Making **choice and control** a reality for disabled people

Government response to the consultation on the Right to Control

Office for Disability Issues
HM Government
Thank you and acknowledgement

The Right to Control Team would like to thank everyone for the time, effort and commitment they have shown towards this consultation and for the enthusiasm shown within the responses that we have received.

We would especially like to thank those people and organisations who have hosted consultation events. With your help we have been able to consult with a wide range of disabled people’s organisations, service providers, local authorities and individuals, helping us to engage as many people as possible on the consultation.

We recognise the achievements of all who are currently involved with delivering increased personalisation through Individual Budgets, direct payments and people focused services and would like to thank those people and organisations who are pushing forward these ideas.

We hope that we can continue to build on the expertise and experiences of people and organisations that responded to the consultation and others, as we plan and implement the Trailblazers to ensure the Right to Control provides real and meaningful choice and control for disabled people.

With thanks
The Right to Control team
# Making choice and control a reality for disabled people

Government response to the consultation on the Right to Control

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Foreword

Rt Hon Yvette Cooper MP
Secretary of State for Work and Pensions

The Right to Control represents the next step in the journey towards equality for disabled people. It has been developed in direct response to the widely held ambition of disabled people around the country to have choice and real control over the support they need to go about their daily lives.

Significantly, we have developed the policy through a genuine process of co-production with disabled people themselves. We have been determined to listen to people, understand what they want to achieve, how they want to achieve it and then work with them to deliver it.

This consultation continues our commitment to work in partnership with disabled people so that their experiences and expertise can inform the development and implementation of policies that affect them. We have already acted on what disabled people and others told us during the consultation, and made amendments to our legislation to ensure that adult Community Care can be aligned with the Right to Control in the Trailblazers. We recognise that this is an important source of support to disabled people, and we will test how it can be aligned with other support they use.

Overall, the consultation responses will help us to shape the Right to Control in a direction that will offer real choice for disabled people, as well as ensuring that we can deliver the support that people want in the most efficient and effective way possible. The responses in this document will therefore help us make progress towards our objective of delivering a real transformation in the relationship between disabled individuals and the public agencies and service providers to whom they look for support.
I want to thank everyone who has given a response to the consultation and in particular I would like to extend my thanks to those people and organisations who have been involved in holding consultation events. These have been crucial in helping this consultation reach so many people, and have meant that we were able to engage fully with those who would be affected by the Right to Control.

Our next steps are to select the Trailblazer sites and continue working with disabled people to see how this right can work in practice. We have a busy and demanding agenda ahead of us until the Trailblazers start in late 2010. But I am sure with everyone’s input and commitment, we can make the Trailblazers a success.

Rt Hon Yvette Cooper MP
Secretary of State for Work and Pensions
Executive summary
Background

The Department for Work and Pensions’ White Paper ‘Raising expectations and increasing support: reforming welfare for the future’, published in December 2008, set out our proposals for the Right to Control. The Right is about empowering disabled people by giving them greater choice and control over public money currently spent on their behalf. This would put disabled people in charge of deciding how their support needs can be best met. From late 2010, we will test how the Right to Control will work for disabled adults in a number of local authority areas, in England only. These will be called Trailblazer sites. The outcome of the Trailblazers will be used to inform any decisions on wider roll-out.

Consultation

We have worked in partnership with disabled people throughout the development of the policy and will continue to do so. Between 11 June and 30 September 2009, we carried out a national consultation on the detail of our proposals. We asked:

- what support should be included in the Trailblazers
- what help will disabled people need to exercise the Right
- how we should continue working with disabled people and their organisations to develop Trailblazers
- what the Right to Control means for service providers and other support services
- views on the cost, affordability and viability of services.

We received over 175 responses, some of which incorporated the views of many individuals. Disabled people and their organisations made up the largest group of responses but we also received views from local authorities, service providers and third sector organisations. We also supported over 30 events across England during the 16-week consultation period.
The responses to the consultation were broadly positive but they reflected the complexity of combining different funding streams and streamlining services, as well as communicating this clearly to disabled people and their organisations. We recognise that we will need to communicate what the Right means in practice very clearly in the Trailblazer areas.

**Government response**

The focus of the government’s response, set out here, is on issues that need to be resolved before Trailblazer authorities are selected, as well as on matters on which we will need to introduce regulations to operate the Trailblazers. Once Trailblazer sites are selected, we will continue to work with our Advisory Group, chaired by Baroness Jane Campbell and with disabled people, local government bodies and service providers in Trailblazer areas, to make the Right work in practice.

**Choosing what to include in the Trailblazers**

Responses to the consultation supported the inclusion of:

- Access to Work
- Work Choice
- Independent Living Fund
- Supporting People (non-statutory housing-related support), and
- Disabled Facilities Grant.

These funding streams will be included in the Trailblazers and we will work closely with the Department for Communities and Local Government, housing providers and disabled people to resolve any practical barriers to the inclusion of Supporting People and Disabled Facilities Grant.

There were strong views from respondents on the need to include adult Community Care in the Trailblazers. We have responded to this and worked with our Advisory Group to amend our legislation. As a result, adult Community Care (including community equipment) will be included in the Trailblazers, ensuring we build on the current programme to transform Adult Social Care.
There are certain funding streams that we will not be including at present, like Disabled Student’s Allowance (DSA). But powers in primary legislation allow the inclusion of this and other funding streams if a decision is made to roll-out the Right more widely following the evaluation of the Trailblazers. The Department of Health is piloting personal health budgets and National Health Service funds will therefore not be included in the Right to Control Trailblazers. We will, however, be looking for opportunities to co-locate Right to Control Trailblazers and personal health budget pilots where possible.

Benefits such as Disability Living Allowance, Attendance Allowance and Employment Support Allowance will not be included in the Right to Control. We will also not include any employment programmes with a mandatory element such as Pathways to Work or the Flexible New Deal.

**What to do about services used by both disabled and non-disabled people?**

Where a funding stream is available to both disabled and non-disabled people, disabled people will be able to exercise the Right to Control over support that is allocated to overcome barriers associated with their illness or impairment. The only funding stream amongst those selected for Trailblazers that is available to both disabled and non-disabled people is Supporting People (non-statutory housing-related support).

**Working together to support disabled people and to develop Trailblazer sites**

Disabled people, their organisations and service providers, all emphasised the need for their early involvement in implementation plans, availability of clear, consistent and accessible information and joined-up support. We will ensure these points are addressed by including them as criteria by which Trailblazer applications will be assessed.

**Cost, affordability and viability of service within the Right to Control**

The Right to Control will create new relationships between the service user and provider. We will encourage local authorities to mitigate any risks to existing services. We will monitor and evaluate any effects on the cost-effectiveness of existing services, the affordability of the Right and the impact on outcomes for disabled people. We will develop strategies to manage these risks in preparation for Trailblazers and test these approaches.
Helping people to use the Right to Control

We acknowledge the need for high quality information, advice, advocacy and brokerage services to many disabled people and the key role that user-led organisations play in providing this service. The government has provided funding over the last few years to English regions to develop a stronger user-led organisation infrastructure and to help councils transform the way in which social care is provided. Trailblazers’ plans for the provision of information and advice, advocacy and brokerage will be one of the criteria against which applications are assessed. We will also encourage Trailblazers to test out different ways of funding such services and will ensure that the evaluation fully captures disabled people’s experiences and preferences.

What if someone is unhappy with a Right to Control decision?

We will support Trailblazers to address any barriers to maximising access to the Right to Control. We expect access to existing review mechanisms to be made as easy as possible and that, if they need it, disabled people are provided with support to ask for a review of a decision.

What the Right to Control means for service providers, voluntary groups and people who set up support services

In testing how the Right to Control will work, we will work closely with Trailblazer sites, relevant organisations and service providers to fully understand the challenges it brings to service providers and those who commission services. User-led organisations and independent advocacy services will play a key role in helping disabled people and service providers work together to develop flexible and responsive services.
Executive summary

Next steps

The Right to Control builds on progress made over a number of years, involving a wide range of disabled people, through policies and initiatives such as the implementation of direct payments, personal budgets for Adult Social Care, the In Control and Individual Budget pilots, Person-Centred Planning for people with learning disabilities and other initiatives. We know that one solution does not fit all, but our intention is for the Right to Control to provide choice and control to disabled people and for the Trailblazers to help us understand how to ensure this happens.

