providers best work together with the service user to agree an individual's support plan and support them to achieve agreed outcomes? <ul style="list-style-type: none"> <li>• Who should have the lead responsibility?</li> <li>• How should reviews of the support plan work?</li> </ul>	Where available CIL's should take the lead on this area of work. If a trail blazer area has no CIL or other user-led organization capable of overseeing this work then Public Authorities should actively recruit/employ/pay services users already successfully engaging in the Right to Control to oversee this work.
Q.15 P.39	Are there particular implications for third sector organisations and how can they be addressed in the Right to Control trailblazers?	Many third sector organizations are folding purely to the lack of funding for core activities. Adequate start-up funding and ongoing core cost funding needs to be made available to these bodies to ensure that they have the capacity to support disabled people throughout this process
Q.16 P.39	What are the implications of the Right to Control for the commissioning of services and how can commissioners be assisted to play their part in the Right to Control trailblazers?	Commissioners need to be provided with up-to-date accurate information on the progress of Right to Control trailblazers to enable them to commission the most appropriate services to meet user's needs.
Q.17 P.39	Are there any issues or concerns not addressed above about the Right to Control that you would like to comment on?	<p>The SIA helpline has recently received many calls from Spinal Cord Injured (SCI) People that have had as financial re-assessments which have significantly increased their contributions towards care packages – SIA believes due to incompetent or inappropriate assessment that assessors are not correctly accounting for SCI people (and other impairment groups) disability related expenses when calculating contributions. It is therefore necessary that any assessment is done by a independent body such as a CIL.</p> <p>Other issues highlighted by callers to the SIA helplines that may affect how effective the Right Control initiative has on their lives if they are involved in any</p>

		<p>trailblazer:</p> <ul style="list-style-type: none"><li>○ Lack of training in SCI care for Care Assistants</li><li>○ Elderly callers needing care/support for first time &amp; Elderly parents caring for high lesion SCI people who have never had any/or had very little help and support needing support for the first time having difficulty navigating the care and support system</li><li>○ Poor care while in hospital and un-organised discharges</li><li>○ Requests for equipment by older callers because of health deterioration who do not know where to go for support</li><li>○ Some SCI still relying on District Nurses to manage such procedures as bowel care</li></ul>
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