Regulations

Our next step is to develop regulations to provide local authorities with a more detailed framework of how they will need to deliver the Right to Control to disabled people during the Trailblazers. These will be developed in consultation with disabled people, their organisations, providers and local authorities.

Trailblazer selection

Alongside the government’s response to consultation we are also publishing ‘Right to Control: prospectus for potential Trailblazers’ that has also been shaped by this consultation. The prospectus will support local authorities to prepare their applications to become Trailblazers. We will continue to work with disabled people and their organisations as we plan, develop and run the Trailblazers from late 2010.
Making choice and control a reality for disabled people
Government response to the consultation on the Right to Control

Background
What is the Right to Control?

Many disabled people do not have the sort of choice and control over their lives that non-disabled people take for granted. Too often, the services they rely on for support are structured in ways that prevent them being in charge of their own lives and to access the same opportunities as non-disabled people.

The government is committed to enabling disabled people to have choice and control over the support they need to go about their daily lives. The Right to Control is about shifting the balance of power from the state to the individual, acknowledging that disabled people are the experts in their own lives and enabling them to use available resources to achieve their aims and aspirations. The Right to Control will be piloted in around eight trailblazing local authority areas with the outcome of the Trailblazers used to inform any decisions on wider roll-out.

This is a policy which has been developed in partnership with disabled people and their organisations. In pioneering direct payments for social care 20 years ago, disabled people demonstrated that choice and control can deliver better outcomes. The In Control pilots demonstrated similar benefits of enabling individuals and families to have choice and control over an individual budget, while the Department of Health-led pilots further tested the benefits of individual budgets and of extending self-directed support beyond social care. The progress towards personalisation in social care culminated in the cross-sector concordat ‘Putting People First’ and the commitment to introduce personal budgets and self-directed support for all users of adult Community Care. The proposals set out in the ‘Shaping the Future of Care Together Green Paper’ suggest ways for addressing the challenges facing the funding of our care system and sets out our vision for a care and support system that is fair, simple and affordable for everyone.


In ‘Improving the Life Chances of Disabled People’, we set out our aim of full and equal citizenship for all disabled people. In their responses to our Green Paper, ‘No-one Written Off’, disabled people told us that an entitlement to choice and control is a key part of having the same opportunities as other citizens. We therefore made a commitment to ‘ensure that choice and control are recognised as a right, not a privilege’.

The Right to Control would mean that disabled people have a clear idea up-front about how much money is available to pay for support to meet agreed outcomes. People exercising the Right to Control would still have to meet existing eligibility criteria, and spend their money to meet their support needs. They would however, be in the driving seat in terms of deciding how resources should be used to meet agreed outcomes.

Choice and control matter in all aspects of disabled people’s lives but they have told us that responses to their support needs are too often fragmented across different agencies and services. It is therefore important that the Right to Control Trailblazers encompass a range of sources of support and that neither social care nor any other service should be the sole gateway. Bringing together funding streams from more than one agency should enable a much more streamlined approach, with scope to simplify or integrate processes such as assessment, support planning and budgets. The aim should be for a disabled person to only have to ‘tell us once’ and for there to be a joined-up approach to meeting their needs.

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What are the Right to Control Trailblazers?

From late 2010, we will test how the Right to Control will work. We will do this by trying out the Right to Control for disabled adults in a number of local authority areas in England only. These will be called Trailblazer sites. We have published a ‘Right to Control: prospectus for potential Trailblazers’ for local authorities wishing to submit a proposal to become a Trailblazer. The prospectus contains important information about what we want to test and evaluate.

The Right to Control Trailblazers offer the opportunity to further test how to implement our commitment to choice and control. We will do this by building on the lessons learned from the Individual Budget pilots, providing the legislative framework to enable different funding streams to work together and putting in place the entitlement to choice and control that disabled people have told us they need.

Disabled people taking part in the Right to Control Trailblazers will have a legal right to:

• be told how much support they are eligible to receive
• decide and agree, with the public body, the outcomes they want to achieve, based on the objectives of the funding streams they access
• have choice and control over the support they receive, and
• be able to choose how they receive the support.

Disabled people taking part in the Trailblazers will be entitled to choose:

• to continue their existing services, should they be happy with them, or
• for a public body to arrange for a more tailored service which better meets their needs where this is reasonably practicable, or to procure equipment that they need, or
• to take a direct cash payment and buy services or equipment, or
• a combination of these.

Why did we consult?

We have developed all elements of the Right to Control in partnership with disabled people. In other words this policy has been co-produced with disabled people. As we move from legislating for the Right in Parliament\(^7\) to testing how it might work in the Trailblazer sites, we wanted to ask disabled people, their organisations, service providers and others about some of the issues the Right to Control raises. This will mean that we can design the Right to Control to offer real choice and control for disabled people.

The consultation

‘Making choice and control a reality for disabled people\(^8\)’ was launched on 11 June 2009 by the Secretary of State for Work and Pensions, Rt Hon Yvette Cooper MP. The consultation exercise ended on 30 September 2009.

The aim of the consultation was to listen to people’s views and those of different organisations before making a decision on how certain aspects of the Trailblazers might work. We particularly wanted to get the views of disabled people and their organisations on the best way to deliver the Right to Control in the Trailblazers. It is important that we understand what works best for disabled adults to access and exercise their new right. We also wanted to hear from those individuals and organisations, such as public bodies and third sector organisations, who are involved in delivering, commissioning and monitoring services to disabled people.

This government response is based on what people have said in response to the 17 questions that we asked. We worked with an organisation of disabled people, Disability Action in Islington, to develop a toolkit to support disabled people and organisations to respond to the consultation. We also produced a shorter list of questions to make it easier for people to respond. Answers to these questions have been incorporated when preparing the government’s response.

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7 The Welfare Reform Bill received Royal Assent on 12 November 2009.

What did we consult on?

The questions we asked fell into the following broad themes:

• Choosing what to include in the Trailblazers
• What to do about services used by both disabled and non-disabled people
• Working together to support disabled people and to develop Trailblazer sites
• Cost, affordability and viability of services within the Right to Control
• Helping people use the Right to Control
• What if someone is unhappy with a Right to Control decision
• What the Right to Control means for service providers, voluntary groups and people who set up support services
• Anything else you want to tell us
Responses to the consultation
We launched our consultation at events in London and Liverpool. Each event was attended by over 100 people. Participants included disabled people, their organisations, service providers, public bodies and relevant third sector organisations. We provided materials to facilitate local groups in setting up their own consultation discussions and events. We supported and/or attended 34 events held across the country during the 16-week consultation period. In addition to input received at these events, we also received a total of 176 written responses:

- 81 were from individuals
- 45 were from disabled people’s and/or carers’ organisations
- 25 were from service providers
- 16 were from local authorities and other local public bodies
- 8 were from other organisations such as the Association of Directors of Adult Social Services.

Respondents commented where they had views or relevant experience and did not necessarily answer all 17 questions. A small proportion of responses contained a narrative, not linked to the questions, but at times covering issues that the respondent had strong views on or was closely associated with.

Many responses from organisations were the outcome of consultation events that they held, which although counted towards a single entry, were in effect the views of many people. For example, the response received from the Independent Living Fund (ILF) was a collective response from over 500 individuals (who contributed by writing to ILF) and 127 people who attended their 8 events.

This government response is based on the views received from both written responses and from feedback at consultation events.
What we were told and the government’s response
The 17 questions in the consultation exercise were grouped into specific themes in the consultation document. In responding to the consultation exercise, we have grouped the 17 consultation questions into 8 broad themes. We have listed the questions within each theme.

The focus of the government’s response is on particular issues that need to be resolved, and decisions made, prior to the commencement of the Trailblazers. For some of these issues we will be discussing next steps with our Advisory Group, which is helping the government develop plans for Trailblazers. The Group is chaired by Baroness Jane Campbell and comprises of disabled people, their organisations and representatives from public authorities and service providers.

Once Trailblazer sites are selected in 2010, we will have further discussions with disabled people, public authorities and providers in those areas. In addition, there are several issues about how the Trailblazers will operate. We will only be able to test these options during the Trailblazers. We have specified where this is the case in our response.
Choosing what to include in the Trailblazers

**Question 1:** What criteria should we use to select funding streams to be included in the Trailblazer sites for the Right to Control?

**Question 2:** Which funding streams do you think could and should be included in the Trailblazers?

Introduction

The White Paper ‘Raising expectations and increasing support: reforming welfare for the future’ was published in December 2008. It set out the following criteria that could be applied when considering whether funding streams should be included under the Right to Control:

- to enable individuals to overcome barriers associated with illness or impairment
- to address the additional needs and difficulties experienced by disabled people, thus enabling disabled people to fully participate in all aspects of their lives, including at home, at work and in the community, or
- to have a positive impact on the lives of disabled people and will enable more efficient delivery of services administered by public authorities.

The White Paper also said that funding streams would not be included in the Right to Control either in the Trailblazer sites or in any subsequent extension if:

- the funding stream is already paid as a cash benefit, for example Disability Living Allowance
- the funding stream is for a universal service where eligibility is not determined by an individual needs assessment, such as defence, primary and secondary education, public transport, refuse collection or libraries.
National Health Service funding streams are also not included in the Right to Control Trailblazers.

We asked for views about how funding provided by the Department for Work and Pensions (DWP), particularly Access to Work, ILF and specialist disability employment programmes could be included in the Trailblazers.

In addition to these programmes, we also asked whether there were other funding streams that disabled people would want included or aligned in the Trailblazers, such as Disabled Facilities Grants and locally-administered funding such as non-statutory housing-related support (Supporting People).

> You should include anything that is specifically for disabled people to enable them to live at home (including going shopping), work, be educated, take part in leisure, community and belief activities.

*Individual*

> All existing funding streams should be included in ‘Right to Control’ especially those around employment such as Workstep, Work Preparation and Access to Work, and those around living independently in one’s own home.

*South Yorkshire Centre for Inclusive Living*
Consultation response

There was broad support for the criteria set out in the White Paper. Respondents emphasised the need to include support that enables disabled people to achieve independent living. A majority of individuals and organisations said we should test all of the funding streams that support disabled people, to explore the real benefits of the Right to Control. Shaw Trust was one of many organisations which said that any funding stream which can either positively or negatively impact on an individual’s capacity to move from dependence towards independence should be included in the Trailblazer sites.

Most respondents agreed with the inclusion of the funding streams named in our consultation document. These are funding streams that are designed to help disabled people into work, help them to go about their daily lives and overcome barriers associated with their impairment. They agreed that the criteria suggested in the White Paper were sound.

“I think it is a mistake leaving out Social Care. All funding streams should be combined or made available to a central contact point, so that disabled people are not having to go to lots of different teams throughout different organisations.”

Individual

There was widespread support amongst all respondents for the inclusion of Adult Social Care (also referred to as community care funding) in particular from local authorities. Several respondents suggested that health funding should be covered by the Right to Control, also extending to include aids and equipment funding (provided by Integrated Community Equipment Services).

Many responses considered that cash benefits, in particular, Disability Living Allowance and Attendance Allowance should not be included. Others pointed out that disabled people could use cash benefits alongside support provided under the Right to Control.
Support that promotes financial inclusion, either through training or job preparation, was also popular with some respondents. However, some service providers favoured an incremental approach, to minimise potential difficulties for Trailblazers trying to administer too many funding streams. Some employment support organisations, like the British Association of Supported Employment, agreed with the funding streams currently proposed but wanted the Right to go further to include funding for additional learning support within education or training.

The criteria [for selecting funding streams] should be based on what each individual needs to be able to have an individualised personal package that reflects their aspirations, desires, expectations and unique needs.

British Association for Supported Employment (BASE)

Some respondents suggested including a range of funding streams currently open to disabled and non-disabled people, such as Train to Gain and Pathways to Work. Some also said that Disabled Students Allowance should be included.

Respondents also suggested that Trailblazers should test the difficulties in bringing together different types of funding streams, for example, those that are administered locally (Disabled Facilities Grant) and others that are administered nationally (Access to Work).

Responses from local government and the National Housing Federation recognised the benefits that personalisation brings. They also pointed out a number of practical difficulties Trailblazers will need to work through to effectively deliver the inclusion of non-statutory housing-related support (also known as Supporting People) and Disabled Facilities Grant within the Right to Control.
Age Concern and Help the Aged questioned the rationale in the White Paper for excluding all universal services that are not determined by an individual needs assessment. They said that, if a disabled person receives a service delivered by a local community centre (accessed by both disabled and non-disabled people) instead of a specialist day centre, then this provision should be included in the Right to Control. They also suggested that services purchased using cash payments made under the Local Government Act 2000 well-being powers should be included in the Right to Control.

Some organisations stressed that government should not simply focus on including traditional ways of supporting disabled people and that this was an opportunity for other services like counselling to be included.

Although the long-term aim should be for the Right to Control to be exercisable in relation to all disability-related funding streams, the trailblazers should restrict themselves to a maximum of six streams….Once alignment and integration of this number of funding streams has been achieved, the government could then incorporate additional sources of funding.

Government response

Our legislation would enable us to give disabled people choice and control over the publicly-funded support that enables them to fully participate in all aspects of their lives. Eligibility for the funding streams to be included within the Right to Control Trailblazers and the broad outcomes they are expected to achieve will not be altered as a result of the Right to Control.
Decisions that are made now about which funding streams to include in the Trailblazers, do not exclude the possibility of extending the Right to Control to other funding streams if it is rolled out further in the future. We set out below the decisions that we have made concerning the funding streams to be included in the Trailblazers.

**Adult Community Care**

We have listened to the large number of respondents who made representations on this issue, in particular to disabled people themselves. We will include adult Community Care within the scope of the Right to Control for our Trailblazers. To ensure the Right to Control is delivered to disabled people in receipt of adult Community Care, the Department of Health (DH) will issue instructions to Trailblazer sites to make this happen. This will ensure that the Trailblazers can build on the current programme to transform Adult Social Care.

**Integrated Community Equipment Services (as part of adult Community Care)**

We have also listened to respondents’ suggestions that community care funding, that is used to provide equipment to help people live independently in the community, often known as Integrated Community Equipment Services, should be included in the Right to Control. Based on this consultation, this funding has now been brought within the scope of the Right to Control Trailblazers.

**Non-acute and continuing health care**

Support relating to disabled people’s continuing and non-acute health needs will not be included in the Right to Control. In a separate initiative, DH is testing personal health budgets in a number of Primary Care Trusts across England. The personal health budget pilot programme is expected to start recruiting patients later this year and will last three years, including two years of piloting direct payments for health care from mid-2010. We are working with DH to identify whether any of our Trailblazers could be co-located with a personal health budget pilot. This will enable us to explore the scope for joining-up care planning for health needs with other types of support provided under the Right to Control.

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9  The Health Bill received Royal Assent on 12 November 2009.
Disabled Facilities Grants and non-statutory housing-related support (Supporting People)

We recognise that there are practical difficulties in including Disabled Facilities Grant and Supporting People funding in the Right to Control, but we want Trailblazers to test what can be achieved. Supporting People supports a wide range of people with housing-related needs, often as part of a wider accommodation package. Issues relating to the block commissioning of services have been tackled in the personalisation of Adult Social Care and we will build on the learning and experience from the Individual Budget Pilot sites and Putting People First, and from the achievements of personalisation in Supporting People (non-statutory housing-related support) programmes. The difficulties with the Disabled Facilities Grant programme relate to its classification as a capital resource rather than revenue and to the time it can sometimes take to deliver these services. We will work closely with Communities and Local Government (CLG), housing providers and disabled people to take this forward.

Local community services

The Right to Control includes funding streams that enable individuals to overcome barriers associated with illness or impairment, and to address additional needs and difficulties experienced by disabled people. If an individual disabled person’s use of a local community centre was funded by a Right to Control funding stream, such as adult Community Care, then they would have the Right to Control over this funding. However, if an individual’s use of a community centre was not funded by a Right to Control funding stream (for example, a lunch club for older people, a youth club for young people with learning disabilities, a community centre for local residents of a housing estate) this would not come within their entitlement to a Right to Control.

Support provided under local authorities’ well-being powers

Local authorities have powers under the Local Government Act 2000 to do anything which they consider is likely to promote social, economic or environmental well being in their area. This includes a discretion to provide cash payments, outside of social care direct payments. Some respondents raised the question whether services provided by cash payments through well-being powers should be included in the Right to Control. We have taken on board these views and will explore this issue further with local authorities selected to be a Trailblazer.
Access to Work

Access to Work will be one of the funding streams tested in the Trailblazers. Some respondents argued that some work-focused support could be used to encourage volunteering. However, we will not be changing Access to Work to enable this as it would represent a fundamental change in the programme’s eligibility criteria. Such changes are outside of the scope of the Right to Control initiative.

There are no future plans to extend Access to Work funding to volunteers. We recognise that volunteering can play a valuable role in helping some disabled people prepare for work, but the Access to Work programme is designed to help and support disabled people in, or entering, paid work. Work is defined as activities from which disabled people earn their living.

Funding streams to be included in the Right to Control Trailblazers

The Trailblazers will include a range of support to give disabled people greater choice and control. They will include:

- Access to Work
- Independent Living Fund
- Disabled Facilities Grant
- non-statutory housing-related support (also known as Supporting People), and
- Work Choice.

Adult Community Care (including Integrated Community Equipment Services) will also be included within the Trailblazers, ensuring that we will build on the current programme to transform Adult Social Care.

Over the next few months, we will be working with the relevant government departments, successful Trailblazer sites, providers and disabled people to plan how to deliver the Right to Control. In particular we will work closely with CLG, housing providers and disabled people to resolve any practical barriers to the inclusion of Supporting People and Disabled Facilities Grant.
Funding streams and benefits not included in the Right to Control

Benefits such as Disability Living Allowance, Attendance Allowance and Employment Support Allowance will not be included in the Right to Control. This is because they are already paid as cash benefits.

If entitlement to a universal service is not determined by a needs assessment this will also be excluded from the Right to Control, such as defence, primary and secondary education, public transport, refuse collection or libraries.

We will also not include in the Trailblazers any employment programmes with mandatory elements such as Pathways to Work or the Flexible New Deal.

Disabled Students Allowance

A number of respondents suggested the Trailblazers include Disabled Students Allowance, currently delivered by the Student Loan Company. In October the government announced a review into the delivery of funding for English students and we therefore do not propose to include Disabled Students Allowance in the Trailblazers. Our primary legislation includes broad powers. If a decision is made to roll out the Right to Control more widely following an evaluation of the Trailblazers, Disabled Students Allowance, and other support not included in the Trailblazers, could be included in the future.
What to do about services used by both disabled and non-disabled people

Question 3: 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?

Introduction

The Right to Control will apply to all disabled adults in the Trailblazer areas who are eligible for support provided under the Right to Control funding streams, and are new users of a funding stream, as a minimum. We want to ensure that we can include support to disabled people even when the funding stream is accessed by both disabled and non-disabled people. In our consultation document we only identified non-statutory housing related support (also known as Supporting People) as a funding stream that is available both to disabled and non-disabled people (eg women fleeing domestic violence or teenage parents). We asked whether the government’s current definition of a disabled person contained within the Disability Discrimination Act 1995 is sufficient to identify those who should have a Right to Control the support they receive, or whether a new definition would be needed.

We feel that the legal definition contained within the Disability Discrimination Act should be the guide, but there should be room for discretion for those who fall outside the criteria.

Kent Adult Social Services
Consultation response

Overall, 75 per cent of people responded to this question but only 25 per cent of these provided an opinion on what definition we should use. The majority of these respondents favoured a clear definition based on the Disability Discrimination Act (DDA) 1995 which defines a disabled person as someone who has:

“a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.”

However, some respondents also expressed concern that using the DDA definition may not fully capture the intention stated in the White Paper, ‘Raising expectations and increasing support: reforming welfare for the future’. Therefore, although the most common suggestion was to mirror the definition in the DDA, a number of respondents suggested adopting a new definition specifically for the Right to Control, with a greater focus on independent living or based on the social model of disability.

The group wanted a statement which focussed on the barriers faced by disabled people and how we deal with them. The social model is not about diagnosis but about barriers and so language used should reflect this. [It] must be about barriers – can ‘cure’ barriers by fixing society not disabled people.

York Independent Living Network
Some respondents favoured self definition and others suggested that people should be able to opt in or out of the funding stream depending on their support need. There were others who suggested that receipt of certain benefits should act as a ‘passport’ to the Right to Control. Some respondents noted that funding streams accessed by disabled and non-disabled people could be at risk of legal challenge if only disabled people could exercise the Right to Control.

**Government response**

The intention set out in the White Paper is that the Right to Control should be made available to disabled people to address the additional needs, difficulties and barriers associated with illness or impairment. We recognised that some of the funding streams that might be included in the Right to Control could be available to both disabled and non-disabled people. In practice the only funding stream within the scope of the Trailblazers that is available to both disabled and non-disabled people is Supporting People (non-statutory housing-related support).

Supporting People goes to a wide range of recipients with very different needs. We concluded that Trailblazers should be enabled to give the Right to Control over non-statutory housing-related support where it has been allocated to overcome barriers associated with illness or impairment. So, for example, the non-statutory housing-related support of a person with a learning disability would come within scope of Right to Control, but support given to a disabled woman fleeing domestic violence would not unless it were being given to overcome barriers associated with her impairment. Therefore the Right would not cover support being given to meet any needs that she might have in common with other women fleeing domestic violence.

This simple approach seems preferable to developing a new definition of disability for the purposes of Right to Control. We acknowledge that in practice it may not always be easy to separate out different types of support needs. We will monitor how this works in the Trailblazer areas.
Working together to support disabled people and to develop Trailblazer sites

Questions 4: 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?

Question 12: What do we need to do to ensure that disabled people and their organisations play a full part in the Trailblazers?

Introduction

We would like public bodies who administer the funding streams included in the Right to Control to consider how they can best work together to deliver a joined-up service of support to disabled people. Trailblazers should be developed in partnership with:

- disabled people themselves
- public bodies responsible for the selected funding streams
- service providers
- commissioners
- third sector organisations, including user-led organisations.

We consulted on ways that this could happen.

Many respondents focused on the need for disabled people to receive clear, accessible and consistent information from the Trailblazers. We have incorporated these responses, and the government response, into the section ‘Helping people to use the Right to Control’ on page 45.
A key issue here is to have one contact person sufficiently trained and knowledgeable of the system that Right to Control users can communicate with.

_Individual_

Provider bodies need to align their eligibility, management and delivery systems with each other... [There should be] one point of entry to services eg truly one-stop shop and one point of decision making.

_The Association for Spina Bifida and Hydrocephalus_

Consult from the beginning – in a way that disabled people can understand... Be honest, open and understandable.

_Individual_

Insist on genuine co-development where power and responsibility are equally shared in policy and practice development. The ‘disabled person’ participants must have real ‘power’.

_Hampshire Centre for Independent Living_
Consultation response

Involvement of disabled people and their organisations

There were some common themes in responses received from all stakeholders. Both service providers and local authorities felt strongly that disabled people and their organisations need to be consulted ahead of and throughout the Trailblazers and this should be demonstrated in the Trailblazer proposals.

If we are asked then we should be listened to.

Leicestershire Centre for Integrated Living

Disabled people’s organisations advised that early partnerships with Centres for Independent Living and other user-led organisations will be key to administering the Right to Control. These organisations should advise local authorities on developing their applications to become Trailblazers. Respondents also recommended that before the Trailblazer sites are launched, staff in public bodies should be fully trained and aware of what the Right to Control will mean for disabled people and where disabled people can go to apply for the range of support available.

Both service providers and disabled people’s organisations recommended that a user-led organisation or Centre for Independent Living be represented on the panel that selects the Trailblazer sites.
The importance of information

People told us that we need to ensure that Trailblazers engage with disabled people and their organisations from an early stage. This should be done through availability of clear, consistent and accessible information supplemented by a targeted awareness campaign. Service providers recommended that the government should consider launching a wide-scale multi-channel advertising campaign to raise awareness about all aspects of the Right to Control, using for example the internet, radio, newspapers and disability-specific publications.

"People should explain it clearly. They should use good communication – sign language, pictures, hearing aids, signs."

Connect Advocacy Drop In Group

They felt that currently the personalisation agenda is understood and owned by few people outside of the social care sector. Respondents believed that the goals of the personalisation agenda need to be far better communicated to the general public.

Joining up support

Some organisations recommended that Trailblazer authorities set up ‘one-stop shops’ to simplify processes and remove some of the bureaucracy disabled people would have to go through to receive different funding streams and develop a support plan. Many respondents recommended that disabled people should be able to access information and support about the Right to Control through any public body, even if they were not eligible for the funding stream it administered.
Several responses stated that some disabled people feared that streamlined assessments could lead to a reduction in the amount of support they receive. They also recommended that public authorities try to ensure that monies or services from different funding streams are transferred or made available to the individual at the same time. Others recommended that the Trailblazers should test the alignment or synchronisation of different funding streams. This would enable a more joined-up approach to how support is delivered. However, there was also a view that disabled people and funding stream administrators should still be aware of how much money came from each funding stream.

Respondents generally favoured one assessment of need and one support plan, with data shared between public bodies, where appropriate and with the consent of the disabled person. This approach would ensure that future review dates were aligned and would reduce the fragmentation of support many disabled people experience. Local authorities welcomed this approach, and in some cases highlighted work that was already underway to streamline or integrate assessments and reviews.

**Government response**

**Involvement of disabled people**

The Right to Control policy was originally developed in response to disabled people’s wish to have choice and control over the support they need to go about their daily lives. We have worked in partnership with disabled people and their organisations each step of the way. The government acknowledges that disabled people are experts in how best to meet their own needs, and how best to use public resources to deliver the goal of full and equal citizenship. This is why we aim to move beyond consultation and work together not just on the policy and legislation but also on how the Right to Control Trailblazers can be successfully delivered. This process of co-production will therefore continue to be integral to our approach to testing out how to implement the Right to Control through the Trailblazers.

As a result of responses we have received, we will be asking a representative from an organisation of disabled people to sit on our Trailblazer selection panel and to be fully involved in the selection process. We will also continue to work with our Advisory Group on the process and criteria for Trailblazer selection.
In addition, we will expect local authorities who apply to become Trailblazers to fully describe how they have involved disabled people in developing their application. They also need to describe how they will involve disabled people as they change their services.

We will continue to draw on the experience and expertise of disabled people and their organisations throughout the implementation of the Right to Control Trailblazers. We will expect and will support the Trailblazer sites areas to do this as well.

The importance of information

We fully acknowledge the importance of informing disabled people, and others living in Trailblazer areas, about who is eligible for the Right to Control and what it means. Once we have selected our Trailblazer sites we will work with them to develop a targeted and accessible awareness campaign about the Right to Control, tailored for the selected Trailblazer sites and aligned with their current information and communication strategies.

We will work with both service providers and commissioners to help them address the range of information and support that individuals might need in order to access the Right to Control, and this is covered more fully on pages 54-59.

We will continue to seek advice from disabled people and our Advisory Group on how best to fully inform disabled people about the Right to Control. We will also seek to ensure that local user-led organisations are fully involved in the provision of information.

Joining up support

Effective service delivery will be key to making the Right to Control Trailblazers a success. We have drawn lessons from the Individual Budget pilots about the barriers to a more joined-up approach to delivering support. We have therefore taken powers in our legislation to remove any barriers to integrating funding streams and making their administration more flexible. We will ensure that, where necessary, we provide powers for authorities to share information and streamline services.

We are also working with ILF and their Trustees to amend the ILF Trust Deed where necessary. This Deed sets out the framework within which the ILF can operate. Making changes to the Trust Deed will ensure the flexibilities of the Right to Control can be delivered to people who receive funding from the ILF in Trailblazer areas.
The Access to Work and Work Choice programmes have already been designed to work effectively together, so that customers experience the minimum of difficulty as they move from one programme to the other. We expect that this close cooperation will be further developed in Right to Control Trailblazers.

Our aspiration is that, with these barriers removed, the Trailblazers will be able to test how far administrative barriers to integrating or streamlining different funding streams can be removed or reduced. We will also explore how different public bodies can share information about individuals securely, to help different types of support to become more joined-up and easier to understand and access.

We propose to set out key provisions which Trailblazer authorities must include in the Trailblazers. We want Trailblazer authorities to be as ambitious as possible in streamlining services, promoting ‘one-stop shops’ of information and support for disabled people and to move – where appropriate for the individual – towards an integrated approach to delivering support.

We accept that an integrated approach to the customer journey is not something that can be achieved at the start of the Trailblazers. In some circumstances this approach may not be appropriate. However, we wish to support Trailblazers to test out circumstances in which it is desirable and feasible for disabled people to have one assessment, one support plan, one budget and one review process.

Making staff roles more flexible, changing or adapting existing systems and procedures and co-locating services where possible, will all help to create more joined-up service delivery. We will work with Trailblazer sites to help them develop a system that will offer real choice and control for disabled people. Our prospectus provides more information about what will be expected of the Trailblazer sites.

The operation of the Trailblazers will be monitored and evaluated, so that any areas of concern or ideas on best practice can be shared between the Trailblazer sites. This will form an element of a comprehensive evaluation of the Right to Control that will be conducted by an independent evaluation team. A full report will be published after the completion of the Trailblazers.
Cost, affordability and viability of services within the Right to Control

**Question 5:** 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?

**Question 6:** 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?

**Question 7:** 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? How should they consult on this with service users?
Question 8: 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?

Introduction

The Right to Control should help public bodies and other service providers to be better able to support disabled people to live as they choose. The idea is that, in almost all circumstances, public bodies will be able to help an individual exercise their Right to Control over the support they receive.

However, there may be some circumstances where the Right to Control causes some problems for disabled people who use current services. The Right to Control could make it harder for some disabled people to continue to use those services, especially if other disabled people leave existing services to spend their funding elsewhere. Equally, public bodies are often able to negotiate discounts for equipment from suppliers, savings that might be lost if individuals approach suppliers separately.

“Change always causes difficulties for someone, but this is not an excuse not to change things for the better.”

Individual
Consultation response

There was agreement amongst service users, service providers, user-led organisations and local authorities that services should be delivered in a way that gives disabled people choice and control. Such a goal is in line with current developments concerning the personalisation of public services generally. Respondents commented that most local authorities already commission services to agencies or providers who seek to respond flexibly to the needs of individual service users and such flexibility should already be reflected in the cost of their service.

The guiding principle should be to support individual choice and control: if a majority of people choose to leave a service then this must surely bring into question the quality and validity of that service?

Breakthrough UK Ltd

Some user-led organisations felt that the market needed to develop in order to ensure a supply of services that are responsive to the needs of disabled people. This could take time and government support may be needed during this transition, but some respondents were optimistic about the longer-term potential for market development. Breakthrough UK Ltd, for example, said

“Service providers have a period of change in front of them in as much as their ‘customer base’ will be disabled people themselves and the providers will need to research their customer base to assure themselves that they are selling what the customer (the disabled person) wants.”

Some respondents pointed out that it is unlikely that people will move from existing services in large numbers straightaway. The change may be gradual and easy to manage. Respondents pointed to the role of commissioners in developing more flexible contracts and in supporting users if services change. They pointed to a role that commissioners could play in supporting the market to respond appropriately to their ‘new’ customers and their requirements.
The public body and service provider must look at what is being provided to disabled people, gauge satisfaction levels and change if necessary.

Individual

Respondents agreed that if a service has to close, the public authority needed to ensure that support is provided to disabled people who may be losing a service they enjoy. Centres for Independent Living and other user-led organisations should also be enabled to play a role to help guard against people becoming isolated.

Organisations representing older people told us it is important that the process that public authorities use when reconfiguring services focuses on, and fully respects the rights of, service users.

Some local authorities and user-led organisations suggested there is a role for them in negotiating discounts or supporting groups of disabled people to secure discounts. There was also a view that individuals should be able to add their own funds to the publicly funded resources in order to purchase the particular service or equipment they wanted.

Discounts could be negotiated by public bodies but a service user could purchase equipment or services themselves from the wider choice available.

Individual

Health and safety legislation was also mentioned as a potential barrier by individuals, as in some instances public authorities may be more likely to enforce low risk solutions, rather than empowering the disabled person to have greater choice and control and seeking more innovative solutions.
Government response

The Right to Control will help create a new relationship between service user and provider. Service providers will need to work closely with disabled people to understand whether the services they provide meet their needs and deliver choice and control. We will expect relevant authorities in the Trailblazer sites to work closely with service providers in their area to ensure that they are aware of the Right to Control and what it means for them. We will also expect Trailblazers to manage the Right to Control within their existing budgets and baselines.

The Right to Control Trailblazers are highlighted in the Invitation to Tender for the Work Choice contracts. Work Choice providers will be expected to work closely with Trailblazer local authorities, once both are selected. The government has made available some extra funding above the amounts that will be contracted to Work Choice providers, so that those customers eligible for Work Choice wishing to take a cash payment are able to do so.

We will encourage and support the Trailblazers to take preventative action to mitigate any risk to existing services. For example, through early involvement of providers once sites are selected and by supporting existing services to develop more flexible and tailored responses to the needs and aspirations of service users. We will also encourage Trailblazers to draw on a range of products developed by DH which include a framework document providing information for commissioners. During the Trailblazers, we will expect local authorities to explore the best ways for disabled people to procure equipment and services at favourable rates. This may mean supporting groups of disabled people to negotiate discounts.


We will monitor whether the Right to Control threatens the viability of existing services and how local authorities work to mitigate this risk alongside any duties they may have to provide services. We want individuals and those who support them to use the Right to Control as creatively as they wish. However, this will mean that we, and public bodies, have to manage the risk that this brings. We will further develop strategies to manage these risks before the Trailblazers are launched and will test these approaches during the Trailblazers.

The Right to Control will not change the obligations that local authorities have under Health and Safety legislation. However, we recognise that approaches to risk can sometimes be experienced by disabled people as unnecessarily restrictive. We will work with Trailblazers and with nationally administered funding streams, to ensure that where disabled people are developing innovative solutions to meet their needs that local authorities and service providers can be as flexible as possible. We will work closely with DH to identify lessons from the delivery of Individual Budgets pilots to build in flexibilities into the system.

The Right to Control Trailblazers will be subject to an evaluation before a decision on any wider roll-out is taken. The evaluation of the Trailblazers will look to address some key questions relating to the impact the Right to Control has on the cost-effectiveness of existing services, the affordability of the Right and the impact on outcomes for disabled people.
Helping people to use the Right to Control

**Question 9:** What information and support will disabled people need in order to enable them to exercise their Right to Control?

**Question 10:** 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?

**Introduction**

During the Trailblazers, it will be important that all disabled people who are entitled to a Right to Control, including those with limited capacity to make decisions, have choice and control over the support they receive. We know that disabled people choosing to exercise the Right to Control will be taking on additional responsibilities and some will want to be supported in this.

Disabled people have told us that it will be important that advocacy or support is available if everyone entitled to the Right to Control is to be able to exercise the Right. Such support may take the form of good quality information and advice, peer support, independent advocacy, and/or support brokerage. It may also take the form of supporting a disabled person to employ their own support workers. During the Trailblazers, we want to test what level and type of support is likely to be required, how much it might cost, and which organisations or individuals are best placed to provide this.
Information is power…. Everyone should be able to access clear and concise, up-to-date information from a variety of sources.

Individual

Having all the information will help lots. Without information there is no choice!

Cornwall People First: The Get Real Team

The best way to make sure people know about support is via user-led organisations and advocacy services.

Individual

Disabled people should be offered the support of an advocate to help them to speak up for themselves about the services and support they need and want to help them live their life. Advocacy empowers people to speak up and have a voice.

Gateshead Advocacy & Information Network
Consultation response

Most respondents were clear that people should have access to independent advocacy to enable them to make informed decisions about the type of services that are available to them. Many also said that clear information and training for people providing advocacy and brokerage services would be necessary, to build understanding about the Right to Control and how it would work. Disabled people and their organisations also said that peer support was important to them.

Responses strongly favoured the need to have clear and consistent information. This was raised by over half of respondents. Respondents wanted information to be fully accessible and available in a variety of media and languages. Some people were also particularly keen on using the internet, with the possibility of having a central information hub including interactive forums and using networking sites. However, organisations representing older people stated that a much smaller proportion of older people use the internet regularly. As a result, they suggested that traditional means of informing people of government services should also be used.

Respondents also highlighted where there was good advocacy support in local areas. Many highlighted the work of Centres for Independent Living and user-led organisations in this field.

“Thriving and financially secure user-led Centres for Independent Living and disabled people’s organisations are a vital component of the vision of equality, choice, control and independence, enabling disabled people to come together and become confident individual budget users.”

Disability Action in Islington
Some service providers and local authorities also suggested that they themselves had a role to ensure disabled people could access impartial advice about services that are available.

Many individuals and organisations of disabled people stated that if disabled people needed advocacy or support services, these should not cost individuals extra. The services should either be free at the point of delivery, or the cost should be included as an additional amount into the support plan.

**Government response**

We acknowledge that high quality information, advice, advocacy and brokerage services are very important to many disabled people. We believe that local authorities and their partners are best placed to decide how these services should be provided. Councils have been given over £500 million over the period 2008-11 to help them to transform the way in which social care is provided, including ensuring people have access to information and advocacy services where they need them.

We also know that user-led organisations have a key role to play in providing independent information, advice, advocacy and brokerage services and in particular, that peer support they provide is valued by disabled people. They could ensure wider access to the Right to Control by helping disabled people, who are at particular risk of losing choice and control, to make informed decisions.

For the financial year 2009/10 ODI gave a total of £733,000 in funding to the English regions to support capacity building work with user-led organisations. The aim is to help develop a stronger user-led organisation infrastructure in each region. DH has also provided financial support of £1 million over 2008-10 for capacity building. In addition, DH is also investing £1.65 million over the same period to support 25 user-led organisations as Action Learning Sites. These sites share best practice for organisations interested in becoming a user-led organisation.
The government has also – with the Local Government Association and the Association of Directors of Adult Social Services (ADASS) – disseminated a document to local authorities, *Putting People First: working together with user-led organisations*[^12]. This outlines the benefits of user-led organisations and provides advice to local authorities on how to work in partnership with them. ADASS and the National Centre for Independent Living have recently agreed a [protocol][^13] for the provision of user-led organisations and user-led support services.

Nonetheless, in spite of these commitments and progress achieved, we also acknowledge that the provision of information, support, advocacy and brokerage services currently varies between areas. We will ensure user-led organisations are fully engaged during the Trailblazers and will ask local authorities applying to become Trailblazers, how they will ensure these services are available for disabled people who may wish to use them. This will be one of the criteria to be considered in the selection of Trailblazers.

We will ask Trailblazers to develop plans to communicate the Right to Control to disabled people in their localities – targeting, but not limited to, those who could receive the Right to Control funding streams. We will expect high quality and accessible information to be widely disseminated in the Trailblazer areas so that disabled people are fully informed about their Right to Control. We will evaluate the most effective ways of providing information to different groups of disabled people.

During the Trailblazer period, we will also be evaluating how disabled people access support, advocacy and brokerage services. We will encourage Trailblazers to test out different ways of funding such services and will ensure that the evaluation fully captures disabled people’s experiences and preferences.


[^13]: ADASS, NCIL and LGA, 2009, ‘Joint Protocol between National Centre for Independent Living (NCIL), Association of Directors of Adult Social Services (ADASS), and the Local Government Association (LGA) for the provision of User Led Organisations (including Centres for Independent Living) and User Led Support Services’ available at: www.adass.org.uk/images/stories/Learning_Disability/ADASS%20-%20NCIL%20protocol%202009%2014%201%2009.doc (last accessed 17 November 2009)
What if someone is unhappy with a Right to Control decision

Question 11: 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:

• Challenge a decision that they are not happy about?

• Request and take part in a review of a decision?

Introduction

We want disabled people to feel confident that, if they are unhappy with a decision about their access to the Right to Control in the Trailblazers, there are easily accessible ways to:

• challenge the decision
• seek a review of the decision.

We wanted to find out how best to support disabled people who want to challenge a Right to Control decision.

“Always inform individuals they can challenge decisions – in a way they understand.”

Individual
It is hoped that the Right to Control will increase collaboration and cooperation between commissioners and service users. Therefore, it is hoped that there will be less need to complain against or challenge a decision.

National Autistic Society

The process must be fast and simple. There should be one process not several as now, a simple and easy complaints procedure and independent review process.

Individual

Information about all complaints or appeals processes needs to be user friendly, comprehensive, clear and fully accessible. It also needs to include information on people’s rights through the process including the right to have an independent advocate.

Disability Action in Islington
Consultation response

Overall, respondents told us that they find the current complaint and review systems for the various funding streams too confusing. Because of this many disabled people who have complaints do not voice their concerns. Respondents wanted the Right to Control to have a single, simple, independent and easy complaints process. Each part of the decision needed to be clear and provided in an accessible format. Respondents recommended that information on how to challenge a decision should be made available at the same time that the decision is communicated to the disabled person.

In terms of accessing information, and help and advice about making a complaint, respondents felt that this should be freely available and easily accessible from a central source. There were various views on how this could work but the majority favoured a single website where all information could be accessed or that there should be an independent organisation or ombudsman that does not have any ties to public bodies or local authorities.

“We would not want the person a complaint is made to, to be the same person who delivers or control the service. There needs to be an independent organisation or party. People are often scared – they should have someone independent to complain to, support to do that if needed, someone you can trust to help you.”

South Lancashire Physical Disability Partnership
Government response

It is important that people are able to challenge decisions that are made in regard to their Right to Control. However, creating and funding a separate appeals body for the Trailblazer sites would be costly, and it is unlikely that it would be ready for when the Trailblazer sites are launched in late 2010. Each funding stream has a complaints and review mechanism. We expect these mechanisms to be developed during the Trailblazers, to enable disabled people who are refused the Right to Control to request a review of this decision. We also expect mechanisms to be developed for addressing situations where authorities and individuals cannot agree a support plan.

We expect the number of refusals to be small, however, and will seek to support Trailblazers to address any barriers to delivering the Right to Control. We will monitor this through our evaluation.

We will expect the selected Trailblazers to learn lessons from both the Individual Budget and the In Control pilots and to use the time between selection and launch in late 2010 to consider how to maximise access to the Right to Control. We would also expect this work to include ensuring that access to existing review mechanisms is made as easy as possible, and that, if they need it, individuals are provided with support to ask for a review of a Right to Control decision.
What the Right to Control means for service providers, voluntary groups and people who set up support services

Question 13: 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?

Question 14: 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?

Question 15: Are there particular implications for third sector organisations and how can they be addressed in the Right to Control Trailblazers?

Question 16: 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?
Introduction

The Right to Control will have implications for service providers, third sector organisations and commissioners of services. We wanted people to consider the following issues and provide any views they may have on how to address them.

- Those responsible for commissioning services will have an important role to play in ensuring that disabled people have genuine choices about how to use the resources available to them.
- The experience of the Individual Budget pilots illustrated the importance of changes in attitudes and approaches amongst service providers.
- If disabled people are to experience a more joined-up approach to their needs, this will require closer working between different public bodies.
- It will be important – for both disabled people and public bodies – that systems are in place to check whether agreed outcomes are being achieved.

“Service providers need to work with disabled people to understand the likely needs and issues.

Individual”

“We feel that [service providers] must all adopt the principles of personalisation. In this way they will ensure that the service user is placed at the centre of decision making about how their aspirations can and should be met.

Kent Adult Social Services”
Consultation response

A large number of responses, including from disabled people and from organisations providing services to disabled people, focused on the need for service providers to be more flexible and responsive to the needs of their customers. Many of these respondents felt that this would be an opportunity for providers and commissioners to work with disabled people as they set up and develop services, although several organisations commented that a market could not be grown from scratch. Some government support or an incremental approach would be needed to provide a range of products and support that disabled people could purchase. Service providers agreed that they will need to reorient themselves for a changed customer base – disabled people, as opposed to the commissioning body.

Another strong theme from the consultation was that people felt service providers will need to be given clear information of what will be expected of them during the Trailblazers. This should be supplemented with training programmes providing information on the Right to Control and independent living.

Clear information about Right to Control is, once again, a key element of enabling service providers to respond. They need to be fully aware of the opportunities and also of their responsibilities.

Individual

Respondents felt that local authorities would need to work with service providers in their Trailblazer applications to ensure these organisations were fully aware of what was being required of them. Service providers will need to understand that the introduction of the Right to Control may mean that some services may have to be provided differently. Similar views were expressed in relation to third sector organisations and commissioners. Some organisations, including local authorities, commented that commissioners would have to strategically manage future spending and not to tie up large amounts of resource in block contracts.
There is a need to commission a wider range of services, reduce block purchasing to enhance choice. Public bodies must monitor quality of services commissioned and must be more flexible in their approach to what or who they commission.

*Individual*

Respondents felt that commissioners should involve disabled people when making decisions on the type of services they procure. Commissioners should recognise the role that user-led organisations can play in advising disabled people and be more pro-active in signposting these services.

*Third sector organisations need to be involved in advocacy and advice and information services. They may also be able to offer peer group brokerage. They should be members of the Trailblazer Board.*

*Lancashire County Council*

In terms of developing support plans, most respondents agreed that the disabled person should be at the heart of the process for completing a person-centred plan. This plan should be based on their needs and aspirations, with the support of someone of their choice if they require it.
There should be clear links to person-centred planning. The customer needs to know what choices are available to them before deciding on actions.

**Disability Action in Islington**

There was strong support for clear, accessible and comprehensive information being made available to support disabled people as they completed their plan. The support plan could then be shared as necessary and with the agreement of the individual.

Some respondents said that financial investment in third sector organisations in the Right to Control trailblazing areas was necessary to ensure there would be sufficient provision of support.

**Government response**

The Right to Control is not solely about giving disabled people direct payments with which they can buy and commission their own services – although some may choose to do this. Rather, it is also about giving people the opportunity to work with existing service providers to shape services which meet their needs. Once Trailblazer sites are selected, we will be working with sites, and the relevant organisations and service providers, to ensure everyone understands the implications of the Right to Control during the Trailblazers.

As we test how the Right to Control could work within the Trailblazers, we will want to fully understand the challenges it brings to service providers and those who commission services. User-led organisations and independent advocacy services will play a key role in helping disabled people and service providers work together to develop flexible and responsive services. The aim is to enable services to tailor their provision to the needs and aspirations of the individual, so that disabled people have choice and control over the support required to deliver agreed outcomes.
Some local authorities have already begun to address these issues, particularly in the context of Adult Social Care and of housing-related support services. As a result there are many good practice examples and resources on which the Trailblazers should be able to draw. For example, DH’s personalisation programme is working to support service providers to develop outcome-focused services. We will support the Trailblazers to learn the lessons from this and similar initiatives.

We acknowledge the importance of bringing about cultural change in the organisations responsible for delivering the Right to Control. As part of the implementation of the Independent Living Strategy we have recently completed research on what influences the attitudes of professionals delivering health, social care and employment services. We will be using this research to plan how to support organisations to bring about the cultural changes required in order to deliver the Right to Control. In doing so, we will build on and support the communication activities associated with the implementation of Putting People First.

We know that the involvement of disabled people and their organisations will be a key part of enabling commissioners and service providers to successfully deliver the Right to Control. We will expect the Trailblazer sites and their partner organisations to have strong relationships with local user-led organisations. We will support them to maximise the involvement of local disabled people in both the commissioning and provision of services.

Anything else you want to tell us

Question 17: Are there any other issues or concerns not addressed above about the Right to Control that you would like to comment on?

Introduction

This section was for people to provide us with any views they still had or any topics they wanted to raise with us that were not covered in the other questions.

“Life is all about choices, priorities and preferences. Disabled people should take this responsibility like anyone else.”

Individual

“Right to Control is also about organisational and cultural change, impacting our roles as public bodies and on our methods of service delivery.”

Health and Adult Social Services
Northamptonshire County Council
Consultation response

The main additional points made by respondents are noted below:

• One solution does not fit all situations and that the Right to Control may not work for some disabled people.
• The Right to Control must never become an ‘obligation to control’.
• Government should learn lessons from previous pilots – particularly the DH-led Individual Budgets pilot.
• Entitlements to support should be portable in that, if you move from one area to another, all aspects of your support plan should move with you.
• We will have to change society’s attitudes so that non-disabled people think about disabled people’s real needs not their assumed needs.

“If there is truly a choice over whether to exercise the Right to Control, keeping with the old system must not be stigmatised.”

National Autistic Society

Government response

The Right to Control builds on progress made over a number of years, involving a wide range of disabled people, through policies and initiatives including the implementation of direct payments, personal budgets for adult Community Care, the In Control and Individual Budget pilots and Person-Centred Planning for people with learning disabilities. In particular, there are many local examples of disabled people, family carers and others coming together with service providers and commissioners to deliver more personalised responses to the needs of people with complex and significant impairments and/or long-term health conditions.
We understand that one solution does not fit all people. Our intention is that the Right to Control will provide an entitlement to choice and control and the Trailblazers will provide an opportunity to test both the most effective methods of delivering this entitlement and any limitations. Our policy does not seek to impose anything on disabled people but to create a framework where they (and, where appropriate, family carers and/or others acting on their behalf) can access the personalised support needed to go about their daily lives.

One key lesson which has been learnt from all previous initiatives and pilots is the importance of bringing about attitudinal changes within organisations responsible for funding and delivering services to disabled people. We will seek to build on these lessons and, in particular, to work with disabled people and their organisations to assist Trailblazers in bringing about the cultural changes required to deliver real choice and control.

We acknowledge that many disabled people feel that current systems of delivering support can sometimes act as a disincentive to moving from one geographical area to another, or from one job to another. However, changes to deliver ‘portability’ at a national level are outside the remit of the Right to Control Trailblazers.

The government’s Green Paper, ‘Shaping the Future of Care Together’ acknowledges the wide variations in the standards and quantity of care and support offered by different local authorities. It recognises that such postcode lotteries are worsening as funding struggles to keep pace with rising numbers of older people in need of support. There are few clear rights or entitlements underpinning the service and what people can expect to receive is often unclear until they actually apply for support. The government has stated that the ambition is to have a ‘national care service’ where people are able to get really good care wherever they live, in response to whatever they or their family need.

The issue of ‘portability’ is therefore one which the government is considering in the context of the future of Adult Social Care. The Green Paper sets out options for addressing the difficulties identified by disabled people. The consultation on these options closed on 12 November and the government’s response is expected in 2010.
Prospectus to support the Trailblazers

The Right to Control policy and its implementation will be tested in local authority areas. To support this, we are publishing ‘Right to Control: prospectus for potential Trailblazers’. This document sets out how to apply to be a Trailblazer.

Around eight local authority Trailblazers will be selected to test how the Right to Control can be best implemented. A full independent evaluation will be undertaken to examine the costs and benefits.

The Prospectus is for local government bodies who are interested in testing the Right to Control. It will also be of interest to service providers, disabled people and their organisations, third sector organisations and local user-led organisations.

The Prospectus will set some minimum requirements for Trailblazers about the scope and scale of the sites and some key principles.

Regulations

We have put in place a legislative framework to support the delivery of the Right to Control Trailblazers through the Welfare Reform Act 2009. Our next step is to enact regulations to support the running of Trailblazers. These regulations will provide local authorities with a more detailed framework of how they will need to deliver the Right to Control to disabled people during the Trailblazers.

We have always made clear that we will develop the Right to Control Trailblazers in co-production with disabled people, their organisations, service providers and local authorities. We will use the responses to this consultation to shape the development of the regulations. In early 2010 we will undertake a formal 12-week consultation on our draft regulations.
Annex
List of organisations who have responded to the consultation

A4e
Action for Carers Surrey
Action for Children
Age Concern and Help the Aged
Alliance for Inclusive Education
Arthritis Care
Association for Spina Bifida and Hydrocephalus
Association of Directors of Adult Social Services (ADASS)
Barnsley Service Users and Carers
Black Disabled Peoples Association
Breakthrough UK Ltd
British Association for Supported Employment (BASE)
Buckinghamshire County Council
Chorley and South Ribble Link Up Group
Citizens Advice
Connect Advocacy Drop-In Group
Connexions Northumberland
Cornwall People First: The Get Real Team
Council for Disabled Children – National Transition Support Team
Derbyshire County Council
Disability Action Belfast
Disability Action in Islington
Disability Employment Advisory Committee (DEAC)
Disability Information and Advice Line (DIAL UK) / Southend
Association of Voluntary Services (SAVS)
Disability Wales
Down’s Syndrome Association
Durham County Council
Elcena Jeffers Foundation
Enfield Disability Action
Equality 2025
Equality and Human Rights Commission
Equality and Human Rights Commission Scotland
Essex Coalition of Disabled People (ECDP)
Gateshead Advocacy & Information Network
Gloucestershire Service User Forum
Hampshire Centre of Independent Living
Headway Cambridgeshire
Hearing Concern LINK
Inclusion London
Inclusion Scotland
Inclusive Living Sheffield Ltd
Independent Living Fund
Independus
Kent Adult Social Services
Kirklees Council
Lancashire County Council: Adult and Community Services Directorate
Leeds City Council
Leicestershire Centre for Integrated Living
Lincolnshire Association of People with Disabilities
Lincolnshire County Council: Joint Improvement Partnership Programme
London Borough of Sutton: Adult Social Services and Housing
Low Incomes Tax Reform Group
MacIntyre My Way
Mariners Resource Centre
Mencap
Mind
Motor Neurone Disease Association
Multiple Sclerosis Society
National Association of Deafened People (NADP)
National Association of Schoolmasters Union of Women Teachers (NASUWT)
National Autistic Society
National Centre for Independent Living
National Housing Federation
Neurodiversity International
Newcastle Learning Disability Partnership Board
Northamptonshire County Council: Health and Adult Social Services
North Yorkshire County Council: Adult and Community Services
Nottinghamshire County Council
Nottinghamshire Supported Living Providers Forum
Oaklea Trust
Organisation of Blind African Caribbeans (OBAC) & African Community Development Association (ACDA)
Office of the Third Sector
Papworth Trust
Portland College
Redbridge & Waltham Forest Learning Disability Partnership
Redbridge Disability Association
Rethink
Royal Association for Disability Rights (RADAR)
Royal National Institute for Deaf People (RNID)
Royal National Institute of Blind People (RNIB)
Ryder-Cheshire Volunteers Reading
Scope
Scope – Rotherham Day Service
Sense Scotland
Shaw Trust
South Lancashire Physical Disability Partnership
South Yorkshire Centre for Inclusive Living
Spinal Injuries Association
Sunderland Carers Centre
Supporting People in Suffolk
Surrey Coalition of Disabled People
United Response
Vision Sense
Volition
Walsingham
West Berkshire Disability Alliance (WBDA)
Wiltshire County Council – Transformation Team, Department of Community Services
York Independent Living Network
Glossary
Aligned
The joining up of funding available from different sources, for example Community Care, with the other funding that will be included in the Right to Control Trailblazers.

Commissioners
Organisations (like local authorities and government departments) that give contracts to service providers. Commissioners also try to think ahead to plan for what services will be needed.

Consultation
This is when we ask people what they think about our plans.

Criteria
These are the questions we ask when trying to decide whether to do something or not.

Direct payment
This is when a council gives a disabled person money so that they can pay for their own care and support rather than receiving services direct from their local council.

Eligible
When someone qualifies to receive a particular service.

Funding stream(s)
The money that a public body spends to deliver a service.

Green Paper
This is a government report about changes it may make to the law. It is written so people can talk about the changes, ask questions and then tell government what they think about the changes.

Independent Living Strategy
This is a plan about how the government will help disabled people live a full life in which they choose and control the services they use.
**Individual budget**
This is when a disabled person is in control of the money for their support. They can then choose what they spend it on.

**Involving/Involved**
Being involved is not the same as being asked. Being involved means disabled people playing a bigger part in planning, not just being asked about work carried out by other people.

**Office for Disability Issues (ODI)**
This is a group of people who work for the government. They help other government workers learn more about disabled people and how to make things fairer for disabled people.

**Personal budget**
A term used to describe when someone who is eligible for Adult Social Care services is told how much money is available for their support, and is given choice and control over how that money is spent, including cash payments as a direct payment if they wish.

**Pilot(s)**
A process to test to see if and how something will work.

**Public body**
An organisation providing public services, such as a local authority or Jobcentre Plus.

**Right to Control**
A right that will allow disabled people to control how their own funding is spent on support to meet their individual needs.

**Service providers**
Organisations that provide things like support workers, information and advice, and employment training and support.
**Support**
The help that disabled people get from the government, their local council or other public body. This may include services, such as help from someone to get up in the morning, or the equipment that someone needs to do their job.

**Third sector organisations**
Organisations that are not run for profit (voluntary and community organisations, including social enterprises, charities and Community Interest Companies). They include large national organisations, such as Mencap and Shaw Trust, and local organisations such as Centres for Independent Living.

**Trailblazers**
Selected local authority areas that will try out the Right to Control.

**White Paper**
A government document which says what government intends to do.
This publication is also available in audio, Braille and Easy Read. If you would like a copy in either format, please contact us.

We welcome your feedback on this report. Please use the contact details below if you wish to do so.

This publication includes photos from the Office for Disability Issues’ Images of Disability Photo Library. For more information visit www.odi.gov.uk/iod

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